KNOWING CARE: AN EXPLORATION OF SECONDARY TRAUMA INVOLVING CAREGIVERS OF PEOPLE WITH MENTAL ILLNESS

Cindy Lea Eggington

B App Sci (Dis) Hons, Dip Community Welfare, Dip Youth Work

School of Medicine

Faculty of Medicine, Nursing and Health Sciences

Flinders University Adelaide Australia

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SUMMARY

The main emphasis of the current literature on mental health caregivers describes the burden and enduring impact of psychological trauma on peoples' lives and the increasing costs associated with the caregiver role. This emphasis is arguably problematic, as it does not provide caregivers with the means to move beyond concepts about burden that have come to define their trauma and anxiety experiences.

The background to the study involved a review of the historical, cultural and social context of care and trauma. It involved an overview of human and social organization to understand how increasing social tension over time has led to current discourses about trauma and care, specifically in the separate fields of medical science, psychiatry and mental health policy. Within this context, deinstitutionalization has increased perceptions about social inequality in relation to the treatment of mental illness, with consequences for secondary trauma for caregivers. This research explored how caregivers are predisposed to secondary trauma in relation to the contradictions they experience when endeavouring to achieve mental health outcomes for the people they care for. In response, many caregivers have transformed their traumatic experiences to become new community role models as advocates for people with mental illness and their caregiver peers.

The program aimed to explore mental health caregivers' issues more deeply by using Harry Stack Sullivan's Interpersonal Theory to examine their experiences of secondary trauma and the development of vicarious stress. Sullivan's framework was applied as part of participatory research data collection using a survey, interviews and forum with a sample of mental health caregivers in South Australia. It involved Sullivan's four stages (Reception, Reconnaissance, Detailed Enquiry, and Termination), that contained heuristic explorations about caregiving based on the formation of building blocks of enquiry. These stages also provided a gradual learning environment, informed by deliberate and conscious reflection about caregiving experiences at each stage of the data collection and analysis.

Interpersonal Theory recognizes that the caregiving relationship involves an interpersonal context that naturally communicates with caregivers' diverse cultural and social experiences, here understood through the exploration of the caregivers' significant developmental milestones. Findings revealed how the participants' interpersonal situations through their development contributed to their current caregiving roles.

The use of Sullivan's Interpersonal Theory framework established a clear relationship between developmental experiences and secondary trauma, in contrast to the prevailing literature about caregiver burden. This analysis contributes to a more rigorous conceptualization of the indicators of vicarious stress for mental health caregivers. It may also be crucial for identifying, understanding, informing, and supporting practical caregiving applications that can enable both caregivers and services to work toward more effective strategies to address secondary trauma and lessen its impact. It is hoped that this new focus on developmental aspects of the caregiving personality can inform interventions and interactions to support the prevention of secondary trauma in mental health caregivers.

DECLARATION

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

Cindy Lea Eggington

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CHAPTER ONE

Overview of the Research Program

1.1 Problem Statement and Research Strategy

This research explores how caregivers cope with, and comprehend, the psychological stress associated with the complex demands of caregiving for people with mental illness. The literature refers to an increasing incidence of mental illness worldwide, involving a combination of affective mood disorders and substance use disorders. Kessler et al. (2009) associated the high incidence and early age onset of mental disorders with adverse societal costs. To provide an illustration of the emerging context of the caregiving role in society, the Australian Bureau of Statistics (ABS, 2010) reported that women are more likely to experience long-term (more than two weeks) mood disorders than men, with a resulting loss of confidence and self-esteem, as well as reduced energy and/or activity.

Kessler et al. (2009) added that the current diagnostic criteria underestimate the prevalence of clinically significant mental illness, and therefore, undermine the potential for best-practice treatment to reverse the burden of care for caregivers and wider society. Besides alluding to caregiver exposure to these situations and events, the literature also highlights the impact of diagnostic exclusion rules upon access to treatment for comorbid mental illnesses. The ABS (2010) acknowledged that in 2007, the most common pairing of mental illnesses (at 38%) involved affective and anxiety disorders for a period of more than 12 months. Kessler et al. (2009) therefore highlighted mental illness as the *cause* of impaired role functioning. They noted that only a modest number of serious mental disorders receive attention, with even less receiving high-quality treatment.

Corrigan and Watson (2002) outlined how caregivers face the double challenge of assisting people with mental illness to cope with their symptoms and disabilities, while they struggle to deal with the effects of stereotypes and prejudice on their conceptions of themselves. They added that caregivers may also be exposed to the righteous anger of people with mental illness resulting from ongoing prejudice, ‘stolen’ opportunities for a good quality of life, and the adverse impacts of stigmatisation, increasing disability, and social marginalisation on their lives (2002). Caregivers of people with mental illness are also affected by a two-fold burden in the Western world in relation to the associated stigma around mental illness in society (Corrigan &Watson, 2002).

While general awareness about mental illness disability is improving in Western societies overall, the literature describes how perceptions of burden are associated with caregiving and increasingly involve primary mental health caregivers (such as immediate family, relatives, and friends), as well as mental health caregivers in organisational contexts (Shah, Wadoo, & Latoo, 2010; Szmukler, 1996). The further impact of vicarious stress upon caregivers has also been identified in the literature as an area requiring more research (Canfield, 2005). Hence, this study recognises the particular context of the challenges and ongoing nature of the concerns facing caregivers in relation to their ability to understand their own situation. These contexts may also determine how caregivers are presently able to access carer associations, education and information about mental illness and treatment, peer support, counselling, and respite services, and their immediate benefit for, and relevance to, caregivers’ needs.

Bell, Kulkarni, and Dalton (2003) highlighted the ways in which distinct constructs of vicarious stress have encouraged a re-examination of the relationship between trauma and distress and the challenge of developing new forms of agency and social organization. Bhui, Warfa, Edonya, McKenzie, and Bhugra (2007) proposed that the integration of mental health policies, and their specific histories and attitudes is dependent upon the local and diverse context of cultural competence concerning people with mental illness and their caregivers in society. Bhui et al. (2007) highlighted that increasing organisational awareness about culturally competent values and anti-discriminatory practices involves changing the current focus away from impact assessments and organisational performance. They also emphasised that the teaching of cultural competence will increase the need for complex policies that will then require new community approaches to ensure that people with mental illness and their caregivers directly benefit from interventions which are also aligned with their own needs.

As stated by Bhui et.al. (2007), a cultural and social exploration of caregiving requires a more complex methodology and approach to ensure that the participants may agree upon, and share in, the research outcomes as well as directly benefit from their own contributions. The current literature also identifies the need for a sound and detailed method that may establish ongoing approaches for the intervention and prevention of secondary trauma in caregiving populations. Therefore, Interpersonal Theory has significant potential for exploring caregiving experiences and minimising the anxiety associated with vulnerable populations, such as the caregivers of people with mental illness, because of its specific design (Bleiberg & Markowitz, 2005; Sullivan, 1956).

1.2 The Interpersonal Framework

The value of this research emerges from its emphasis on caregivers’ experiences of secondary trauma and the development of stress. The exploration of this topic will involve four distinct stages of data collection, drawn from the framework of Harry Stack Sullivan’s Interpersonal Theory (Sullivan, 1954). The general thesis is that the exploration of participants’ individual experiences of caregiving will ascertain and define the various levels of stress involved in the different typologies of vicarious stress and secondary trauma, and confirm the use of an interpersonal model by mental health caregivers across a diverse caregiving sample. The applied method put forward within Interpersonal Theory therefore aims to define a new generic approach that will improve understandings of the relationship between caregiving, secondary trauma, and types of vicarious stress overall.

Harry Stack Sullivan, an American psychiatrist, developed Interpersonal Theory during the 1930s (Sullivan, 1954). His theory has influenced a wide range of therapeutic applications and empirical practices that have emerged since that time. These include group therapy and systems or family therapy (Powdermaker & Frank, 1953; Yalom, 1975), as well as empirical practices such as social learning theory (Bandura, 1977; Ferster & Skinner, 1957) and developmental theory (Furman & Buhrmester, 1985; Stern, 1985; Youniss, 1980). He is also acknowledged for his major role in linking psychiatry to anthropology and the social sciences (Evans, 1996; Lasswell, 1930; Perry, 1982; Sapir, 1936-37; Sullivan, 1964).

The methods adopted in this research stem from Sullivan’s Interpersonal Theory because of its emphasis on a developmental framework, specific stages of data collection, and a shared agreement about the goals and aims of research (see Chapter 5). Interpersonal Theory recognises that the caregiving relationship involves an interpersonal context that naturally communicates with caregivers’ diverse cultural and social experiences. Exploring the ongoing impact of stress upon mental health caregivers also provides the current study with the opportunity to present an interpersonal assessment of caregiving culture based on participants’ shared understandings and meanings.

This thesis offers an exploration of the caregiving role in order to define the characteristics of vicarious stress (here understood as caregiver stress), as it is currently experienced by caregivers. This will be achieved through working with the three main categories of vicarious stress identified in the literature: vicarious trauma, compassion fatigue, and secondary trauma

(Figley, 1999). This research enquiry also focuses on secondary trauma to provide further information and clarity about two gaps in the knowledge that appear in the literature; to identify a conceptualisation of the indices of traumatic stress (Figley, 1999), and to increase understandings of the contagion effect (Kishur, 1984) involving the transfer of symptoms of Post-Traumatic Stress Disorder (PTSD) to caregivers.

Secondary trauma has been linked to PTSD symptoms in caregivers (Figley, 1999) as it mimics PTSD responses (Zimmering, Munroe, & Gulliver, 2003). PTSD is listed in the American Psychiatric Association (APA, 2013) Diagnostic and Statistical Manual (DSM-IV R, DSM-5) and the International Classification of Disease and Related Health Problems (ICD-10 R) (WHO, 2015). Secondary trauma is classified in the DSM by two main criteria involving exposure and response to a traumatic event (see Chapter 2). It is recognised by three groupings of symptoms characterised by flashbacks or re-experiencing, avoidance or numbing, and hyper-vigilance and the startle effect (APA, 2013). According to these DSM classification and diagnosis criteria, people are required to experience at least three of the above symptoms, including two hyper-arousal symptoms for more than one month (APA, 2013). As such, secondary trauma in this thesis is defined by the ways in which caregivers of people with mental illness respond to traumatic events (APA, 2000).

Research-based studies suggest that while secondary trauma does not meet the criteria for a clinical diagnosis of PTSD, little is understood about the caregiving relationship and the type of interactions that may have an impact on persons with mental illness, alongside the cultural factors in the recovery process that may be at play for caregivers who experience secondary trauma (Figley, 1999; Zimmering et al., 2003). According to Interpersonal Theory, the dynamics of caregiving may involve integral responses in human development, interpersonal relationships (Sullivan, 1956), and survival strategies (Ironside, 1980; Valent, 2002). To explain how certain interactions produce and relate to secondary trauma, this research will explore significant developmental milestones and the diverse social and cultural influences on the participants' caregiving roles. A study that focuses on the developmental aspects of the caregiving personality is crucial for identifying, understanding, informing, and supporting practical caregiving applications that reach beyond this research, enabling both caregivers and services to work toward more effective avenues for intervention, and for the prevention of secondary trauma in mental health caregivers.

1.3 Statement of Aims and Orientation to the Thesis

Itemised below are the overall aims of the research program with reference to the chapter in which each is addressed. The intention and content of each chapter is then briefly discussed:

1. To define trauma specifically and the context of care for mental illness, providing a background understanding of trauma and the development of approaches to caregiving for mental illness (Chapter 2);
2. To introduce the caregiving setting of interactions and participation in treatment that typifies the care of mental illness, and to demonstrate the link between theoretical positions, vicarious stress, and secondary trauma to date (Chapter 3);
3. To define and critique previous research and theoretical perspectives on vicarious stress and secondary trauma as applied to caregiving overall, providing further justification for the current program (Chapter 4);
4. To explore and explain the methodology of Harry Stack Sullivan in relation to the exploration of secondary trauma, and to outline the research questions and the four stages of the research (Chapter 5);
5. To introduce Stage 1 of the research including a description of the method employed in this stage (survey), as well as the results, statistical analysis, and a preliminary discussion (Chapter 6);

6. To introduce Stage 2 of the research, including a description of the method involved in the interpersonal interviews, as well as the results, analysis, and a preliminary discussion (Chapter 7);
7. To introduce Stage 3 of the research, including a description of the method involved in the detailed enquiry, as well as the results, analysis, and a preliminary discussion (Chapter 8);
8. To introduce Stage 4 of the research, including a description of the method involved in the interpersonal forum, as well as the results, analysis and preliminary discussion (Chapter 9);
9. To provide an integrated discussion of the overall findings of the research, illustrating how the mental health caregiving role is understood and provided by caregivers, outlining the strengths and limitations of the thesis, and providing a number of implications of the findings (Chapter 10).

1.3.1 Chapter Two

Chapter 2 will provide the background to the study through a review of the historical, cultural, and social context of care and trauma. It will introduce the human group in the total care situation. Chapter 2 comprises an overview of human and social organisation and describes how increasing social tension led to subsequent cultural developments that relate to current discourses about trauma and care, specifically in the separate fields of medical science, psychiatry, and mental health policy. This chapter will describe how the present caregiver role has emerged from the context of rapid economic growth that has also facilitated the shift from institutional care to the treatment of mental illness in the community. This chapter will thus highlight and contrast prevailing ideas about trauma in the literature and the implications of ongoing economic change for caregivers concerning the treatment of mental illness today. Overall, Chapter 2 will provide a background understanding of trauma and care, in the context of the relationship between the development of psychiatric treatment for mental illness and the caregiving role in the present day.

1.3.2 Chapter Three

Chapter 3 will discuss the dynamics and relationships that describe the existing model of care and mental health service delivery for people with mental illness. It will explore the implications of science-based treatment and the development of Mental Health Service (MHS) policy, as well as the impact of mental health service reform on caregivers in the community. In order to achieve this, the chapter will describe the association between political organisation, the implementation of mental health policy, and the breakdown of care in the community. It will also define the relationship between current approaches to care and caregivers' experiences of trauma associated with accessing mental health services for people experiencing mental illness. In addition, this chapter will review various theoretical positions found in the literature, including the significance of secondary trauma for caregivers of people with mental illness and their need for empowerment in the community.

1.3.3 Chapter Four

Chapter 4 will introduce the three categories of vicarious stress identified in the literature: vicarious trauma, compassion fatigue, and secondary trauma. This chapter will provide a review the current interpretations of vicarious stress and identify the specific interactions that relate to development, secondary trauma, and PTSD. The relationships that occur between the categories of vicarious stress and their current context in the care-giving relationship will be explored, and the chapter will also introduce theoretical perspectives about the present levels of awareness about caregiving and the particular issues that surround secondary trauma, in addition to providing an overview of existing approaches to the treatment of mental illness. The unique context of vicarious stress and secondary trauma concerning their interrelationship with PTSD in the context of the current study will then be investigated. Overall, Chapter 4 will complete a critical study of vicarious stress and how it is interpreted and determined in the literature as the justification for research into secondary trauma.

1.3.4 Chapter Five

Chapter 5 will explain the methodology of Harry Stack Sullivan and Interpersonal Theory, including its significance for the development of approaches to mental illness and its place in the current research. The four stages of action research are outlined, including procedures that illustrate the importance of a heuristic and chronological development of data. They are: (1) reception, (2) reconnaissance, (3) detailed enquiry, and (4) termination.

Chapter 5 will also provide a justification for the use of Interpersonal Theory as the basis of the data collection processes detailing the need to reduce exposure to anxiety for participants. It will also establish the researcher as a participant and observer of interpersonal interactions and clarify the advantages of obtaining collective knowledge through action research about secondary trauma that remains responsive to caregivers own interpretations of caregiving. The conclusion of the rationale for this methodology will introduce the research questions.

1.3.5 Chapter Six

Chapter 6 will introduce Stage 1 of the research, including a description of the survey method used. It will describe how the recruitment process occurred in the community to provide respondents with a familiar context for ongoing participation in the research based on their anonymous and voluntary participation. The chapter will also explain the purpose of the survey design, and will describe the survey results including a statistical analysis of the respondents’ demographic information and their replies to the survey questions. The chapter will also describe how the survey questions relate to the overall research process and contribute to the development of a profile about caregivers of people with mental illness.

1.3.6 Chapter Seven

Chapter 7 will introduce Stage 2 of the research, including a description of the interpersonal method involved in the interview with participants about their caregiving impressions and expectations. The chapter will discuss and summarise the results of Stage 2 through a description of stage-specific, developmental caregiving experiences based on the participants' personal caregiving history. The chapter will also present the important cultural and social influences upon participants' caregiving roles and their current caregiving situations and the particular developmental milestones that characterize the typologies of vicarious stress and that may provide the basis for ongoing research and analysis. Overall, Chapter 7 will explore the participants' discussions about the caregiving role as a reconnaissance into their experiences in preparation for the detailed enquiry, as outlined in Interpersonal Theory.

1.3.7 Chapter Eight

Chapter 8 will introduce Stage 3 (detailed enquiry) by providing a description of the concepts outlined in this research by Interpersonal Theory in relation to vicarious stress and secondary trauma. How the participants' feedback on the researcher's preliminary findings about the reconnaissance stage will be demonstrated (interviews, Chapter 7). It will illustrate how these key interpersonal concepts provided the participants with a basis for discussion about vicarious stress. This chapter provides an assessment of caregiving domains based on the preceding information, as well as an account of the participants' caregiving acts and ideals. This chapter will also present the results of a detailed enquiry into caregiving by exploring participants' self-awareness, self-organisation, and orientation to their own personifications of care. Overall, Chapter 8 will summarise and present the participants' descriptions of the tensions and interpersonal developments involved in their caregiving roles.

1.3.8 Chapter Nine

Chapter 9 introduces the researchers' preliminary analysis of the participants' cognitive modes based on feedback from the Stage 3 interview transcripts. This analysis follows the concepts outlined in Interpersonal Theory that portrays how participants' interpersonal tensions culminated in distinct interpersonal integrations that produced their own unique caregiving outcomes. Chapter 9 will also describe the methods undertaken for the fourth and final stage of the data collection, and will present the results of the open forum and public presentation of the preliminary findings of the research. In total, Chapter 9 will present the forum participants' responses to the research findings and will provide an analysis of the results based on the processes outlined in Interpersonal Theory.

1.3.9 Chapter Ten

Chapter 10 will reveal how the participants' interpersonal situations throughout their development contributed to their current caregiving roles, as well as explaining how Interpersonal Theory assisted with clarifying the findings about secondary trauma and outlined the consequences of its development. Chapter 10 will discuss the findings of the four stages of the research, as well as the concept of secondary trauma in the context of the research aims. It will describe how the participants integrated vicarious stress as outlined through cognitive modes in Interpersonal Theory. This chapter will also illustrate how interpersonal communication facilitated the participants' foresight and will discuss the context of their subsequent social and cultural empowerment based on their collective knowledge about mental illness in their respective communities. Chapter 10 will demonstrate how the theoretical conceptualisation of the indices of vicarious stress have contributed to and improved understandings about the relationship between secondary trauma and PTSD. Finally, this chapter will describe the implications and limitations of the research. Overall, Chapter 10 will combine a synopsis of the research design and analysis of the findings that corresponds with the existing literature about caregiving and secondary trauma.

1.4 Significance of the Research

It is anticipated that the outcomes of this research will be of likely value in four key ways. First, the background chapters provide a chronological description of human responses to trauma throughout history. This may serve as a reminder of the possible ways that mental health caregivers have become traumatised as result of their role. Second, the methodological framework involves specific stages of data collection that explore caregiving experiences throughout interpersonal development. The use of this framework may establish a clear relationship between developmental experiences and secondary trauma, in contrast to the prevailing literature about caregiver burden. Third, this research incorporates analyses about the integration of interpersonal situations throughout development. These analyses may contribute to more rigorous conceptualisations of the indicators of vicarious stress. Finally, this research may outline clear strategies that address secondary trauma, illustrating what can be done to prevent or lessen the impact of secondary trauma upon caregivers in the future.

CHAPTER TWO

Trauma and Care

2.1 Introduction

This chapter will outline the factors that have underpinned human understandings of trauma, and how this contributes to current thinking about the caregiving role. The emerging importance of trauma concerns researchers in two ways: the impact of real and irrefutable events upon people; and caring responses to trauma involving human compassion (Fassin & Rechtman, 2009). The main emphasis of the current literature, however, describes the enduring impact of psychological trauma on people's lives and the increasing costs associated with the caregiving role (Fassin & Rechtman, 2009; Figley, 1999). Given the complexity of trauma, an understanding of its impact upon human beings may include the types of injury that may or may not be physical in nature but which are associated with evolutionary responses deeply connected to human psychological development. Therefore, the *wound* of trauma both translates to traumatisation and to trauma, defined as:

> *… an emotional shock following a stressful event sometimes leading to a long-term neurosis; a distressing and disturbing experience; any physical wound or injury; the consequent physical shock characterised by a drop in body temperature, mental confusion …* (Australian Oxford Dictionary, 2006, p. 1522).

The following review of trauma and care records historical observations of trauma to the present time. The main arguments presented illustrate the importance of trauma for human development and concern information that contributes to a complete social anthropology (Fassin & Rechtman, 2009). This chapter also makes an original contribution to the current body of knowledge by proposing a cultural anthropology (Sullivan, 1953) through the exploration of the relationship between trauma and care over time. Chapter 2 therefore explores the developmental processes that have contributed to humans' ability to integrate their experiences of caregiving stress, developmental tensions, and trauma.

The first section, termed 'The human group', begins with the study of human groups in order to explore the interpersonal, social, and cultural interactions associated with stress and trauma and how these are reproduced through the caregiving role. Human adaptation to trauma mirrors the evolutionary importance of communication to produce language which allows humans to think, and thus, to use it as a basis for all social and interpersonal exchange. Subsequently, the uniquely human development of collective responses to trauma increase social unity and organisation that enhance the human desire to belong. Equally, this review about trauma and care also provides an early outline of the basis of social inequality through an exploration of complex organisation as the product of trauma and rapid social change.

The second section, termed 'Increasing tensions', introduces a number of ideas about trauma through which human consciousness prospers for the realisation of symbolic and political power. This section incorporates an exploration of both social ritual and collective myth as developing narratives that describe how increasingly, political influence defines trauma, and how it supports post-traumatic growth and the development of collaborative responses to trauma as those that define the future management and treatment of mental illness. The increasing politicization of trauma is then described in the context of the growing reliance of society on forms of social control involving collective trauma in growing human populations.

The third section explores the subsequent implications of increased social organisation on caregiving by describing the processes including institutionalization, that led to the emergence of medical science and the recognition of trauma as a nervous disorder. This section will introduce psychiatry and psychoanalysis as official procedures for treatment, which are based on scientific explorations of trauma as human recollections.

The fourth section explores the subsequent development of trauma and care discourses in the context of war-related therapies and formulations in the industrial world, including the treatment of shellshock, and the introduction of group therapy.

The final section outlines the emergence of the caregiver role. This section defines the modern context of trauma, involving the creation of civil rights movements and womens' empowerment, coinciding with a rationalist movement towards deinstitutionalisation and the community treatment of mental illness. This section acknowledges the modern context and conflict between trauma and care concerning the survivor witness and the emerging global economy. The chapter concludes with a discussion of the development of psychiatric classification systems for the treatment of mental illness and PTSD that define current approaches to trauma and care.

2.2 The Human Group

This review explores adaptations to trauma through human evolution and our unique capacity for social and cultural development that has also formed our initial observations and self-awareness in evolutionary survival. Mithen (1996) noted that early human responses to trauma addressed the ongoing threats that endangered survival. This section contributes to the current knowledge about trauma and care by presenting research featuring the unique nature of human evolution and adaptive human responses to trauma (Van der Kolk, 2000).

The first adaptation to trauma in human evolution includes responses to real or perceived threats relating to the ancient reptilian limbic system and involving basal brainstem development (Goleman, 1995). This enabled the limbic brain to retrieve information through sensations in the body and process information by smell, hearing, and sight, thus linking primary awareness to survival and reproduction (McFetridge, Aldana, Hardt, & Slavinski, 2004; Van Der Kolk, 2002).

Apart from the limbic system, mammalian humans also share the amygdala, enabling the categorization of traumatic material according to the intensity of the immediate threat. The amygdala or emotional brain is responsible for storing information as significant memories and important emotions, which provide the context for human connection (McFetridge et al., 2004; Van der Kolk, 2002). The significance of emotional intelligence is outlined by Goleman (1995), who described it as the first and most reliable antecedent and real seat of intelligence in the human species. Goleman (1995) added that emotional intelligence is driven by empowerment and imagination, and by behaviour, that combines both cognition and action, with beneficial consequences for autonomy and personality growth.

The development of the prefrontal cortex in humans allowed responses to trauma through a virtual neural pathway, producing an accompanying visual image (Anechiarico, 2009). The prefrontal cortex, or human mind, is therefore linked to complex problem-solving skills and conceptual understanding (Goleman, 1995). The conceptual mind also permits significant cognitive responses to anxiety and trauma, important for adaptation and development. These include foresight, based on similar emotional states and recall, activated by external circumstances (McFetridge et al., 2004; Sullivan, 1954; Van der Kolk, 2002).

The cognitive adaptation of the prefrontal cortex also allows for the integration of a world view, as the new information stored in active memory is modified and completed (Horowitz, 2006). Alternately, as periods of extreme stress and persistent anxiety result in hyper-arousal, the subsequent damage to the brain creates a significant obstacle for learning processes essential for survival (Anechiarico, 2009; Sullivan, 1956). Consequently, Sullivan (1956) linked humans' advanced adaptive capacity to their innate tendency towards mental health. The ability to emotionally discriminate among different types of traumatic experience will now be explored through the unique human development of communication and language.

2.2.1 Importance of Communication in Minimising Trauma

Adams and Galanes (2006, p. 13) defined communication as “the perception, interpretation and response of people to messages produced by other people”. As a form of communication, the attainment of language is widely recognized as a major evolutionary milestone in human development. Lanzetta and Englis (1989) stated that this ability may have originated as a form of coping response to environmental events involving human expression that led to communication to benefit the entire community. Campbell (1972) stated that this movement toward greater social organisation, and the refinement of communication, underpins the origin and early function of human culture. Leach (1976) and Szasz (1974) outlined three types of communication that define language: the causal connection between sign and object (indexical); the indication of relationship and/or similarity (iconic); and, the interpretation of rules and social customs through accepted conventions (symbolic). Similarly, the attainment of language also enables the shared meanings of human responses to traumatic events, which emphasise learning opportunities throughout human development, such as representative knowledge and symbolic rules and customs (Szasz, 1973). As such, the understanding of language is largely dependent on an individual’s familiarity with the customs and conventions of a given cultural community over time (Leach, 1976). Therefore, self-expression and self-composure in human young occur in coordination with significant others as caregivers (Huneman, 2008; Morreale, Spitzberg, & Barge, 2007).

According to authors such as Campbell (1972) and Sullivan (1956), in human culture the learning of language coincides with prolonged caregiving for the ‘unfinished’ human young. Consequently, human infancy has provided much of the basis of research into human development. In epigenetics, biological processes related to reproduction involve early modifications and differentiation of cells for the creation of life (McFetridge et al., 2004; Van der Kolk, 2002). After gestation, birth represents the first traumatic event for the fully-formed individual. Early responses to trauma connect bodily sensations through zones of interaction that signify the biological needs of infants (Sullivan, 1956). Early cognitive representations of trauma, classified as emotional memories, are therefore associated with the early satisfaction of biological needs and the maintenance of interpersonal security (Sullivan, 1956).

These early experiences of anxiety are based on the infant's interactions with, and defence of, the primary caregiver (Campbell, 1972; Sullivan, 1953). Subsequently, interpersonal concepts define the self and establish the operations in which human young maintain interpersonal security to safeguard against trauma in early development (Sullivan, 1956; Van der Kolk, 2002). These initial empathetic exchanges with the caregiver provide the basis for object relationships that eventually define the self and others as "selves that function in our experience" (Davis, 1948, p. 211). The rapid acquisition of language, therefore, is to inherently contain the cognitive structures that guide, represent, or symbolise meaning, as well as those that describe the types of reactions or influences that occupy the life space and adaptability of individuals (Lewin, 1952; Sprott, 1958). The exploration of trauma concerns the attribution of the meaning given to a life and its place in the group which are particularly significant as defining stages in personality development (Lewin, 1939; Sullivan, 1953). Szasz (1973) thus describes how human advances in autonomy and personality development have arisen out of the ability to modify the rules of language and to construct new ones.

2.2.2 Social and Cultural Adaption as Collective Responses to Trauma

Adams and Galanes (2006) described how the primary caregiving group establishes interactions and social roles that safeguard against anxiety and danger in the care of the young as a requirement of family and small community life. The role of 'we-ness' serves a therapeutic purpose for communities and is central to community life involving extended family as a "collective and meaningful response" to trauma (Danieli, 2006, p. 37). Belonging to a primary group provides humans with the basis of a collective emotional economy based on, and involving, face-to-face communication, real-life instances, and role exchange (Huneman, 2008; Mithen, 1996; Sprott, 1958). To provide differentiation in the social structure, individual roles develop from infancy through a range of social classifications and kinship relationships. As roles involve repeatable skills and similarities in conduct, they also ensure that the ensuing social classifications conform to prevailing standards of discipline as those that can be accepted and identified as the standards or norms of the group members (Sprott, 1958). Roles therefore establish the concept of self that is fulfilled in the "common life and purpose of the group" (Cooley, 1909, p. 23), and which have objective value concerning the social nature and ideals of individuals (Leach, 1976; Sprott, 1958).

Primary groups are important for maintaining group standards and norms that contribute to cultural identity and social prestige (Sprott, 1958). To maintain social standards, primary groups also establish frameworks of expectation and measures of esteem to communicate and reciprocate (esteem) or the feeling of being liked (Sprott, 1958). For this reason, the development of 'selective inattention' is important for excluding information that has no immediate interpersonal relevance, as well as for maintaining interpersonal security, such as the control of anxiety in childhood compared to adult life (Evans, 1996; Sullivan, 1956). Alternatively, the concept of the unique individual represents self-consciousness for group members due to its abstract and symbolic meaning (Sullivan, 1937).

The social and cultural setting therefore supports individuals through various interactions and relations that define social position and support the management of trauma and anxiety (Lewin, 1939). Subsequently, as time increases its influence on behaviour during development, changes in perspective occur in line with the goals or values of others (Lewin, 1936). Changes in individual perspective are able to be estimated and adapted to become "our way of behaving" (Sprott, 1958, p. 13). In relation to trauma, primary groups establish the basis for the collective perception and awareness of unity that gives humans the power to act with one accord towards their environment (Smith, 1945; Sprott, 1958). As ongoing dependence upon the environment represents formal organisation, it also determines the demands that call the group into being around an informal common purpose (Sprott, 1958).

This awareness also ensures that individual anguish relating to mortality is relieved through participation in the larger group (Campbell, 1972). In this way, the act of mourning establishes a position of dependence within the primary group that re-schematizes beliefs about identity. This new social affiliation then establishes an accord between the inner working models of the self and the world (Horowitz, 2006). Social watchfulness or systems of self are thus based on the balance of external (formal) and internal (informal) organisation, so that necessarily as formal change occurs, it involves informal attitudes and behaviours (or exposes the risk of group disintegration) (Homans, 1951; Sprott, 1958). Aldenderfer added:

> *"this situation poses three distinct but related threats: the wielder of [formal] power faces the possibility of loss of prestige or power; former co-operators face a loss of group level benefits; and, the erosion of the basis for collective action"* (Aldenderfer, 1993, p. 14).

Therefore, group cohesion incorporates fields of tensions or dynamics based on incremental systems of reward. The measurement of rewards according to behaviour relates to one or all of formal (material and economic gain), informal (companionship, goal attainment, prestige of belonging), and/or the risk of exclusion from the group (Sprott, 1958).

2.2.3 The Need for Group Unity and Dependence in Response to Trauma

Szasz (1974, p. 251) stated "persons need not only other people, but also rules worth following, or more generally, games worth playing". As institutions and broader areas of prestige involve class structures in society, secondary groups are formed for a purpose and for the control of particular social needs (Adams & Galanes, 2006; Sprott, 1958). In terms of prestige, social institutions support the evolutionary function of groups by promoting increased role specialisation. Institutions contain rules that permit relationships between roles to form and the administration to organise and coordinate ongoing interactions. These interactions are guided by characteristic patterns of behaviour and are understood through the sharing of the rules (Machado & Burns, 1998). Lewin (1939, p. 887) confirmed that “not similarity, but a certain interdependence of members constitutes a group”. Correspondingly, ‘social class’ designates “both an interdependent group and a number of persons who show similar properties” (Lewin, 1939, p. 887). Lewin (1939, pp. 886-887) added that well-organized groups typically have a “high degree of unity and include a variety of members [who have] different functions within the whole”. As general standards are learned within the primary group, they are also incorporated to conform to the special standards imposed by the secondary group, where unity is supported by language (Sprott, 1958).

Despite their interdependence, group standards refer to different issues. Therefore, primary and secondary groups have their own specific problems (Sprott, 1958). While primary groups form the basis for interpersonal exchange in human development, membership in secondary groups highlights the integral relationship between the normative standards associated with persons and roles and the (abstract) personality (Szasz, 1973). Thus, the formation of secondary groups emphasises unified education and respect for common symbols as those that contain the imagined and symbolic beliefs of belonging (Sprott, 1958). Reputation is an important social characteristic of the collective and collaborative achievements of secondary groups that lead to the identification of influential leaders. Therefore, personality development incorporating opinion leadership among group members is important for the management of trauma, providing a controlling influence for members of the group and offering the capability of foresight that integrates hope for the future (Sullivan, 1953).

2.2.4 The Importance of Belonging for the Integration of Trauma

Notions of belonging are widespread in the trauma literature and are generally associated with equality, safety, healing, and involve higher levels of cultural integration (Ajdukovic, 2004; Sullivan, 1954). The desire to belong and to survive incorporates all the known responses to trauma and is associated with prestige as an informal reward (Lifton, 1979; Mithen, 1996; Sprott, 1958). According to Aldenderfer (1993), the expectation that the benefits associated with belonging will continue is dependent on the maintenance of social categories and the belief process that the group will continue to meet their needs. Aldenderfer (1993) adds that, communication rituals justify existing social relations and provide an ongoing basis for mediation. Therefore, a sanctioning and persuasive form of social ritual includes the formal belief in communicative power, as the means of providing mediation during times of conflict. Accordingly, Aldenderfer, (1993) says that the management of group cooperation involves processes of manipulation that reach beyond ideas about rewards and punishment and group cohesion. This is particularly important in relation to group performances that conform to the existing cultural system, and which require ongoing mobilisation and collective action. Consequently, group communication rituals based on cooperation and conformity both provide a control function and act as a potential agent for change (Aldenderfer, 1993).

Group interaction with similar cultures occurs through symbolic gestures of respect, knowledge of the environment and of other cultures (Paynter, 1989; Sprott, 1958). In this way, the integration of norms offers a symbolic basis for belonging and for the incorporation of multiple goals (Burns & Carson, 2002). As forms of changing dynamics, traumatic events also shift perceptions about the social role and direction of behaviours as cognitive attitudes (Lewin, 1939). Sudden change leads to uncertainty about the achievement of the psychological goal as the guiding structure and dynamic of the group (Lewin, 1939). As unfamiliar situations are unable to be traced within emotional memory, the feelings signify a problem without solution. For example, Gallant (1991) described the interpersonal and interclass relations surrounding ancient Western communities as being rife with conflict, with increasing competition over access to resources acting as the trade-off for honour and status.

Communication hierarchies involve the dominant representatives or group leaders in addressing persistent social stress and ongoing concerns about structural change and resource inequality in the local and historical environment (Aldenderfer, 1993). This type of cooperation between groups allowed early communities to prepare for the probability of disaster so that subsistence cultures could develop a system of rights and obligations based on (emotional) reciprocity to fulfil the standards that had already emerged (Gallant, 1991). Similarly, Lightfoot (1995) described how tribal group populations were transformed, and even created, through increased cultural contact with displaced native groups and populations escaping from epidemics who formed colonial settlements and refugee camps. Equally, the literature associates displaced populations with historical trauma concerning the loss of social and cultural support systems and poor health outcomes (Ajdukovic, 2004; Pena, 2011). Consequently, Hippocrates' discourse on *airs, waters,* and *places* offered crucial advice about disease intensity or endemnicity regarding colonisation in ancient Greece (Porter, 1994).

Therefore, in the context of rapid social and environmental change, cultural transmission involves the communication of indirect bias that establishes adaptive traits as cultural variations, exposes neutral traits to drift, and inhibits maladaptive behaviours relating to prestige that diminish rituals of communication as the leading adaptive choice and response to trauma (Aldenderfer, 1993). Respectively, cooperation based on ritual forms of communication protects the group from failure and scepticism by associating failure with outsiders, by making outcomes dependent on difficult conditions and, most importantly, by changing the context of cooperation and communication to paradox and contradiction (Aldenderfer, 1993). Accordingly, the “movement toward greater organization, greater differentiation of structure, increased specialization of function, higher levels of integration and greater degrees of energy concentration” is related to complex organisation having its origins in social inequality (Paynter, 1989; White, 1949, p. 367). Therefore, increasing communication methods is significant for creating a sense of belonging, and to restore and mediate complex types of relationships during times of rapid change.

2.2.5 Historical Inequality as a Product of Trauma

This section explores caregiving outcomes resulting from increased social complexity in human relationships with, and between, human groups. Ongoing speculation in the literature concerns the motivation for social complexity as originating from outside of the culture in order to solve problems of increasing supply and demand. The increase in production systems to address environmental degradation, population growth, and declining living conditions also highlight mechanisms of constraint (such as circumscription through gender relations) that further pronounce the limitations of resources for the group (Paynter, 1989). As a form of exchange theory, (achieving self-organisation through) circumscription involves cooperation and conformity with the psychological goals of the group to ensure that the benefits of membership outweigh the costs associated with belonging. As such, complex organisations increasingly became associated with cultural and social forms of inequality and the problems arose “from the efforts to maintain it” (Paynter 1989, p. 374).

To coordinate the formation of complex groups, three organizations or structures have been defined in the literature. These are network co-ordination through horizontal or vertical relations (with informal rules); formal market or contractual co-ordination with horizontal relationships (and formal type rules); and administrative co-ordination, with vertical relationships (and formal rules) (Machado & Burns, 1998). Therefore, inequality describes a hierarchical measure of the complexity being faced by the cultural system as the "inevitable outcome" of problem-solving (Paynter, 1989, p. 374). Cohen (1985, p. 112) noted that "complex social organization not only solves logistic problems in coordinating people with resources, it also relieves interpersonal tensions generated by relatively inflexible, close association with large numbers of other people".

Accordingly, the advancement of societies linked agricultural capability to the idea of surplus to sustain the rise of an organised military (Elliot, 2012). Increasing military coordination, to relieve interpersonal insecurity, therefore incorporated early ideas about social capital and social breakdown. Ajdukovic (2004) described how these relations and mediation processes included organised violence to shape the social context of trauma. The intention to traumatise selected groups and individuals sent a "symbolic message to other communities" that "such violence has a clear instrumental purpose" (Ajdukovic, 2004, p. 129). Warfare was fostered among cultural leaders to encourage the importation of valued goods and arms in support of the local economy as well as to reinforce the existing social hierarchy. In this way, the role of trauma was vital for facilitating cultural change, by supporting the development of regional trade economies and emerging political centres (Harde, 2005).

2.3 Increasing Tensions

This section explores how tensions have arisen in humanity over time. It makes an original contribution to knowledge in this area by contributing to ideas about the development of caregiving outcomes involving increased social complexity in humans' relationships between human groups. Understanding traumatic events as a variable of social change involves four traits which Sztompka (2004, p. 158) described as:

1) the *timing* of change, which involves rapid and sudden traumatic events or cumulative trauma that result in new awareness, such as in instances of belonging among refugee communities;
2) the *scope* of change, which concerns collective experiences of trauma as those that constitute a social fact (such as ongoing access to resources in the environment);
3) the s*tructure* of change, which is affected by formal social organisation (such as in the formation of complex societies);
4) the *culture* of change, which impacts upon community norms, and involves group values, beliefs, roles, and meanings.

Sztompka further described cultural forms of injury and consequent trauma as the most difficult to heal for communities undermined by change due to the important role of culture in providing “continuity, heritage, tradition, and identity” (2004, p. 162).

Seeking alternative metaphors for cultural change redefined the relationship between individual and culture. The increasing exercise of power and the integration of ideas about trauma (Paynter, 1989) meant that the rise and fall of human civilisations involved periods related to the environment (e.g., the discovery of precious resources in rising civilisations, and the impact of drought and famine upon falling civilisations) which occur interdependently of human life and adaptation (Hobfoll, 1998). As access to resources is associated with increased cultural power and capability, the veneration of knowledge correspondingly occurred relevant to the era (i.e., knowledge of iron heralded the Iron Age) (Hobfoll, 1998; Sprott, 1958). In this way, human proximity to resources defines power, and determines who has access to knowledge about the resources, thereby increasing veneration of the object (Hobfoll, 1998). Therefore, those individuals or groups who best manipulate and control access to strategic resources also increase their control in strategic hierarchies, and are thus established as the most legitimate and competent level of the culture (Paynter, 1989).

Within these hierarchies of control, these individuals and groups increasingly exclude others from accessing positions of authority, and therefore emerge as monopolizing and potentially institutionalizing systems of inequality (Paynter, 1989). Subsequently, historical and cultural transformation follows periods of cyclical conflict and limited growth, and is associated with the relatively rapid emergence of the state (Paynter, 1989; Wright, 1986).

Shaw (2000) provided the example of the Old Kingdom of Egypt (2686-2160 BC) which demonstrates how the above processes were integral to the development of the state by engaging trauma as a variable of social change. In order to monopolise time and to formally organise the social structure, the class elites devised forms of state and political control by sourcing reliable labour during the flood season as the period that posed the greatest potential for unrest (Mendelssohn, 1971; Paynter, 1989). This pattern of activity then formed the basis for the development of the pyramids and the emerging dynasty of the state. Initially engaging the unruly population to move piles of dirt during the formation of the Egyptian state (3200-2160 BC), the earliest pyramids were constructed over a relatively short period of time, and highlighted inequality by exceeding the number of pharaohs (Shaw, 2000). Paynter (1989, p. 384) added that, in this way, the "logical connection … between objects and the construction of selves" involved formal organisation through social policing, and informal control involving greater degrees of energy concentration, such as through slavery. As the Egyptian elites lost control, their means of legitimizing state and political control were to re-institutionalise inequality through terrorism and mass burials (Paynter, 1989).

Thus, forms of social order also included sequential hierarchies to displace kin and community demands and to undermine alternative centres of power (Paynter, 1989). In this way, the Egyptian hierarchies proclaimed the global age of celestial order, such as "himself-thus come", which outlined a model for life on earth and further established systems of inequality (Campbell, 1972, pp. 55-6). Therefore, the development of the nation state was based on social rites, laws, and social classes of citizens with moral roles that described the collective principles of the controlling culture and history (Jefferys & Tait, 2000). Subsequently, the monotheist philosophy of a single god involved the development of the "trans-individual" in Western culture and indicated a momentous change in the perception of trauma as a transcendental experience (Campbell, 1972, p. 22). By representing venerated knowledge in the pursuit of immortality, references to physical sickness did not exclude those concerned with emotional suffering and conditions (Smith, 1998). Egyptian civilization provides the earliest medical account of psychological trauma as a stress-related disorder (Campbell, 1972). Consequently, the existence and transmission of trauma and its (secondary) effects are images that are often shaped by design (Danieli, 2006), by including the moral, religious, and political values that are determined by reacting to, and being part of, a society (Lewin, 1939). Thus, in order to better manage experiences of trauma, humans also developed ideas based on their future and ongoing prosperity.

2.3.1 Integrations of Tensions as Ideas on Which Humans Thrive

This section explores how ritual and mythology have provided unique human responses to trauma during periods of increasing change. Szasz (1973) highlighted the foremost crisis of self-development during traumatic periods and rapid change, involving severance from the primary group based on normative standards and roles and the emerging development of the (abstract) personality. To further distinguish peoples' membership in secondary groups from primary group structures and early group formation, communication rituals were used to convey information about a particular social form "as a system of control as well as a system of communication" (Aldenderfer, 1993; Douglas, 1973, p. 79). The consequent production of a shared symbolic reality involved two or more people meeting and coming together to engage in in-group attention through rules, words, gestures, actions, and objects (Machado &

Burns, 1998). This collective mood through ritual allowed the group to express their shared feelings and sentiments, as well as their conceptions about coping with the impact of change.

2.3.2 The Objective of Change in the Shamanic Ritual

Symbolic group rituals are pronounced in the trauma literature as performances that interpret the impact of development upon the human group. Blakeley (2000) described the great risks associated with disintegrating tensions (involving charismatic and anti-structural power in primary groups) and institutional and organisational designs (in secondary groups). By engaging in symbolic ritual, the shaman guide represents the patterns of the stage left behind based on performing the actions that identify meaningful patterns among the group (Campbell, 1972). The shamanic ritual is also significant for restoring community sentience, or the group worldview, depending on the unique cultural and social context. In relation to human communities' ability to cope with trauma, shaman consciousness unifies the immediate forms and feelings associated with emotional or soul loss as inter-dependent parts involving the "supernatural other" reconstruction of self (Aldenferer, 1993, p. 12). Cultural restoration re-establishes consciousness in body, emotion, and mind, as the shaman retrieves life deeds or traumatic fragments and restores their value for the community (Paulson & Krippner, 2007). The rituals of the shaman therefore contain important social structures that incorporate interpersonal tensions as the human rites of passage that assist with the individual's rebirth upon returning to the normal world (Campbell, 1972; Lewin, 1939). For this reason, Blakeley (2000, p. 125) described the role of the shaman for the community "as a power too great to allow, but too substantial to forego".

2.3.3 The Power of Mythology

Humans have a need to transform developmental tensions into meaningful patterns within the group and trauma narratives translate individual life crises and life deeds into classic impersonal forms or myths to represent the inherent properties of a culture in relation to its environment (Campbell, 1972). Therefore, trauma dominates certain needs that direct a change in philosophy of the future, as a distinctly human characteristic (Maslow, 1943). In this way, mythologies replace subjective experience with a psychological economy and as speculations based on an impersonal symbolic object (Campbell, 1972). As such, trauma represents an unknown reality, latently experienced as events that connect to another place and time (Caruth, 1995; Kilby, 2002). As trauma experienced in the past is deprived of political desire, its future is the focus of the political imagination (Kilby, 2002). Therefore, the haunting power of historical injustice relies on politics to “bring the real event into being” (Kilby, 2002, p. 208). Similarly, coming to terms with trauma as the reality of the past concerns political justice that “demands an audience with the future” through narrative (Herman, 1992; Kilby, 2002, p. 208). The personal myth of the dreamer hereafter becomes the depersonalized dream of myth and provides the intermediate source of transformation as problems and solutions which are “directly valid for all mankind” (Campbell, 1972, p. 19). Accordingly, mythologies contain cultural archetypes as the “unquenched source through which society is [forever] reborn” and describe emotions, held in place by injury, as those emotions learned about through traumatic experience and that carry the whole of humanity forward into the future (Campbell, 1972, pp. 20, 29).

The earliest mythological account of trauma in written history involves the Mesopotamian Epic of Gilgamesh (3000 BC). Gilgamesh describes the traumatic pain associated with the loss of a close friend that leads to his futile quest for immortality (Campbell, 1972). The literature suggests that this mythology, or folklore, had a strong following based on the bigger than life character of Gilgamesh whose experience of psychological trauma openly challenged the norms defined by the collective culture of that period (Campbell, 1972). Birmes, Hatton, Brunet, and Schmitt (2003) described how the grief reaction is consistently re-experienced through recurrent and intrusive recollections of the traumatic event. Therefore, one characteristic of trauma is that it is experienced after it is forgotten so as to maintain social categories. As a set of broken recollections or traumatic memories, traumatic stress concerns the meaning of personal truth and existential existence involving human vulnerability and humanity's capacity for evil (Herman, 1997; Lasiuk & Hegadoren, 2006). Similarly, Leys (2000) and Radstone (2007) described the de-centring and de-stabilizing effects of trauma on personal control and memory and how 'forgetting' negotiates grief and loss for the subject. Radstone (2007, p. 17) added that the subsequent "lack of sovereignty and … unconscious processes of mediation and meaning-making" have provided the basis for the development of ideas in current trauma theory.

2.3.4 The Symbolic and Political War Hero

As cultural mythology was subject to periods of collective conflict and cumulative trauma, it inevitably absorbed a political objective. The symbolic and political power of the war hero demonstrates the importance of interpersonal conflict in human development (Alberts, Martin, & Kakayama, 2011). The first account of the war hero, from 2000BC in Egypt, describes the anguish experienced by the combat veteran Hori (Bentley, 2005, p. 1) as "the soul that lies in his hand". Similarly, Fassin and Rechtman (2009, p. 18) outlined the importance of experiencing individual suffering as it "bears witness to the traumatic aspect of the collective drama". Ajdukovic (2004, p. 122) added that integrity "connects the individual traumatic event with the meaning of collective violence in the societal context".

Ajdukovic (2004) highlighted the historical role of caregivers in the community in order to raise awareness about the consequences of trauma and to provide the means for social transition and treatment for the vulnerable and those most in need. Ajdukovic (2004) added that since caregiving involves the difficult search for meaning in relation to the violation of basic human rights, support mechanisms for trauma are typically inadequate for meeting individual and community needs. Subsequently, community and social reconstruction starts with the assumption that the basic and existential needs of people are being met. Ajdukovic (2004) explained that in order to achieve social recovery from collective trauma and loss caregivers need to seek new relationships through structures and institutions that provide a different context for normal social functioning.

Therefore, the emotional expression of, and reaction to, trauma is dependent on the management of tension or tolerance in the particular social or cultural setting, so that while cultural ideologies vary, humans' "emotional reaction to failure" may still be transformed by praise or change in the social environment (Lewin, 1939, p. 869). The cultural and civic institution of the Athenian theatre provides a well-documented illustration of trauma management involving the collective expression of feeling and emotion articulated as moral standards of conduct involving the entire community. The Athenian response to psychological trauma included public dramas involving hero mythologies, war epics, and rituals that "purified, healed and reintegrated" soldiers back into the community (Shay, 2002, p.103). As Kirmayer (1996, p. 189) confirmed, "trauma shared by an entire community creates a potential public space for retelling". The Athenian plays helped the community by allowing individuals to experience their own trauma as being an experience shared by others. This community collaboration (Sullivan, 1956) formed a sense of identification and common ground towards the interpretation and shared creation of a new narrative (Denham, 2008). The writings of Homer (approx. 850-500 BC) were originally for performance as oral narratives by traditional bards (Shay, 2002). Later, they were transcribed and edited, becoming the official religious texts of Athens, paralleling the canons of the Old Testament.

At the level of interpersonal community and group relations, the restoration of damaged social functioning increased efficiency and self-esteem, improved the quality of life, and supported feelings of safety and belonging in the community. The Athenian dramas highlighted the power of communication and language to define a “common abstract reality”, and a meta-narrative as a system of social ideas (Leach, 1976, p. 5). Tedeschi and Calhoun (1995) describe how epics mirror the universal elements of tragedy: 1) as experiences of shame and horror that lead to suffering and the reality of human suffering itself, involving (actual or imagined) life circumstances and crises generating knowledge; 2) as knowledge that creates insight into, and understandings of, the human condition; and 3) by affirming this knowledge, the new insights and understandings equip people to cope with traumatic experiences. Similarly, more contemporary trauma scholars, such as Shay (1994), uphold Aristotle’s statement about tragedy being a form of catharsis in response to terror and compassion. In this way, Campbell (1972) explained how the Homeric writings pronounced care as involving distinct stages of cognitive and emotional readjustment that transport the physical body from terror and war to a place of safety or belonging. This established intellectual and psychological recovery from trauma as specific traits of character in the collective consciousness (Campbell, 1972; Shay, 1994).

Accordingly, the Indian battle of the Mahabharata (950 BC) narrated the Bhagavad Gita or gift (great teaching), matching celestial events with historical outcomes considered beneficial for humankind, providing a model for human conduct (Campbell, 1972). These teachings recount the advice of the charioteer (Krishna) to the commander (Arjuna) in relation to his anguish over engaging in battle with his relatives and kin (Campbell, 1972; Murthy, 2003). Arjuna’s struggle with trauma transforms his consciousness about loyalties to the primary group (as obedience to formal rules) and to the demands of battle and adherence to the will of God. Such modified circumstances highlighted the beginnings of social sophistication as group rules "become [the] means of reciprocal accommodation" for the sole purpose of playing games (Sprott, 1958, p. 36). As well, the Bhagavad Gita contains ideas about symbolic and interpersonal development, with increasing cultural and social sophistication in relation to responses to deeply traumatic circumstances and events (Sprott, 1958).

Similarly, the Spartan battle at Thermopylae Pass (480 BC) describes the intermediary power of the Gods, involving the efforts of the commander King Leonidas. Although vastly outnumbered, Leonidas first evaded defeat by dismissing the soldiers who had been rendered unfit by terror and blindness associated with psychological trauma. Sparta was safeguarding her greater future and Leonidas' battalion of 300 ultimately assured their (cultural) immortality through martyrdom (Crowdy, 2007; Cunningham & Reich, 2009). By contravening the strict codes of moral conduct imposed by the military state, Leonidas displayed adaptive behaviour usually reprimanded by death or lifelong public disgrace (see also the Battle of Marathon, Birmes et al., 2003). Thus, Leonidas asserted an independence of moral judgement that demonstrated awareness of the extenuating circumstances and special factors involved in the learning of values (Sprott, 1958). The battalion of 300 also demonstrates the conflict in principles and competition of allegiances in the secondary group (Sprott, 1958). This story highlights the different contexts of shame and honour associated with trauma and of humanity's great requirement for redemption in relation to the risk of ongoing stigmatization in the community (Garrison, 1991).

The story of the 300 also defines trauma as tension and provides grounds for a cause and a reinterpretation of history. Similarly, Fassin and Rechtman (2009, p. 16) described how historical gains in knowledge originated from the minds of vanquished people seeking an answer to their problems that called for a "different way of remembering". The consequences of not having symbolic structures were outlined by the Anglo-Saxon chronicle (1003) below, that describes the psychological stress of King Alfred and his failure as an important role model when leading the Anglo-Saxons into battle against the Danes.

> *"... but he took to his old tricks: as soon as they were so close at hand that each of them looked on the other, then he pretended to be ill, and began to retch so as to vomit, and said that he was taken ill, and thus deceived the people that he should have led ..."* (Anglo Saxon chronicle, 1003).

2.3.5 Western Post-traumatic Growth as Symbol of Cultural Change

According to Birnbaum (2008), the biblical narrative of the Israelites offers the earliest documented description of collective post-traumatic growth. The biblical setting combines creation mythologies with historical accounts of civilization and monotheistic belief systems. The belief in a single God established the Israelite nation and led to the cultural transmission of Judeo-Christian principles in Western culture. The formation of spiritual beliefs, initially based on the cooperation and conformity that facilitated collective action, was surpassed by the acknowledgment of trauma involving gratitude in the knowledge of God and through affirmations of knowledge such as contained in the book of Psalms (Tedeschi & Calhoun, 1995). Overcoming the collective symptoms of loss and trauma involved group behaviour influenced by the attribution and perception of control. Individual and collective experiences of trauma emerged as dynamics in the field of life that included long-term social consequences (Abramowitz, 2005; Birnbaum, 2008). Contributing to the Israelites enduring awareness of trauma, the awareness of consequences helped to re-stabilize pre-existing norms and to re-establish important rituals that unified the group and demonstrated the resilience of their social and religious structures (Alberts, Martin, & Kakayama, 2011; Birnbaum, 2008).

These traumatic experiences included imminent death through plague, distress and fear of the Egyptians, rebellion, and the fear of leadership (Birnbaum, 2008; Exodus 5:21). Collins (1971) and Smith (1998) subsequently describe prayer as an emotional expression that conveys a message to the community and to God and that propels action towards a goal beyond its literal meaning. Examples from the Old Testament described Job (Chapter 7: Bible) in the aftermath of his experiences of loss and despair involving his family and livelihood. Samuel (13, 19-20) described Princess Tamar's (daughter of King David) prayer for justice in relation to her experience of rape. The literature discusses how this prayer defines the silent victimization of women as those defined by the inequity of historical cultural systems and by individuals who endorse fraternal and patriarchal institutions (Casey, 2010; Christ & Plaskow, 1989; Levenson & Halpern, 1980; Van der Walt, 2011). From this perspective, the growing human awareness of trauma involves two mutually inter-dependent dynamics: the 'meaning' given to an event or fact, and its position in the field of life that offers opportunities for learning (Lewin 1939). The Western adoption of the New Testament symbols of Christianity links human responses to trauma with a profound understanding of life and an appreciation for the therapeutic value of suffering as knowledge that combines the elements of tragedy with symbolic ideas about belonging (Tedeschi & Calhoun, 1995).

Discipleship and identification with Christ creates a distinction between coping for the management of traumatic experiences that provide avenues for personal transformation. Tedeschi and Calhoun (1995, p. 6) describe how the crucifixion of Christ at the height of the Roman Empire offers a "counterpoint to retributive suffering". The Lord's Prayer is spoken by Christ as the new spiritual leader of the Kingdom of God, also fulfilling the Israelite belief in their promised leader or messiah. Subsequently, the "internal capacity to cope … [with trauma and] to transform tragic experiences into creative encounters with life" is strengthened by reliance on God, the lives of others, and on the human will (Tedeschi & Calhoun, 1995, p. 8). In this way, the biblical narrative offers higher levels of cultural integration through the human collective and universal expression of trauma that crosses time.

2.4 Social Organisation

This section explores how new forms of social organisation incorporated ideas about trauma and care. It also explores how western collective trauma has emerged as a social and political symbol. This section makes a contribution to the knowledge in this area by exploring the power of medical science to advance notions of social control. The Middle Ages concluded the informal organization of the primary group and kinship-based feudal systems of ownership and social cooperation (Sprott, 1958). During the Middle Ages, scientific knowledge became the defining power that replaced superstition and ignorance, and the blind acceptance of authority (Hobfoll, 1998). This meant a decline in the extent to which norms were common and clear, as well as less frequent inter-personal interaction (Homans, 1951; Sprott, 1958). Leiss (2011) described the Enlightenment as the era that seeks to master human existence through the application of mathematical rules and the self-evident laws of nature as opposed to subjective experience. The control of nature for the benefit of humanity reiterated institutional structures of power involving the domination of some people over others (Leiss, 2011). Subsequently, the principles and values of the Age of Enlightenment that followed the Middle Ages involved political circumscription based on the perception that other peoples of the world, and women, were emotional and irrational (Hobfoll, 1998).

The Enlightenment period of history encompassed the French and American revolutions and established the world dominance and influence of Northern Europeans and an ideology that advanced European colonisation worldwide (Hobfoll, 1998). This dominance and colonial spread of influence brought with it new concepts of racism. Memmi (1986, p. 1) described racism as “the generalized, permanent exploitation of real or imaginary biological differences, to the advantage of the accuser and to the detriment of his victim, for the purpose of justifying aggression”. The most recognised form of colonisation in the Western world involved the African slave trade to the new colonies of North America. Stam and Spence

(1983, p. 3) therefore described colonisation as a process "by which European powers … reached a position of economic, military, political and cultural domination in much of Asia, Africa and Latin America" which underpinned the current circumstances involving developing third world countries. As well, the systemic exploitation of fear included terror and involved the devalued status of other human beings (Memmi, 1986).

The literature describes the social value of the high status citizen based on their impartial and moral framework, such as the account of psychological trauma involving the British politician, Samuel Pepys (1666), who described the emotions that engulfed and continued to haunt him following the Great Fire of London (Birmes et al., 2003). Hagen (2003) highlighted that the Age of Enlightenment focused on increasing cooperative success and decreasing the risks associated with social failure and political conflict among the powerful classes. Increasingly, the definition of socialisation and social control depended on natural interactions to "inhibit and facilitate various activities", including social bargaining (as an evolutionary strategy) to modify social ties and renegotiate contracts (Yinger, 1965, p. 157).

Trauma authors recognise that around this time William Shakespeare (1564-1616) demonstrated an advanced knowledge of psychological trauma (Hagen, 2003; Shay, 1994; Tick, 2005). In the following portrayals, Shakespeare's characters, many of who were absorbed in life crises and interpersonal conflict, made extensive reference to psychological trauma as associated with combat (Henry IV); concerning moral needs (Henry V); in tragedy 'not in the stars but in ourselves' (Julius Caesar); the soul in experience (King Lear); in death (Macbeth); and in intimacy (Troilus and Cressida). In England, the traumatic event had its "origin in the production of a representation" (Elsaesser, 2001, p. 194) as suspended in belief, or that occurs without a witness (Felman & Laub, 1992; Radstone, 2007). Therefore, Shakespeare demonstrated an artistic genius that clearly articulated the tensions of the period as being bargains with fate (Paris, 2009). Fassin and Rechtman (2009) thus described cultural trauma as a collective memory that remains hidden in place and time until characterized by the appearance of the first symptoms.

2.4.1 The Implications of the Institutional Treatment of Mental Illness

Institutions of social control defined both the development of beliefs about the treatment of mental illness and the patterns of social intercourse and reflection that would follow (Sprott, 1958). Institutionalisation in England and France during the 16th to 18th centuries became synonymous with the separation of productive members from others in society, according to their social relevance (Somers & Gibson, 1994). The English 'poor law' established workhouses, or houses of correction, as methods of collectivist revenue. The two main types of collective centred on a parish-based system through which cash and food were supplied for the needy and during failed harvests; while the other consisted of housing and healthcare accommodating hundreds of country people and thousands in the town centres (Smith, 2008). In France, formal relief occurred through large urban institutions (Smith, 2008).

In the context of rapid social change, Western urban and industrial expansion included ideas about public hygiene that would denote the cultural progress of civilisation and define the ways in which disease and trauma were now perceived (O'Sullivan, 2012; Porter, 1998). Due to rapid population growth, preservation of the socio-economic fabric was a necessary adaptation to the increasing risk of social dislocation and fragmentation (La Berge, 1992). This period resulted in an increased emphasis on scientific knowledge that was based on emerging information about disease causation, sanitation, and prevention (Cohen, 1983; La Berge, 1992). As a new institution, Public Health would address the need for reform and welfare concerns as significant state issues by promoting educative principles about disease through a collective social paradigm (La Berge, 1992). This paradigm emerged from early

Western capitalism and the booming mercantile industry that introduced medical policing of health for growing urban populations at risk of endemic disease and plague (Porter, 1994). The communication rituals of the Enlightenment period thus occurred in the context of new and emerging social issues such as reform, liberation, power, and control, by raising important questions that also required agreement (Adorno & Horkheimer, 1997; Leiss, 2011; Rocco, 1994). In this way, institutional and collective trauma involved the dynamics of socialisation and/or social control as it concerned the care of mental illness (Yinger, 1965). Thus, the Age of Reason or the Enlightenment (16-18th Century) proclaimed the human condition as the subject of scientific study (Hobfoll, 1998; Leiss, 2011).

Thus, administration through observation and medical techniques adapted the 2000-year-old work of Hippocrates' "Regimen Sanitatis", or rules for health, as a rationale and justification for the new intellectual class (Wilcock, 2007, p. 6). This occupational perspective on health included six main areas of focus: "air and environment; motion and rest; food and drink; sleep and waking; evacuation and repletion (including sex); and affection of the soul (including joy, anger, fear, and distress)" (Wilcock, 2007, p. 6).

The growing sense of alienation in society highlighted an evolving responsibility of the state to assume a lead caretaking role and to establish new frameworks for belonging based on trust systems of relationship and faith (Herman, 1992). Therefore, a new and detached language of medical science advanced the discrete values of society as subjective assumptions and social judgements of the time (Somers & Gibson, 1994). Kahn (2013) noted that modern reason evolved a *counter-instinctive* and sophisticated consciousness in direct opposition to social instincts and behaviours. This process aimed to protect the heterogeneous personality from surrendering to overwhelming angst. Kahn (2013) described how evolutionary *herd instincts*, once useful for reacting to certain types of distress have assumed a vestigial role as new social instincts, such as *panic anxiety*. Foucault (1988) and Hobfoll (1998) suggested that the change and transition to the Age of Reason teaches much about human disconnectedness. This disconnect replaced the religious social order with medical science, for the diagnosis of trauma and management of problems through thought (Szasz, 1977). The thought machine of reason focused on enlarging and refining the control of trauma by increasing medical administration (Leiss, 2011; Rocco, 1994).

2.4.2 The Military Symptoms of War Trauma

Johannes Hofer's (1669-1752) dissertation, *De nostalgia* (1688), recognised nostalgia as a formal clinical entity and an accepted medical condition involving the symptoms of homesickness in young Swiss soldiers. The symptoms of nostalgia included insomnia, anorexia, digestive problems, wasting, dysentery, and fever (O'Sullivan, 2012). Pathological changes in the lungs, associated with frustrated longings, were believed to be fatal, although frequently, the symptoms were recognised as meningitis, gastroenteritis, and tuberculosis (Lowenthal, 1975). Nostalgia described the biological and geographical 'home' that had been drawn into conflict that isolated trauma as a passage through which the enlightened man should come (Rosen, 1972). The fatality of homesickness described growing young men involved in involuntary military service who had lost hope of safe return to their beloved homeland (Rosen, 1972). It was believed that the body diverted its normal functioning (Rosen, 1972) and the men were described as being indifferent to the maintenance of life, "sad, taciturn, listless, solitary, musing, full of sighs and moans" (Rosen, 1972, p. 448). Nostalgia was not limited in its recognition to Swiss soldiers. At the same time, Spanish physicians termed this condition as Estar Roto (to be broken), while homesickness (Heimweh) was recognized in German soldiers (Tick, 2005).

The soldier as a privileged member of an underprivileged minority group and thus socially and culturally defined by symptoms and behaviours (including emotional instability and sensitivity) that emphasised the importance of the many other actors' parts in the field, characterised by the political tensions that prevailed between the rural and urban populations during this time (Lewin, 1939). Phillips (1985) referred to the French soldier as recapturing the mythology of the past by being the spectator of his own thoughts who, like the shaman before him, assured unification for the French republic and its new institutions and political systems through his patriotism (Bentley, 2005). The meaning of nostalgia as a symbol of modern trauma describes the 'marginal man' as being on the periphery of two groups, not certain about identity but belonging to neither (Lewin, 1939). Alternatively, Daniels (1985, p. 85) wrote about nostalgia as "neither catharsis, nor interpretation, nor both together … but … a reliving now to return to the dream of what was and what will be", not through time, but in the constitution of the soldier's body (Daniels, 1985). Hollins (2000, p. 194) confirmed this point, stating "the body for a purpose is almost certainly the rule in the early modern world".

During the 17th Century, physicians prescribed a traditional cure for this ailment (O'Sullivan, 2012). The establishment of French military schools as "the auxiliaries of civilisation" to improve soldiers' education and reduce their sense of isolation, would realise the subsequent decline of nostalgia (O'Sullivan, 2012, p. 244). Regular exercise, listening to music, rural instruction, and limiting the number of years of military service would retain the hope of a safe return and enjoyment of their civic rights (Jones, 1995; O'Sullivan, 2012; Rosen, 1972). In 1761, the Austrian physician Josef Leopold Auenbrugger published "Inventum Novum" which legitimized nostalgia as a disease. Medical respectability spread knowledge of the disease from provincial soldiers and relocated the dominant ideology and community consciousness from the country populations to the educated elites within society (Lowenthal, 1975). Based on the observance of a medical condition, the growing acceptance of nostalgia transformed scientific learning and the development of treatment (Phillips, 1985).

2.4.3 War Trauma as a Nervous Disorder and Crime

The medical invention of ‘percussing’, involving a tapping procedure for detecting changes inside the patient through physical contact with the body, established the model that modern medicine was to follow (O'Neal, 1998; Rosen, 1972). During the late 1800s, Da Costa studied over 300 cases of war trauma and established standard procedures of physical observation and treatment to detect the signs of the heart and its impulse. The goal of care was to locate alterations in the impulse of the heart (the way it started and shuddered) and to prevent their displacement to other parts of the body and other functions. Prevention involved strategies that included periods of convalescence to assist recovery, and advice for the armed services to equip young recruits with ways to address fatigue and reduce risk by limiting disabling manoeuvres to only what was necessary (Da Costa, 1871). Da Costa believed that this knowledge of Irritable Heart (or Da Costa’s Syndrome) would increase recognition of the syndrome and its treatment in the general population (Jones, 2006; Wooley, 1982). Giving scientific validity to the syndrome also exposed unproven causes such as ‘malingering’.

During the late 1800s, reports and death certificates of soldiers involved in the Boer War in South Africa indicated disorders of function involving maladies of the heart (Ray, 2008). Myers (1870) described ‘Soldier's Heart’ as extreme fatigue, tremors, shortness of breath, palpitations, sweating, and sometimes fainting during combat. At the same time, the establishment of the first military hospitals during the American civil war merged the field of medical science with its educative value. Similarly, Da Costa (1871) published his paper on ‘Irritable Heart’ in relation to nervousness resulting from weakness in the organ, being known as ‘neuro-circulatory asthenia’. The literature reports that links between stress-related disorders and military drills were also made in Great Britain at this time (Da Costa, 1871).

2.4.4 Observing and Understanding Trauma Through Psychoanalysis

The writings of the ideologues of the French Revolution included the first ideas about mental illness and insanity, and reforms known as “moral treatment” (O’Sullivan, 2012, p. 626). The thoughts of the ideologues linked the “moral to the material world, psychology to physiology and medicine to politics and to the social sciences” (Ramsey, 1994, p. 53). The ideologues shifted the focus away from health as the inherent right of the French citizen (as outlined by the first French Constituent Assembly), to the citizen patient as having economic value for the utilitarian state (Ramsey, 1994). This meant that health experts were accorded the authority to design and execute public policy as advisors on legislation and for health and public medicine on behalf of society (Ramsey, 1994).

Philippe Pinel, a member of the ‘idéologues’ during the 1800s, is celebrated as the father of psychiatry and founder of the Alienist movement. The Alienist movement perceived society as a scientific object and was focused on discovering organic similarities in illnesses and the significance of their role in human evolution (Barberis, 2003). The treatment established the observation of symptoms and the empirical notion that emotional and mental disorders can result in organic disease or pathology (Huneman, 2008). Writing on mental disease in 1787, Pinel introduced the concept that people with mental illness experienced alienation as a result of the interaction between human psychology and the environment (Lowenthal, 1975).

In 1796, Pinel was appointed physician-in-chief at the Salpêtrière hospice in Paris. The study of mental illness was symbolised by the right of the mentally-ill (as citizens) to humane treatment. Under his supervision, patients were placed in wards and permitted freedom in relation to their own personal safety, and that of others, subject to close observation (O’Neal, 2007). Pinel applied his compassion and his profound and complex understanding of the confusion of the mentally-ill to the cultural setting in which it occurred (O'Neal, 2007; Yinger, 1965). Believing that the inhabitants of mental asylums were deprived of fresh air and liberty, Pinel is famous for removing the chains that added to their distress (Owen, 1971). Pinel opposed the paid and public viewings of inhabitants of the asylums as 'monsters', and rejected the widely-held belief in the 'absolute incurability' of the mentally-ill as a form of simplistic prejudice (O'Neal, 2007, p. 244). The perspectives of the patients themselves were sought in relation to repressive methods. At the Salpêtrière hospice in Paris, Pinel pioneered the way for curative and research work that contributed to the development of analytical medicine and diagnosis (Owen, 1971).

Jean-Martin Charcot inherited the position of physician-in-chief at the Salpêtrière hospice in 1862 (Owen, 1971). Charcot's studies followed the first empirical investigation of hysteria by Briquet (1859) which established the association between hysteria and exposure to extreme stress (Van der Kolk, 1996). Charcot viewed the women patients' experiences of hysteria as a condition of the nervous system, and the women themselves as the subjects of scientific study for the management of trauma (O'Neal, 2007). The diagnosis of hysteria offered a psychodynamic concept of mental disease that recognised the lack of biological damage and resulted in the subject being offered for academic teaching in the School of Neurology (O'Neal, 2007). Charcot was appointed Faculty Chair of mental and brain diseases in 1875, while Alienism gradually declined in influence (Bogousslavsky & Moulin, 2009).

Herman, (1992) described how, at this time in history, the consequences of the historical repression of women's experiences of trauma resurface and emerge in the literature as the unknown and timeless voices of the experiences of violence, exploitation, and rape. As misunderstood and invisible populations, the women found refuge in the Salpêtrière hospice and other asylums (Herman, 1992). Charcot was accountable for no less than 5,000 patients, including 2,500 women whose living conditions, although vastly improved from Pinel's time, were still problematic. Classified as being either mentally inadequate or disturbed, Charcot perceived a number of the women as having "chronic maladies supposed to be incurable and thus reduced to a state of lasting infirmity" (Charcot, 1867; Owen 1971, p. 34). Charcot identified each aliment as a clinical entity in order to understand its cause and to facilitate care and cure (Owen, 1971). Charcot's observations included an index or catalogue of speech, known as 'vocalisations', as the symptoms and signs of hysteria. While women with hysteria were generally believed to be malingerers, Charcot is widely recognised as the first practitioner to restore dignity and objectivity to the condition (Herman, 1992).

2.4.5 Implications for the Care of Mental Illness

Pierre Janet and Sigmund Freud were students of Charcot who sought to discover the cause of hysteria through their professional rivalry. During lengthy conversations and working in collaboration with the women, Janet and Freud uncovered unbearable emotional reactions that had altered the women's states of consciousness and subsequently produced the symptoms of hysteria (Herman, 1992). This discovery broke new ground in the observation and study of vocalisations that resulted in their famous formulations. Janet named the altered consciousness 'disassociation' (as resulting from psychological weakness in the individual), and highlighted the medical perspective concerning human reactions to tragic life crises (Herman 1992, p. 12). Freud and his associate Joseph Breuer believed that it was the women's integrity that had led them to banish extremely distressing events from their memory which they subsequently re-experienced as reminiscences (Herman, 1992).

Thus, Szasz (1973, p. 46) described hysteria as suffering induced by "the persistence of the old (internal) objects and from [an] unmodified relationship to them". This suggests that the traumatic experiences were internalised due to the person not being able to develop new narratives about historical oppression. Freud and Breuer thus independently came to the same conclusion that hysteria was a condition caused by psychological trauma (Herman, 1992). As a result, the 'talking cure' became the first form of psychoanalysis to reconstruct lives through words, and to express long supressed memories and feelings (Herman, 1992, p. 12).

Following this finding, Freud published the 'Aetiology of Hysteria' (1896) which indicated premature sexual experience as the source of hysteria (Herman, 1992). While being the first in the medical profession to share this 'truth' about women's reality, Freud returned to the influential class to re-establish his professional prestige and to recant the controversy associated with his original findings (Eisen, 2001; Herman, 1995). Herman (1995, p. 15) stated that this is where "the study of psychological trauma came to a halt". Early psychoanalysis thus crossed the rift between empathy and experience to regain and refocus attention on social and political events (Fassin & Rechtman, 2009; Herman 1995).

2.4.6 Industrial Trauma and Classification Systems

Hobfoll (1998) described the 'Age of Stress' as including organizational designs and political structures as a paradigm of truth that combined historical trauma with increased production. This introduced the formulation of classification and duty of care legislation for workers at risk of injury or loss of life. John Eric Erichsens' (1867) discourse on 'Railway Spine and other injuries of the Nervous System' described the symptoms of life-threatening railway accidents as fatigue, tremors, pain, anxiety and depression. Similarly, Mendelson (1987, p. 48) referred to Charles Dickens' account of traumatic neurosis following a railway accident as being "curiously weak … [as from a] long illness" with his memories of the event being "inexpressibly distressing". Oppenheim, a German neurologist, also established that psychic shock was caused by exposure to trauma that resulted in traumatic neurosis (Ford, 2009).

Schmiedebach (1999, p. 27) stated that “by dealing predominantly with industrial accidents, Oppenheim problematized the relationship between social class and nervous disorders”. Oppenheim’s published cases of industrial accidents suggested that the workmen entitled to receive the new insurance should include social and legal equality for people with a mental illness. A culture of suspicion surrounded the financial motives of claimants in relation to secondary gains and class interests. Railway workers who failed the criteria of traumatic neurosis were suspected of class-related malingering. This resulted in the stigmatization of workers and associated ongoing complaints of bad faith, otherwise labelled as “compensation neurosis” (Fassin & Rechtman, 2009, p. 39; Pitman, Sparr, Saunders, & McFarlane, 1996). However, women’s experiences of hysteria remained an unfamiliar context in the new social and legal setting and failed to meet the classification criteria (Schmiedebach, 1999).

Consequently, forensic psychiatry was introduced by the state to determine industrial claims. This new sub-specialty was developed to verify and substantiate traumatic neurosis as a medical matter where lawyers lacked the expertise (Fassin & Rechtman, 2009). Forensic psychiatry investigated the compensation and disability claims of workers to counteract ‘sinistrosis’, or the ‘inhibition of good will’ (Brissaud, 1907; Fassin & Rechtman, 2009). Compensation was thus legally controlled and culturally reinforced through professional behaviours and political structures. Subsequently, psychotherapy began to measure “the social conceptions which establish the norm, the value of a subject, the price of a life” through expert medical roles (Fassin & Rechtman, 2009, p. 35).

2.5 Trauma and Care Discourse

The following section contributes to the current knowledge about trauma and care by exploring the implications of social organisation and how these have led to current discourses about trauma and care. Fassin and Rechtman (2009) described the discovery of ‘painful memory' as a major phenomenon of contemporary societies. As such, the trauma discourse is based on real situations and standard examples involving knowledge about behaviour in relation to diverse social roles and rules (Machado & Burns, 1998). Based on social and political events, this common knowledge outlines the basis for interactions involving trauma and concerning the treatment of mental illness. The development of concepts that now define the treatment of mental illness and how modern trauma is defined will be described.

2.5.1 Industrial War Trauma and the Formal Corporation

The battlefield of World War 1 (WW1) transformed the honourable niche of the traditional soldier previously celebrated in the war literature (Leed, 2000). As soldiers, men were poorly trained in the techniques of repression previously instilled in professional armies through history, so that failures of adaptation frequently involved experiences of overwhelming fear and guilt (Herman, 1995). As a result, the soldier's role in the trenches and battlefields of WW1 was reinforced by responses to trauma involving helplessness (Howorth, 2000). Together with the threat of eminent annihilation on the battlefield, the experience of helplessness was prolonged so that it produced "a neurotic syndrome resembling hysteria in men" (Herman, 1995, p. 20). With the close resemblance of war neurosis to hysteria, physicians struggled to distinguish it from the inhibition of good will or cowardice of morale (Van der Kolk, Weisaeth, & Van der Hart, 1996).

During WW1, the institutional hierarchy recognised officers as being the only men with the capacity to understand the gravity of the situation, despite available data from the 1912 Russo-Japanese conflict about the effects of trauma on rank (Fassin & Rechtman, 2009; Jones, 1995). This attitude was reinforced by the bureaucracy and a style of military training that de-skilled the soldiers and forbade purposeful activity outside of war (Howorth, 2000). Subsequently, Bentley (2005, p. 5), quoting Edmund Wilson, described the trauma of WW1:

> *"No-one pretends to give a damn anymore ... whether people are killed or not ... the suppression of the natural bonds between ourselves and these unseen human creatures, is paid by repercussions ... in our immediate personal relations".*

2.5.2 The Consequences of Industrialisation on Interpersonal Communication

Soldiers experienced the following negative consequences. Firstly, for the first time in military history, soldiers were required to change their identity from soldier to civilian once their war service had ended in order to forget war and the unpleasant experiences of battle (Leed, 2000). Secondly, the strain of conversion from military to civilian life meant a loss in familiarity around the soldiers' recollections of war-related events and the modified rules of *give and take* that identified historical military societies (Leed, 2000). Thirdly, no longer having a glorious mythology to support resulted in unprecedented levels of breakdown in recruits numbering 40% of psychiatric casualties, which represented a threat to national morale (Herman, 1995). Finally, the association between class and compensation insurance ensured that state governments, civil servants, and their ministers would apply as narrow as possible an interpretation of war-related injury (Winter, 2000). Gradually, the soldiers came to occupy a theatre of disgrace (Fassin & Rechtman, 2009).

However, during this period, the goal of the psychoanalyst was to make the patient recognise that shell-shock was a problem of the patient and his tendencies (Fassin & Rechtman, 2009). Soldiers were required to confess and renounce their war-related symptoms. As an accident of personal and individual history, confession and the renunciation of symptoms assisted the soldier to recognise that avoiding the battlefield was based on personal advantage and that he had endangered the group and its members (Fassin & Rechtman, 2009). Therefore, the soldier who genuinely admitted his motives to the group benefited most from the treatment. Subsequently, recovery was medically confirmed if, and when, the soldier admitted being better and wanting to return to the front (Fassin & Rechtman, 2009). Therefore, as a trauma discourse that provided a specific representation of reality, the informal and cognitive nature of closure also established and supported the maintenance of social order.

Psychiatry thus conformed to the expectations of military authorities by modifying the rules (involving the use of methods such as disempowerment and helplessness) and language of treatment (Fassin & Rechtman, 2009). As a symbolic process based on concepts involving power, the psychiatric discipline therefore pursued a pre-existing context of structural trauma to explain the impact of the new traumatic event (Fassin & Rechtman, 2009). Therefore, new definitions about 'regimes of truth' meant that the medical profession could orientate their judgements towards ongoing interactions (Foucault, 1972; Machado & Burns, 1998). Conversely, the legitimisation of prestige accompanying the rise of psychiatry represented consolation for the profession through a highly lucrative venture (Fassin & Rechtman, 2009).

2.5.3 The Treatment of Shellshock

The British physician Charles Myer (1915, p. 608) described shellshock as the "loss of memory, vision, smell and taste" resulting from exposure to exploding shells. While the physical cause of shellshock was originally attributed to a physical event, shellshock became increasingly evident in men without physical trauma, so that physicians finally conceded the cause as psychological trauma (Herman, 1995). Charles Myers discovery of shellshock was rapidly followed by his assertion that traumatic memories are dissociative in nature. Based on Janet's concept of hysteria, Myers claimed that the emotional disturbance experiences of soldiers resulted from a "disassociated complex" (Herman, 1995, p. 17).

This meant that while soldiers affected by shellshock could still hear, their memory and other senses were often "lost or distorted" (Ford, 2009, p. 13; Myers, 1915). Soldiers were regularly treated with faradism (a particular type of electro-treatment applied to the skin), and psychological coercion and persuasion (Fassin & Rechtman, 2009; Mendelson, 1987). As a ritual of diagnosis, electricity provided the means of defining the condition of terror caused by combat. Electricity was therefore established as a cure as it produced an image of injury that gave substance to traumatic events and encouraged a persona, or state of mind, that continued to reside in trauma throughout the veterans' lives (Leed, 2000).

Prevention of shellshock through 'forward treatment' was introduced by Thomas Salmon (1917), a British Army Surgeon General. This incorporated three psychiatric principles of treatment: proximity (closeness to battle [explained below]); immediacy (warmth, food, and rest); and expectancy (return to comrades) (Jones, 1995). The importance of the location of treatment demonstrated the immediate power of the group and acknowledged the environment that held memories for soldiers forced to return home (Hemmings, 2005). Subsequently, Rivers' (1918) paper, 'Repression of War Experience' cautioned against standard medical advice to avoid all thoughts of war (Hemmings, 2005; Rivers, 1918). Rivers utilised narrative and healthy memory in the "action of telling a story" and avoided repressing the effects of painful experiences that exacerbated the neurosis (Hemmings, 2005, p.1). Rivers' progressive understanding of trauma facilitated frameworks for treatment which included prompt treatment through the acknowledgement of events in awareness, retelling with an emphasis on meaning for the individual, a collaborative approach to cognitive restructuring, and understanding of the importance of previous experiences (Howorth, 2000). This approach led to current practices in cognitive behavioural therapy, narrative, and self-constructive therapies, and introduced the concept of therapeutic alliance, now utilised as a model for care (Howorth, 2000).

Rivers' collaboration with WW1 veteran, Sassoon, gave voice to traumatic memories as constructing workable associations that established therapeutic treatment through catharsis (Hemmings, 2005). Similarly, William Brown's (1920) approach was detailed in 'The

Revival of Emotional Memories and its Therapeutic Value' (Ford, 2009). Browns' psychoanalysis involved 3,000 soldiers and the retelling of the details of events before hysterical symptoms appeared. Best undertaken while the soldier was still near battle, the cathartic mechanism was engaged to liberate patients from suppressed distress and to produce a re-synthesis of the mind (Ford, 2009; Herman, 1992). Growing public awareness about shellshock established trauma as the central narrative of modern war (Winter, 2000). As a special kind of injury, speculation about shellshock allowed families and communities to bypass the stigma associated with hysteria or nervous disorders and the psychological vulnerability linked with disassociation (Winter, 2000).

2.5.4 The Advent of Psychiatric Care in the Community

Following the events of the First World War, an increased status for Psychiatry and reform was facilitated under the guidance of British commander Thomas Salmon (Cohen, 1983; Garton, 1994). An increasing motivation for community-based psychiatric care was heralded by the 1908 publication 'The Mind That Found Itself' which described first-hand experiences of institutional and systemic abuse in the autobiography of Clifford Beers (Chamberlin, 1990; Kiselica & Robinson, 2001). As a young man of social status, Beers headed a movement for reform that attracted widespread recognition that was to become the Mental Hygiene Movement. Beers achieved this through gaining the financial and symbolic support of influential members of society, including leaders in the treatment of mental illness, author and psychologist William James, and psychiatrist Adolf Meyer (Garton, 1994). Importantly, Beers' advocacy and egalitarian vision for humane treatment for the mentally-ill had originally included his fellow patients and their families. However, Beers succumbed to his own doubts following widespread public prejudice about mental illness and under increased pressure from psychiatrists (Chamberlin, 1990).

Following Beers' motivation for reform, Salmon concentrated on building academic and political prestige to inspire further reform. By 1909, an elite group of like-minded academics, social workers, physicians, and psychiatrists had formed the National Committee for Mental Hygiene (NCMH). As a medical and moral responsibility, the NCMH focused on improving conditions in mental institutions and developing avenues for further research (Cohen, 1983; Mayes & Horwitz, 2005). By 1920, Canada, Britain, France, Germany, and Italy had joined the international NCMH charter (Cohen, 1983, pp. 126-127). As in North America, Australia gained widespread support and vigour for mental hygiene by recruiting elite members of society including academics, doctors, lawyers, educationalists, and feminists to its branch of the movement (Casamajor, 1943; Cohen, 1983; Rieff, 1968). The principles of mental hygiene represent the founding principles of the modern mental health system and are commonly endorsed by governments worldwide (Garton, 1994). Mental hygiene has established a "blueprint for professional surveillance of social life" (Garton, 1994, p. 180). Subsequently, the original hygiene movement has splintered into government bureaucracies of "child welfare, health, mental health, labour, and education" (Garton, 1994, p. 180).

This new emphasis on personality development as a causal factor for disease symptomology resulted in a societal shift of focus from a medical model of responsibility to the family. Childhood represented the "aetiology of maladjustment" and a "golden period for mental hygiene" (Cohen, 1983, pp. 126-127). No period could more greatly represent this shift than the increasing focus of prevention of mental illness in childhood development. Thomas Salmon's Commonwealth-funded 'Program for the Prevention of Delinquency' (1922-1933) (Cohen, 1983), incorporated group and individual psychotherapy in schools assisted by social workers and child psychiatrists as visiting educators (Cohen, 1983; Snyder, 1947). In Australia, child guidance clinics assisted parents to improve, promote, and monitor children's psychological and physical well-being and to recognise the symptoms of personality maladjustment and interactions that led to conflict in the home, as well as to seek expert medical and psychological advice (Garton, 1994). This shift highlighted the parental role and the caregiver's responsibility in the context of a modern society.

2.5.5 Community Mental Hygiene and Social Care

Importantly, mental illness and trauma were redefined as the 'symptoms' of personality maladjustment and as the causal root of all social problems (Cohen 1983, p. 126). The following concepts and rules provide the context that established and largely defined the current treatment of mental illness in society. Three main conceptual and symbolic emphases emerged in care. The first included Adolf Meyer's contribution to mental hygiene through the field of psychobiology which described "the total personality and life experiences of the person" as the context for the symptoms of mental illness (Mayes & Horwitz, 2005, p. 250). The second important influence for the treatment of mental illness involved the work of John B. Watson (1913), whose behaviourist psychology involved the scientific prediction, regulation, and control of evolutionary behaviour. Behaviourism was based on the "assumption that early experience shaped later mental functioning" and expressed the legacies of particular "reinforcement histories" (Pilgrim, Rogers, & Bentall, 2009, p. 236). The third influential field was psychoanalysis which, while still based on Freudian concepts, absorbed the influences of Jung (the collective consciousness) and Adler (the safeguarding of the self) (Cohen, 1983; Synder, 1988). Psychoanalysis combined four approaches for the care of mental illness: "mental health treatment, personal education, reform or correctional process, and moral or spiritual redemption" (Orlinsky, 1989, p. 413).

2.5.6 Background to Worldwide Treatment for Mental Illness

In the late 19th century, public health and mental hygiene principles identified potential sources of agency in society to politically quantify recovery in relation to ongoing socio-economic expansion (Grob, 1991; La Berge, 1992). Given the need for increasing regulation, Emil Kraepelin, a German experimental psychologist, first classified the common symptoms among his many patients as categories of mental illness (Grob, 1991). Kraepelin's generalised and fixed approach to mental disorder pre-supposed mental illness as 'universal entities' of disease, despite the individual circumstances facing his many patients (Grob, 1991). Kraepelin's simplified classification of mental disorders opened the door for modern psychiatry by supporting the definition of mental illness as a disease state, and the development of a medical model for the treatment of mental illness as a modern reference for psychological trauma (Fassin & Rechtman, 2009; Magora, Gripp, McDowell, & Miller, 1978). In his 1896 publication, 'The Pathology and Therapy of Psychic Disorders' (Cushing, 1935), Kraepelin presented a new approach to the treatment of mental illness that corresponded deeply with the medical ambition and thinking of the time (Grob, 1991).

The discovery of bacteria in the late 1800s, and the development of a serum for syphilis, led to the discharge of populations from mental institutions (Ehrlich, 1891; Weitz, 2007). Such an important discovery reframed the definition of mental illness as a disease state and "fuelled the everlasting hope that simular consequences will eventually cure madness" (Magora et al., 1978, p. 41). At the turn of the 19th century, French psychiatrists were voicing their desire to expand their professional expertise to treat the ills of society (Cohen, 1983; O'Sullivan, 2012). In North America, in particular, psychiatrists pursued preventative and clinical methods of intervention, to support their private and clinical practice (Garton, 1994). During this time, a range of events and circumstances contributed to the existing dominance of psychiatry for the treatment of mental illness. The "emergence of psychological man" and the "triumph of the therapeutic" shifted the treatment of the institutionalised "insane, mentally deficient and alcoholic" towards civilising influences and professional motivations for reform (Cohen, 1983, p. 126; La Berge, 1992). As a public health issue, the prevention of mental illness progressed from the "hospital and the mental asylum to the courts, prisons, [and] industry” to focus on and involve wider society (Cohen, 1983, p. 126). This professional motivation was also linked to growing public awareness and concern about the impact of institutionalisation on vulnerable people towards the end of the 19th century.

2.6 The Emergence of the Caregiving Role

This section explores how developments in the treatment of war-related trauma have significantly contributed to the development of psychiatric care and the development of the caregiving role in the community. Leading up to the Second World War, the first phase of an emerging caregiving role for mental illness in Western society corresponded with a number of social, cultural, and political factors that increasingly defined human stress and psychological trauma as a particular class of actions that required formal treatment.

2.6.1 Group Membership and Cohesion

During the Second World War and the Korean War, military psychiatrists Abram Gardiner and Herbert Spiegel introduced the terms ‘war neurosis’, ‘combat stress reaction’, and ‘combat fatigue’ to describe soldiers’ psychological trauma (Ford, 2009). Combat fatigue replaced exhaustion to convey the soldiers’ expectations about group cohesion and participation (Jones, 1995). Gardiner also adapted catharsis, through hypnosis and re-adaptation, to reconnect soldiers with the traumatic state (Van der Kolk, Weisaeth, & Van Der Hart, 1996). Free expression, also known as abreaction, involved releasing previously repressed emotions (Fassin & Rechtman, 2009; Herman, 1992). The forward treatment method (Salmon, 1917) was also reintroduced to protect group membership (Jones, 1995).

Traumatic neurosis was perceived as a genuine mental illness leading to incapacity. It involved the suffering of the patient and those close to him, and thus clearly sanctioned the individuals’ entitlement to receive medical and social attention. However, this entitlement was often associated with negative affect and a threat in relation to society's ability to provide assistance (Fassin & Rechtman, 2009). As with the experience of soldiers during WW1, WW2 soldiers' experiences of trauma were linked to the theory of secondary gains that stated, "if the subconscious benefits of the illness are greater than the discomfort of the symptoms, the illness is likely to continue indefinitely" (Fassin & Rechtman, 2009, p. 58).

Subsequently, in 1942, Marcel Moreau insisted that traumatic neurosis "should be entirely a medical matter" (Fassin & Rechtman, 2009, p. 65). However, due to the belief that the severity and persistence of the symptoms would disappear as soon as the incentive was removed, it was proposed that trauma should not be compensated for in the future, as occurred in Germany post-WW2 (Pitman et al., 1996). Leed (2000, p. 99) explained that "pity is justifiable if we look into the causes of this suffering and examine the terrors humans have made for themselves throughout history". This situation also refers to the presumption "that war and peace are distinct and separate realms of existence" (Leed, 2000, p. 88). By defining "war as an abnormal state of emergency" (Leed, 2000, p. 88), society's attention was placed on forgetting traumatic experiences and the changed identity (Herman, 1992).

The introduction of group psychotherapy in 1945 saw the use of role plays and ego reinforcement to highlight personal qualities as traits of character by focusing on leadership potential and sense of responsibility (Jones, 1995). However, the dominant practices in care still centred on the personal fragility of the soldier. The clinical practice of psychiatry established their "recognition in the field" that turned soldiers' traumatic experiences into a clinical objective that therefore questioned the significance of each subject and their history (Fassin & Rechtman, 2009, p. 67). The new politics of trauma were symbolized by the financial incentives to provide a psychiatric service as a new theoretical construct of exchange (Fassin & Rechtman, 2009). Efforts to shorten recruitment time involved the psychological screening of soldiers through psychoanalytical performance tests, led by the American psychiatrist, Harry Stack Sullivan (1942). Doubtful of their validity following the mass acquittal of recruits, these screening tests were discontinued and the soldiers subsequently re-enlisted (Jones, 1995; Wessely, 2005).

2.6.2 Coping with Failed Attachment and Grief

The post-WW2 belief in a better world focused on the social needs of the community (Grob, 1991). The World Health Organization (WHO) commissioned John Bowlby to advise and make recommendations about the effects of maternal separation and deprivation upon orphaned and homeless children in post-war Europe (Bretherton, 1992). ‘Maternal Care and Mental Health’ was published in 1951, and Bowlby’s clinical and theoretical interests focused on the intergenerational transmission of children’s early attachment relations with parents (Bretherton, 1992). Due to the child’s failure to thrive or gain weight, disordered attachments and maladaptive behaviours resulting from minimal human contact with few staff, were associated with the increasing incidence of mental illness (Sullivan, 2003).

Bowlby thus developed ‘object relations’ to correct disrupted attachment or neglect, focusing on re-establishing attachment through mother-infant contact. Bowlby distinguished four components of attachment: attachment with the caregiver; the proximity of the caregiver; a safe haven; the infant being abused while still in contact with the caregiver (Sullivan, 2003). This breakthrough involved observing the process involved in the grief reaction, consisting of denial, protest, despair, and detachment (Pilgrim, Rogers, & Bentall, 2009; Valent, 1995). Subsequently, Bowlby warned against the influence of institutional care, advising the principal need for early intervention and benign care (Pilgrim, Rogers, & Bentall, 2009).

A social model for the treatment of grief and trauma did emerge in the post-WW2 community, acknowledging the importance of the context of grief for its role in recovery.

Overwhelming demands for treatment and waiting lists in the community of more than nine weeks saw many people give up on seeking care. Following the highly publicised Coconut Grove nightclub fire (where lax building codes resulted in 492 fatalities), Lindemann (1944) and Caplan (1964) developed a model for community-based care that specified shorter periods for treatment and a shift in focus to the group, the family, and the community in the early detection and intervention of mental illness (Darbonne, 1967).

Subsequently, 'Crisis Theory' was developed involving four phases of problem solving which identified adaptive and maladaptive techniques for coping with the effects of trauma (Darbonne, 1967, p. 49). This approach would address the emotional hazards of trauma by exploring individual coping methods and how they affected later adjustment. The context of Crisis Theory and community treatment will be explored further in Chapter 3, within the framework of caregiving and participation in care in mental health services.

2.6.3 The Empowerment of the Witness

In reference to Nazi concentration camps, the statement "the sane consequences of an insane experience" introduces psychological trauma as the original condition of human survival experiences (Fassin, & Rechtman, 2009; Krell, 1984, p. 523). Human survivors of trauma give form to memory and increase moral awareness in collective environments by putting "words, concepts and images to the unspeakable" (Fassin & Rechtman, 2009, p. 74). Fassin and Rechtman (2009, p. 78) added that the survivor witness translates the "philosophical, sociological, psycho-sociological" aspects of trauma and memory as a universal testimony of truth. As the actual verification of trauma is formally impermissible and publically incompatible, the survivor witness introduced new rules by organising informal social networks (Machado & Burns, 1998). Fassin and Rechtman (2009, p. 97) explained how victimhood emerges from the silence to establish trauma as the principle position in society "that annuls other moral and political positions". Consequently, the survivor integrates the "invisible and non-rational" elements of trauma with formal organisation and democratic systems outside of the constraints of the peripheral (Machado & Burns, 1998, p. 380).

Therefore, Radstone (2007) explained that recovery from trauma demands a witness to listen so that testimony can take account of the subject of the trauma. This new idea about the collective witness provided a social memory that occurs in the absence of the symptoms of mental illness but as a legacy of trauma (Fassin & Rechtman, 2009). For this reason, the recognition of victim status released individuals from the specialized boundaries that defined clinical practice, by adapting and authenticating "a collective language to represent humanity" (Fassin & Rechtman, 2009, p. 87). The implications of a new language to describe universal trauma (as a valid experience) led to the development of the civil rights movement and the dis-alienation movement (for mental illness) to resolve "ambiguities, uncertainties, and conflicts and problems of judgements" (Machado & Burns, 1998, p. 380).

The survivor witness subsequently declares a psychological and historical awareness for diverse groups of people and their various social integrations as fellow citizens of the world (Danieli, 2006). Similarly, the societal acceptance of survivors demonstrates social intelligence and humanizes traumatic experiences so that victims and their rights can be recognized (Adler, Rosenfeld, & Proctor, 2007; Fassin & Rechtman, 2009). Therefore, the witness provides an informal network for communication and mediation as a testament of the survivor that is open to local adaptation and negotiation (Machado & Burns, 1998).

Fassin and Rechtman (2009) explained how the survivor's proximity to knowledge about trauma establishes and articulates the ethics that maintain care in the world. Thus, survivor witnesses emphasise object relationships involving personal (self) and collective (other) trauma that reduce the transactional costs associated with improving integration and providing ongoing conflict resolution in diverse groups (Machado & Burns, 1998). Barnard

(1938) added that by minimising the emphasis on diverse forms of transaction, survivor witnesses helped, and continue to help ‘oil the wheels’ of formal organisation.

2.6.4 The Global Empire and Trauma Economy

Object relationships involving survivor witnesses further highlight the prevalence of *us* and *them* tensions where uneven development and shifts in economic and military power toward ‘global governance’ occur (Boswell & Chase-Dunn, 1996). Boswell and Chase-Dunn (1996) described the upsurge in imperial power that joined the centre of world events and their margins following WW2. These world events signalled the emergence of particular political forces and economic colonization that required state interests and capital in the new societies to adopt similar institutions, and thus, to compete and engage in ongoing interactions (Boswell & Chase-Dunn, 1996). Boswell and Chase-Dunn (1996, p. 1) described the repeating cycle of leadership and hegemony since 1942 as a fixed dynamic of the new world-system. Global interdependence is thus cyclic in nature in order to integrate disproportionate and uneven interactions in economic development in which “the core states regulate exchange with peripheral ones through imperial means” (Boswell & Chase-Dunn, 1996, p. 2).

In 1946, the first American Mental Health Act initiated Federal responsibility for mental health care (Cohen, 1983; Darbonne, 1967). Two years later, the United Nations established the World Health Organization (WHO, 1948, p. 28) to manage international health issues. In this new discourse of power, health became defined as a “state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity” and as a human right. Highlighting the imbalance between survivor status and overall health, successive resolutions of the World Health Assembly (WHA) have focused on the prevention of mental illness and mental health promotion to “facilitate effective development of policies and programmes to strengthen and protect mental health” (Herrman, Saxena, & Moodie, 2005, p.

11). Arising from this change in focus “coalition building with civil society and key actions … enhance global awareness-raising and advocacy campaigns” (Herrman et al., 2005, p. 11).

2.6.5 Vietnam War Trauma and the Atrocity-Generating Situation

The ensuing global awareness of extreme conflict defined the modern struggle through the profound nature of trauma. The conflict in Vietnam emphasised the unsettling influence of modern scientific knowledge to discredit taboos, and social disintegration involving vice and disease (Campbell, 1972). Lifton (1973) and Fassin and Rechtman (2009) referred to the ‘atrocity generating situation’ as a traumatic event involving both witness and survivor, victim and perpetrator. These events articulated the decline of mythology to safeguard human consciousness and the strengthening of the social order (Campbell, 1972). As a contest for cultural supremacy (Tick, 2005) and formal control of the environment, the war epitomized the particular character traits to be found within the cultural mythologies of Western/individualistic and eastern/collectivist civilisations (Campbell, 1972). This understanding of the role of mythology now offered the modern therapist an interpretation of personal characteristics as dynamic patterns rather than as static properties (Heider, 1944). As an archetype of psychological trauma, mythologies promote understanding by describing the unity and differentiation that demonstrates “the universal transformation of common themes in the range of their occurrence” (Campbell, 1972, p. 40).

This situation depicted war veterans as being “broken by what they witnessed and by what they, themselves had done” (Fassin & Rechtman, 2009, p. 91). This interpretation of trauma established an official no-fault model attributable to capitalist and economic forces (Boswell & Chase-Dunn, 1996). Further, Herman (1992) stated that the military claims of Vietnam veterans were marked by the public and political amnesia associated with former world conflicts. Therefore, in 1970, the moral credibility and significance of emotional distress and difficulties led to a grass-roots anti-war movement that allowed veterans to retell and relive their intimate and traumatic war-related memories. Unacquainted with the need to agree upon, and resolve, the dialectical tensions associated with the conflict, the American public responded through an “attitude of studied indifference or even hostility to events” (Lunch & Sperlich, 1979, p. 32). An organisation known as *Vietnam Veterans against the War* was established to form impersonal civil rights ‘rap groups’ for the purpose of absorbing negative emotions which aimed to restore and prevent psychological trauma for veterans. This assisted to compensate and control the difficulties (as meaningful experiences in total awareness) involving adaptation, self-actualization, and the generational issues of trauma pathology (Danieli, 2006). Veteran members invited sympathetic psychiatrists, Robert Jay Lifton and Chaim Shatan, to provide professional assistance (Herman, 1992). As support groups formed by and for veterans, group cohesion was based on group loyalty and faith that provided a “holding environment” for the therapists (Danieli, 2006, p. 35). The groups evolved into Operation Outreach, based on a self-help and peer-counselling model of care that provided impetus for Veterans Administration to collate data based on studies of the impact of trauma on the lives of veterans. These studies defined PTSD as a syndrome (Herman, 1992).

The American/Vietnam War also coincided with growing public awareness about the impact of traumatic events, where the social protest, civil rights, feminist, and gay rights movements of the 60s and 70s were mostly represented by growing dissent among the most affected populations. The feminist movement simulated the grass-roots rap groups to discuss the ‘problem without a name’, primarily focusing on consciousness-raising and greater public awareness and discussion of trauma more broadly (Herman, 1992). This resulted in calls for rape reform legislation based on broader understandings of trauma beyond that of veterans and war (Herman, 1992). The understanding of trauma and its universal translation involved revelations and recognition of childhood sexual abuse and trauma that avoided the controversy of early psychoanalysis (Herman, 1992). The women's movement redefined rape as a method of political control which was historically employed to subordinate women through acts of violence and terror and to control them through fear. Subsequently, increased awareness about psychological trauma has transcended the public world of men (war and politics), and the private world of women (fear and domestic violence), as separate discourses that communicate about power (Herman, 1992).

2.6.6 Contemporary Trauma and Classification Systems

Increasingly, war-related trauma dominates public consciousness, although trauma is now also associated with civil acts of terrorism (Van der Kolk, 2002). Persian Gulf Syndrome, prevalent from 1990 to 1999, describes the symptoms attributed to psychological stress in relation to exposure to chemical toxins *(*Fassin & Rechtman, 2009). The literature describes recent traumatic events, including the World Trade Centre bombing, the intensifying tensions of worldwide conflict, and growing refugee populations (Van der Kolk, 2002). The growing global economic disparities, the natural systems facing increased environmental distress, and advancing population growth demonstrate the urgent need for innovative interventions for dealing with trauma (Raphael, 2006; Van der Kolk, 2002). Growing problems within states indicate the need for research to identify how local patterns of distress occur, and to explore the long-term impacts of trauma upon health (Pedersen, 2002).

Capra (1982) stated that the 'objectification' of mental illness has provided science with the necessary rigour, determinism, and philosophical basis for the development of hard technology (such as the development of pharmaceuticals) to support it. By providing and defining constellations of disease, mental illness thereby incorporates and strengthens scientific certainty (Capra, 1982). Similarly, a greater focus on increasing disorder associated with the causes of disease, emphasises the decline in beliefs about behaviour in relation to the symptoms of mental illness. As such, pharmaceutical companies and the medical profession have a global investment (McKnight, 1977) to ensure that they have “specific diseases for their products to treat” (Mayes & Horwitz, 2005, p. 252). The treatment of mental illness similarly represents “those who have power in, and who make money from, a technologically dependent health system” (Talbot & Verrinder, 2010, p. 4). Paynter (1989) described the increasing need to integrate contemporary discourses about trauma into the modern context. Paynter (1989, p. 380) added that only by mobilizing shared “norms and values … around key issues” and “with the exercise of considerable social power” and the “institutionalization of asymmetrical power relations”, society may begin to address inequality.

2.6.7 The Diagnostic and Statistical Manual

The experience of trauma, as such, represents a phenomenon in contemporary society that is best indicated by the present mood that ultimately describes the experiences of trauma as mental disorder and disease. Subsequent advances in psychiatry have concerned the “philosophical, physiological, psychological-physical, socio-logical, and psychiatric” interest in personality and the assimilation of a “psychiatric conception … important to stress” (Cohen, 1983, p. 124; Sapir, 1934). An abbreviated history of the symptoms of PTSD and mental disorder follows. The Diagnostic and Statistical Manual of Mental Disorders (DSM) provides biologically-based orientations for the field of mental health science. It classifies psychological trauma as PTSD. The development of the Diagnostic and Statistical Manual of Mental Disorders and their subsequent analyses highlight the importance of trauma in caregiving for mental illness. In efforts to provide more statistical information, the first American census of mental illness in 1840 referred only to ‘idiocy/insanity’. By 1880, seven categories of mental illness were recorded, including mania, melancholia, monomania, paresis, dementia, dipsomania, and epilepsy (Centers et al., 1994).

In 1917, the National Committee on Mental Hygiene and a Committee on Statistics from the American Medico-Psychological Association (currently known as the American Psychiatric Association - APA), developed a resource known as the ‘Statistical Manual for the Use of Institutions for the Insane’, as a less statistical and more clinical guide to 22 diagnoses of mental illness (Greenberg, Shuman, & Meyer, 2004). It was revised several times by the APA to produce the ‘Standard Classified Nomenclature of Disease’ with the New York Academy of Medicine. The ‘Standard Nomenclature of Diseases and Operations’ designated five main mental health diagnostic categories, including neurosis, personality disorder, alcoholism, epilepsy, and insanity (Kennedy & McNeil, 2006; Stearns & Schwab,1943).

The US medical guide included the ‘Standard Classified Nomenclature of Disease’, which was subject to revision by the US Army who replaced it with the Medical 203. This tried to “express present-day concepts of mental disturbance” (Houts, 2000, p. 93). It was introduced into “clinics and hospitals by psychiatrists returning from military duty” (Centers et al., 1994, p. 1). William Menninger, the Surgeon General, facilitated the field of clinical psychology, in meetings with the APA, to treat normal people exposed to stressful events, as well as the 6% of the hospital population who were veterans seeking care (Houts, 2000).

During the late 1940s, impetus for the DSM was due to the inadequacy of the existing model for military use (American Psychiatric Association, 1952; Kennedy & McNeil, 2006). Similarly, in 1949, the WHO issued its 6th revision of the International Statistical Classification of Diseases (ICD), including mental disorders for the first time (Centers et al., 1994). Meyer’s conceptualisation of psychobiology involving the person’s life circumstances and environment as contributing to mental disorder in the Medical 203 was included and incorporated into the first manual, known as the DSM-1 (1952), as a stress reaction involving psychoanalytical concepts of personality development (Houts, 2000).

The structure of, and concepts within, the DSM-1 were similar to the 203 (sections of the texts were identical), listing 106 mental disorders (Centers et al., 1994). The DSM-1 (APA, 1952) included the category 'gross stress reaction' and listed 106 mental disorders (Centers et al., 1994). The 2nd edition (1968) indicated "transient situational disturbance due to overwhelming external stressor" (McFarlane & Girolamo, 1996, p. 133). Emulating the structure of 203 and DSM-1, the DSM-II dropped the word 'reaction' to "avoid any implications of particular theories in the naming of disorders" (Houts, 2000, p. 947).

A PTSD classification, as a brain disease (Ford, 2009), was included in the DSM-III (APA, 1980). Subsequently, the DSM-III became associated with neo-kraepelin influences that have reverted mental health care to biological and descriptive models, away from efforts to establish a social focus as contained in Medical 203 (Houts, 2000). The DSM-III was prepared within a year and included many new categories of disorder based on two years of field trials sponsored by the U.S. National Institute of Mental Health (NIMH) to test their reliability (Grob, 1994). The DSM-III (APA, 1980) listed 265 diagnostic categories (Mayes & Horwitz, 2005). The term 'neurosis' was deleted by the DSM taskforce because it was perceived as vague and unscientific. The APA Board of Trustees insisted on its inclusion and the word 'disorder' was followed by 'neurosis' in some cases. Robert Spitzer later criticised his work on the DSM-III for avoiding "the context in which those conditions developed" (Davies, 2012, p.iii) and potentially medicalising 20-30% of people in good mental health (Centers et al., 1994). The DSM-III invoked a revolution, or transformation, in psychiatry because of its growing reliability for clinical practice and research and widespread international use by multiple stakeholders (Kraemer, 2007; Mayes & Horwitz, 2005).

The 1987 revision (DSM-III-R) contained 292 diagnoses (APA, 2010). Under the direction of Spitzer, categories were renamed and reorganized, with significant modifications to criteria for diagnosis. It officially recognised PTSD as an anxiety disorder involving two aspects of semiology involving signs and symbols as the basis for diagnosis (Fassin & Rechtman, 2009). This involved the individual and witness in direct exposure, or having knowledge of events outside the usual range of human experience that evoke universal experiences of distress with interactions between the person and the event (APA, 1994; Figley, 1999). In this revised version, human responses included reactions of horror, threat, or intense fear for periods exceeding one month after exposure to the event (APA 2000).

An alternative classification system to the DSM (the ICD-10) was endorsed by the 43rd World Health Assembly in 1990, and has been utilised in WHO member states since 1994. The 11th revision of the ICD-10 classification is underway and should be completed by 2018 (WHO, 2013). In 1994, the DSM-IV listed 297 disorders in 886 pages (Mayes & Horwitz, 2005). Its revision involved conducting an extensive literature review of diagnoses, scrutiny of existing data from researchers, and further field trials conducted across multiple sites, including clinical significance criterion for almost 50% of all categories. This related PTSD diagnoses to clinical practice as symptoms that cause “clinically significant distress or impairment in social, occupational, or other important areas of functioning” (Spitzer & Wakefield, 1999, p. 1856). The DSM-IV-TR, published in 2000, retained most diagnostic categories and specific criteria for diagnosis were unchanged (APA, 2000).

Released in 2013, the DSM-5 described PTSD as a Trauma and Stressor-Related Disorder (APA, 2013). As in previous versions, the behavioural symptoms of the disorder have four distinct clusters: re-experiencing, avoidance, negative cognitions and mood, and arousal. The trigger includes exposure to actual or threatened death, serious injury, or sexual violation. PTSD includes events that are directly experienced, witnessed in person, learned from a close family member or close friend (as actual or threatened death, violent or accidental), or first-hand experience with repeated or extreme exposure to aversive details of the traumatic event (work-related) (APA, 2013). According to the DSM-5, PTSD causes clinically significant distress or impairment in social interactions, work capacity, or important functioning (not related to medical condition, medication, drugs, or alcohol). The PTSD classification includes Adjustment Disorders in children, such as Reactive Attachment Disorder, Disinhibited Social Engagement Disorder, and Reactive Attachment Disorder (Grohol, 2013).

Grob (1991) argued that the development of the Diagnostic and Statistical Manual of Mental Disorders, and their subsequent analyses, involves ongoing change and variability due to the uniqueness of the historical circumstances and social background in which they occur, as well as the diverse ideological, political and moral duties of psychiatrists and other caregivers. The importance of this journey into caregiving for mental illness and its relationship with trauma is explored in the following chapter.

2.7 Summary

This chapter has reviewed the history of trauma as it appears in the literature in order to clarify the relationship between trauma and care. The adaptability of humans and their tendency to cope with traumatic events recounts their immensely rich cultural and social history. These historical recollections contain the mystery in which humans live as genetic processes built into their bodies, and through trauma responses that have provided humans with an environmental and survival advantage. As interpersonal interactions, the main function of the caregiving relationship in social development has been to minimise the impact of traumatic experiences upon development and which, consequently, increasingly lead to more sophisticated methods to manage trauma as collective societies emerged.

This chapter has also clarified the relationship between trauma and care over time, where the understanding of psychological trauma has been influenced by the immediate social frameworks and community expectations about caregiving. This chapter has clearly described how care is supported and defined within the current economic, political and social context, as well as the different agendas now affecting the caregiving role. These historical and cultural developments also assisted in exploring the advancement of medical science that concerned the development of a particular professional and political economy that now underpins the current treatment of mental illness and present understandings about community treatment, trauma and care.

Finally, this chapter has explored how the different social, cultural, and political factors that are contingent to psychological trauma and stress relate to advancing innovation and medical science. This background exploration of caregiver stress has also defined how the total care situation is continually being defined by past, present, and future contexts. The focus of the next chapter, ‘Participation in Care’, will highlight how events in family caregivers’ and professional caregivers’ lives are currently described in the literature. It will explore how the caregiving relationship occurs and will investigate its role within Western society. Chapter 3 will also explore how the context of caregiving for mental illness may precipitate and explain how vicarious stress and secondary trauma affect caregivers today.

CHAPTER THREE

Participation in Care

3.1 Introduction

Chapter 3 explores the context of caregiving for mental illness, defining caregivers as family members, friends, informal unpaid caregivers, or professionals at increased risk of secondary trauma. The social and cultural issues associated with mental health caregivers' experiences of vicarious stress are explored. The DSM-IV (APA, 1994) and DSM-5 (APA, 2013) describe vicarious responses to situations involving stressors that occur outside of the normal range of learning experiences involving exposure to traumatised individuals. This definition includes the secondary impact of traumatic events upon witnesses, such as close family members, friends, or other informal caregivers, who learn of such events.

The DSM-5 (APA, 2013) emphasises that learning about a traumatic event is traumatising in itself. Therefore, this chapter explores the impact of first-hand, repeated, or extreme exposure to aversive details of a traumatic event involving actual, threatened, or accidental violence. This chapter will also explore the potential precursors to secondary trauma for caregivers in the context of rapid and ongoing social change. It will explore the changing social, cultural, and economic circumstances affecting caregivers, precipitated by the shift of care for the mentally ill from institutional settings to treatment in the community.

The first section, on political organisation, describes how deinstitutionalisation has affected caregivers' interactions with the people in their care, mental health services (MHS), and other mental health professionals. This section examines the current understandings within the literature about caregiver stress in the community that highlights an increasing reliance upon diagnosis and involuntary treatment in community mental health settings.

The second section, on communication breakdown, investigates the unique social background and particular circumstances affecting caregivers in the context of community care for mental illness. It explores how collective community perceptions and stigma about mental illness leave caregivers feeling overwhelmed and without personal control over their circumstances. It also explores the relationship between MHS communication, stereotypes, and increased social prejudice about mental illness that have shaped the recovery movement.

The third section, on caregivers' need for empowerment, investigates how the particular socio-demographic issues affecting caregivers have an impact upon the ongoing care of mental illness in the community. It examines the implications of grief for caregivers and the support provided by carer organisations in the community to reduce secondary trauma. Finally, this section explores the particular ideological, political, and moral background that has contributed to a contemporary caregiver paradigm, as caregivers both fulfil and create new community role models as advocates for people with mental illness.

3.2 Political Organisation and Deinstitutionalisation

Deinstitutionalisation has defined the political and economic shift to community-based treatment in Western societies. The literature argues that deinstitutionalisation has increased perceptions about social inequality in relation to the treatment of mental illness, with consequences of secondary trauma for caregivers. As explained in Chapter 2, the Enlightenment heralded the development of public health and mental hygiene principles, culminating in classification systems for mental disorders and the biomedical model of treatment. Subsequently, O'Hagan (2010) stated that current corporate and government-funded systems have adopted the historical and military emphasis on leadership (see Chapter 2) in order to better control resources and people. Young (1990, p.37) described how development and participation represent two universal human values that also "correspond with two social conditions that define injustice: oppression, the institutional constraint of self-development, and domination, the institutional constraint on self-determination”. Herman (1992) added that historically, humans have met fear and threat by attaining common goals (perceived or real) and acknowledging pre-existing sources of trauma (personal and intergenerational) that promote functioning. This section therefore explores how caregivers are predisposed to secondary trauma in relation to the contradictions they experience when endeavouring to achieve mental health outcomes for the people they care for.

The current context of care for mental illness represents an ideological change from state responsibility for social welfare, to community treatment of the individual, hastened by state policies of economic rationalism following the Second World War. An influential figure for mental health reform in the United States, President John Fitzgerald Kennedy, had earmarked state funding to roll out community mental health care, but following his assassination, President Johnson redirected public focus to the Vietnam War (Leifman, 2010). Ironically, as deeply traumatising events that endure in Western consciousness, both the Vietnam conflict and Kennedy’s assassination provide a background to understanding concepts of collective trauma and vicarious stress involving the ongoing adjustment of people with mental illness and their caregivers to the current community treatment model.

Magoro, Gripp, McDowell, and Miller (1978) described the development of Western mental health treatment and the aims of community Mental Health Services (MHS) to represent a far broader set of social concerns that collectively defined, categorised, and exposed human rights issues as personal matters. They added that civil rights awareness and public requests for social equality had occurred only after the individual had ceased to exist on a “conceptual level” (1978, p.62), and further explained that greater awareness about the impact of social equality on mental health developed from the shifting focus from the individual to the social, involving the establishment of Mental Health Acts. Lauder, Kroll, and Jones (2007) thus argued that it is uncertain that caregivers have the ability to resolve the issues of mental illness and increasing social inequality while experiencing increasing insecurity about the policies associated with health care services themselves.

3.2.1 Community Treatment and Secondary Trauma

National Mental Health Strategies provide guidelines intended to ease the transition from institutional to community-based MHS (Henderson, 2004). In Australia, these have included the National Mental Health Strategy and four National Mental Health Plans from 1993 to 2014, coinciding with the Council of Australian Governments (COAG) National Action Plan on Mental Health, 2006 and 2011 (Australian Institute of Health and Welfare, 2012). Whiteford and Buckingham (2005) described the changes following the introduction of the Mental Health Strategy (1993 to 2002) needed to address the legacy of 30 years of deinstitutionalisation alongside the doubling of Australia's population. The inadequate development of community mental health services also paralleled a significant reduction in the availability of psychiatric beds to less than a quarter of the former capacity.

Consequently, care for serious psychiatric illnesses is community-based, which in 2008 accounted for 53% of total mental health spending in Australia (Light, Kerridge, & Robertson, 2012). It is estimated that Australia has almost 2.7 million caregivers, who spend 104 hours per week, on average, in their role, often with little support (ABS, 2008; AIHW, 2016). Approximately 10% of these are mental health caregivers, although this is a likely underestimate due to many not accessing formal processes (ABS, 2008).

The World Health Organisation (WHO, 2001) monitors the regulation and control of treatment for mental illness. To assist individuals to access care in the community, the WHO established that mental health care should occur within the "least restrictive environment"

(Principle 191; UN, 1991). Subsequently, Community Treatment Orders (CTOs) have also been instituted to ensure that community treatment would occur under psychiatric supervision (Henderson, 2004). As a benchmark for state and territory legislation, Australia is committed to the United Nations (UN) Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (Whiteford & Buckingham, 2005). It is also an expectation that state and territory governments ensure compliance as well as fulfil their responsibility to amend Mental Health Acts or to pass new legislation.

Dawson (2007, p. 42) pointed out that the factors influencing CTO use "widely vary in different jurisdictions and within similar legal traditions", noting the changes that occur under specific controls without influencing the law. Subsequently, various independent tribunals across different states have established and monitored CTOs. However, the literature reports that CTOs are escalating worldwide due to an over-emphasis on custodial treatment and an over-reliance on medication in mental health services. Light, Kerridge, Ryan, and Robertson (2012) added that information about the increasing prevalence of CTOs is unclear, both in Australia and worldwide. While the use of CTOs remains commonplace, their use is more apparent with severe and persistent mental illnesses, such as schizophrenia, bipolar disorder, and major depression (Light et al., 2012). Clearly, the transfer of care burden from the state to caregivers in the community also increasingly exposes them to contexts of unmet need. For example, Light et al. (2012, p. 479) pointed to the 2008-09 statistics that indicate that "more than one million of the 6.37 million service contacts with community mental health services in Australia were classified as involuntary".

3.2.2 The Involuntary Treatment Debate

The ethical considerations of community-based treatment are significant for caregivers when determining the rights of people experiencing mental illness. Light et al. (2012) explained how CTOs equally apply to unconsented outpatient psychiatric treatment and the involuntary psychiatric treatment of inpatients on CTOs, regardless of individuals' consent or capacity to refuse treatment. Light et al. (2012) added that, for the most part, no other Australians forcibly submit to medical treatment. They explain that people with mental illness are also at greater risk when refusing treatment, as the decision may be viewed as irrational, possibly resulting in serious harm and even death. Light et al. (2012) stated that an exception might occur where CTOs are regarded as more effective than negotiations about standard voluntary care for people with mental illness. However, Callaghan and Ryan (2012) proposed that a CTO review process in Victoria and Tasmania may represent a new era for mental illness treatment equality concerning persons' ability to self-determine their treatment.

Light et al. (2012) attributed a range of influences on CTO use, including clinicians' attitudes, the availability of other options for the treatment of involuntary outpatients, the real or perceived risk of clinicians' liability for the conduct of persons with mental illness in the community, perceptions of coercion on the therapeutic relationship, that more people are now receiving less restrictive treatment than involuntary hospitalisation, and the adequacy of MHS systems to resource structural responses to recurrent or chronic disorders and disability. Dawson (2006) also described the following advantages of CTOs for mental health professionals, including the marginal requirement to treat outpatients, depending on the capacity of community mental health services to also offer treatment, community expectations about treatment, administrative burdens and liability concerns, and the stigma, coercion and damage to the therapeutic relationship resulting from involuntary treatment.

Szmukler and Appelbaum (2008) explained that the complexity of the changing situation between mental health clinicians and patients is ongoing, when "justified as the act of one person exerting his or her will over another within the context of an ethical relationship"

(Olsen, 2003, p. 709). Szmukler (2008, p. 229) added that it is likely unpleasant for mental health workers to impose "treatment on an unwilling patient; and [that] no experience for the patient … is more humiliating". Szmuckler and Appelbaum (2008, p. 234) therefore described CTOs as involving stressors that may also affect caregivers, including "persuasion; interpersonal leverage; inducements; threats; compulsory community or inpatient treatment". As such, the literature reports that ongoing breaches of the delivery of care within least restrictive environments, and a continuing reduction in civil liberties for people with mental illness, have significantly eroded caregivers' lawful entitlements to access information and to make informed choices and decisions about treatment (Henderson, 2004; Rolfe, Sheehan, & Davidson, 2008). Consequently, Repper and Perkins (2009, p. 89) reported that caregivers often feel "ill-informed and unsupported" and that mental health workers usually fail to acknowledge caregivers for their significant role in facilitating social connections and support for persons with mental illness to better enable them to cope with their living difficulties.

Snow and Austin (2009) highlighted that the ethical debate surrounding CTOs involves balancing individuals' rights to self-determination and the need to protect people with mental illness and the public from harm, with mental health professionals' responsibility to provide ethical and competent care to individuals, families, and communities. Snow and Austin (2009) described how assertive outreach alternatives to CTOs may also be associated with paternalism or interference from mental health professionals who continually monitor progress, as well as observe and administer medication. Snow and Austin (2009) argued that this broad approach to individual support is similarly perceived to be a necessary part of the structure and follow-up of CTOs. However, Canada's best practice model, the Program for Assertive Community Treatment model (PACT), focuses on recovery rather than treatment and improves relationships and community support in order to improve diagnoses and to reduce hospital stays (Snow & Austin, 2009). Snow and Austin (2009) thus emphasised that the CTO’s power to mandate that certain individuals with severe persistent mental illness engage in treatment, are not therapeutic interventions in and of themselves. Responses to the complex social and health issues of mental illness through treatment or compliance also expose the much deeper issues affecting caregivers concerning the persons in their care, such as perceptions, support, and understanding (Snow & Austin, 2009).

3.2.3 Achieving Economic Outcomes

The literature describes how social perceptions about the benefit of community treatment for individuals and caregivers are influenced by economic rationalism. The current context of caregivers’ engagement with community treatment and MHS incorporates market-based economies and a new managerial culture based on achieving measurable economic outcomes (Henderson, 2004; Peel & Chodoff, 1999). In terms of accessing MHS, caregivers also anticipate “the desirability of various outcomes, of the objects, persons or events that are likely to contribute to outcomes” involving individuals in their care (Shapiro, 1969, p.1109). Henderson (2004) thus described MHS as ‘economies’ that treat people with mental illness as consumers of services whose social entitlements are based on their ‘personal needs’. Henderson (2004) explained that the ‘personal needs’ of people with mental illness are often best met by their access to informal networks, family care, and mixed economies. Subsequently, there is an expectation by MHS that individuals and caregivers who can involve themselves with the challenge of confronting and understanding their emotional problems, can utilise coping methods that ensure their adjustment and long-term outcomes.

Repper and Perkins (2003) described how caregivers are expected to seek professional advice and are responsible for compliance to established expectations about treatment, diagnosis, and the care model. Henderson (2004) described MHS workers’ increasing responsibility to supervise treatment in the family home and the community, where caregivers are expected to seek professional advice, and are correspondingly exposed to increasing institutional and political scrutiny surrounding their caregiving role (Henderson, 2004). Wiles (2003) also described a range of extra activities that caregivers perform, including monitoring and training mental health staff; asserting and conceding to treatment protocols; managing schedules and developing system strategies; keeping written records; negotiating unfair relationships; resolving organisational boundaries to access information; and fulfilling an ongoing management role (as suggested by GPs).

Brophy and McDermott (2013, p. 74) described how service providers themselves often feel oppressed and powerless by the approach of “new managerialism, that seeks to control [their] autonomy, creativity, and critical thinking”. Brophy and McDermott (2013) thus pointed to the critical theory paradigm to highlight how powerlessness and oppression are often features of the relationship between service provider and service recipient. Szmukler (1996, p. 450) confirmed that MHS define an ongoing relationship of dependency that highlights power imbalances and also gives rise to disputes about the context of interpersonal exchange and obligation for caregivers. The differences in power that exist between caregivers and MHS providers also reveal how caregivers who engage in power struggles with MHS professionals to achieve treatment, may intensify their own feelings of powerlessness.

Brophy and McDermott (2013) also emphasised that minimal attention has been given to the increasing expectation that mental health practitioners and other social workers will be skilled in working with involuntary clients. Szmukler (2008, p. 229) also questioned why training in approaches aimed at reducing distress surrounding involuntary treatment has received such limited attention, stating “there are no clinical guidelines”. Similarly, Ajdukovic (2004) explained that the increased exposure to new contexts of trauma necessarily involve caregivers and MHS in situations in which they are unprepared, untrained, and ill-equipped.

Clark (2009, p. 203) added that these feelings of powerlessness have collective and symbolic meaning, as the “domains of objects and rituals” of caregiving in the community are reinforced and normalized through societal beliefs about mental illness. Repper and Perkins (2009, p. 89) described how caregivers also feel that mental health “professionals and services implicitly, or at times explicitly, blame them for their relative’s problems”. Capra (1982) highlighted the neglect of education and training concerning the psychological, social, and environmental aspects of care for people with mental illness. Given the economic context of cultural change in MHS, the literature highlights that the unresolved issues of deinstitutionalisation are subsequently being addressed and experienced by older caregivers as the principal advocates of people with mental illness (Savage & Bailey, 2004). Capra (1982) added that periods of rapid social and cultural change emphasise the need to develop new instrumental skills and ideas to meet the changing needs of communities and institutions, and to address the plight of existential meaning for individuals and caregivers in relation to their experiences of social, economic, and political disadvantage in the community.

Orlinsky (1989) therefore highlighted the impacts of urban, industrial, and sociocultural change on the personal lives of individuals that have resulted in perceptions of burden. Szmukler (1996) suggested that ‘burden’, as a word, also contains hidden assumptions and negative stereotypes about mental illness. ‘Subjective burden’ accompanies diagnosis as a form of expert knowledge that increases the likelihood of, and distress regarding, how the illness makes carers feel. Conversely, ‘objective burden’ involves the disruption to family/household life due to the mental illness (Szmukler, 1996). This includes family functioning, relationships, lifecycle, and development (Platt, 1985). Platt (1985) highlighted how sources of information about people with mental illness are associated with burden in the following ways: type of relationship shared, frequency of contact, whether care occurs in the same household, and the quality of interpersonal relationship. A discussion of community treatment and disruption to life follows.

3.3 Breakdown in the Community

The shift from institutional to community care requires new definitions of institutional (involuntary) care and expectations about community treatment. Ironside (1980) argued that the most important factors for the care of individuals with mental illness are their immediate surroundings, particularly their social support system, family and caregivers, and the treatment delivery culture. Besides caring for, and attending to, the personal needs of people with mental illness, MHS are often the only means of accessing and utilizing treatment resources for caregivers. Crocker and Lutsky (1986) suggested that caregivers' need to rely on social institutions, such as MHS, may contribute to maintaining and preserving caregivers' own unique issues as those that increase their susceptibility to secondary trauma. These issues are considered below in the context of community stigma around mental illness.

3.3.1 Stigma and Community Perceptions

Caregiving for mental illness in particular differs markedly from other types of care due to the specific stigma surrounding the treatment of mental illness. Stigma is acknowledged as the key obstacle concerning appropriate access to treatment for mental illness (WHO, 2001). Similarly, Barkway (2009, p. 1) described the re-labelling of mental health and mental illness as defining each of these states by its particular domain and broadening "the application of stigma". Corrigan (2004) also described mental health as an institution with an inherent structural discrimination that undermines care access and robs people of opportunities. Corrigan (2004, p. 622) thus added that "framing stigma as social injustice expands understanding of the phenomena". Corrigan (2004, p. 616) thus cited four main social and cognitive processes involved in stigma: cues, stereotypes, prejudice, and discrimination.

Stigma affects not only the relationship between the perceiver and the stigmatised, but the ways in which schematic processes are organised and practiced in the human mind (Crocker & Lutsky, 1986). Crocker and Lutsky (1986, p. 108) described disruptions to caregivers' "normal social cognition and behaviour independent of associated attitudes", and "further elaborative cognitive activity on the part of the perceiver more likely [requiring] careful self-monitoring" by caregivers. Concerning group membership, visual cues provide reliable and first-hand sources of information about culture, class, and behavioural differences (Crocker & Lutsky, 1986). These "knowledge structures … about a marked social group" (Corrigan, 2004, p. 615) also provide a *sense of the group* (Bergesen, 2004; Durkheim, 1965), as a set of collectively-held beliefs and social stereotypes about people with mental illness.

The psychological disadvantage affecting caregivers also involves public perceptions about the people in their care. Ajdukovic (2004) asserted that the trials of caregiving may be prolonged if the social understanding of care does not extend beyond the symptoms of mental illness to acknowledge the violence that occurs at the core of trauma. Link and Phelan (2001) stated that caregivers' connections to individual experiences of trauma and to collective social beliefs (about mental illness) that give rise to stigma, impacts upon their ability to both recollect and integrate their caregiving experiences. Likewise, Ajdukovic (2004) pointed out that reduced community support might result from the focus on biomedical forms of care.

Corrigan (2004) added that care seeking as a cultural rite is strongly discouraged due to the social harm of being labelled with a mental illness. Likewise, Ironside (1980) described the sensitivity of people with mental illness to attitudes, nuances, rejection, hostility, and disbelief, as communications that threaten their survival, which naturally translate to their caregivers as their primary source of support. Capra (1982) pointed to the contribution of Harry Stack Sullivan and Interpersonal Theory to understand the importance of personality for interactions and relations that exist in social, economic, and cultural networks. In addition, Brophy and McDermott (2013, p. 74) saw the benefits and potential of *de-individualization* for people receiving treatment for mental illness, to recognize their "particular experiences and power relationships" and to increase the value and significance of their group membership and social diversity for the community.

Goffman's (1963) seminal paper, "Stigma: Notes on a Spoiled Identity", explained how falling short of social expectations results in self-modified behaviour (due to failing social esteem), disgrace and shame. Corrigan and Miller (2004) reported that families often experience intense shame in relation to family members' mental illnesses. These experiences of shame are compounded by the situation of individuals with mental illness whose diminished self-esteem and associated loss of social opportunities result in the family being the only source of socialisation. Repper and Perkins (2009, pp. 89-90) confirmed that "too often, informal carers find their own social networks, contacts, and opportunities diminished, and they too may experience stigma and social exclusion". Consequently, Pilgrim, Rogers, and Bentall (2009) highlighted the fact that caregivers' own experiences of stigma have an impact upon help-seeking and further contribute to their social isolation and interpersonal loneliness. As a socially isolated population, caregivers of people with mental illness also experience the trajectories of "power, fear, and guilt" involving marginalised groups in society, that turn minor human differences into major ones (Ajdukovic, 2004, p. 123).

3.3.2 Stereotypes and Mental Illness

Crocker and Lutsky (1986) outlined the importance of sociocultural, motivational, and cognitive perspectives for understanding the dynamics of stigma. The influence of these perspectives on the labelling of people with mental illness as diagnostic stereotypes was initially highlighted by Rosenhan's (1973) research entitled *On being sane in insane places*.

For people with mental illness and their caregivers, the utility of the diagnosis includes the ability to safely identify and access treatment in the community. By way of contradiction, Combs and Freedman (2012) argued that the impact of diagnosis upon the caregiver, and their personality and thinking mirrors the politically powerful discourses in modern society that divide people from each other and invite people to treat themselves as problematic objects. They further described how diagnosis has created both a symbolic way of managing trauma, both emotionally and as a problem to be solved. As Foucault (1961, xxvii) asserted "the language of psychiatry is a monologue of reason about madness".

Similarly, Andreasen's (2007, p. 108) article entitled "DSM and the death of Phenomenology", stated that the psychiatric over-emphasis on diagnostic symptoms and disease, no longer seeks to get to know people with mental illness. Andreasen (2007) argued that the practice of diagnosis is invalid, due to a paucity of research concerning the outcomes of psychopathology and caring interactions involving mental illness. Fassin and Rechtman (2009) also confirmed that, theoretically and institutionally, the diagnosis of mental illness lacks a scientific basis. Equally, caregivers' access to MHS and treatment has been regulated according to strategic hierarchies that highlight the unequal power relations that exist between psychiatrists, mental health professionals, and caregivers (Clark, 2009; Paynter, 1989). Furthermore, for those that can afford it, access to private psychiatry offers a discrete and individualised service, while public mental health care is associated with the greater risk of exposure to increased public scrutiny, discrimination, and prejudice (Stepping Up, 2007).

Similarly, Ajdukovic (2004) argued that by focusing on stereotypes about the symptoms of mental illness and trauma, the social and cultural context is largely neglected. The social institution and orthodox habits of psychiatric professionals to determine others' conduct thus comprise games of strategy (Clark, 2009; Foucault, 1988) that also portray the success of psychiatric and therapeutic treatment as “categories of discourse, value, and authority” (Cohen, 1983, p. 126). Thus, psychiatry, as a social institution, has a purpose in controlling others’ behaviour and setting the dominant discourse, through ‘strategic games’ and the orthodox habits of professionals (Clark, 2009; Foucault, 1988).

Capra (1982) argued that the ‘dose-response’ medical approach results in a spiritual vacuum for caregivers and contributes to the existential panic experienced by people with mental illness. Capra (1982) added that the iatrogenic illness resulting from treatment magnifies caregivers’ responsibilities by increasing the need for counter-therapeutic medications to address ongoing health complications, along with frequently changing diagnoses and drug therapies. Pilgrim, Rogers, and Bentall (2009) explained that these circumstances exacerbate the social inequality of mental illness, with ready links to poverty, class, occupation, (recurring) homelessness, educational attainment, and health.

Caregivers also often link the psychiatric emphasis and the “restricted … interpersonal approach” to mental illness to increased “feelings of isolation, and narcissistic injury” that contributes to their emotional distress and contributes to their perceptions about mental illness (Evans, 1996, p. 172). Ajdukovic (2004) argued that dominant stereotypes about mental illness reinforce the impact of eroding social capital and increasing stigma, which in turn, create communities of fear for caregivers. As a psychiatric pathology, mental illness often supports the impressions and expectations of psychiatrists in interpreting social difference as deviance (Sheldon, Traustadottir, Beresford, Boxal, & Oliver, 2007). The enduring perception that people who experience mental illness are deviant and criminal further perpetuates caregivers’ experiences of secondary trauma and social isolation.

Jemeka, Trupin, and Chiles (1989) found that effective treatment for mental illness is restricted by the growing emphasis on harsher laws that, in turn, lead to greater scrutiny and less tolerance towards offenders, including vulnerable members in the community experiencing mental illness. Corrigan (2004, p. 616) argued that stigma influences the increasing criminalisation of mental illness as “police, rather than the mental health system, respond to mental health crises”. Corrigan (2004) further pointed out that people who exhibit symptoms and signs of serious mental illness in the community are more visible and vulnerable to arrest by the police and are more likely to be incarcerated for longer periods.

The Western world, particularly the United States, has high incarceration rates for people with mental illness in state penitentiaries. This is arguably a form of re-institutionalisation as the dominant model of care to replace MHS (Fellner, 2006). The trauma associated with accessing mental health treatment and ongoing care is also felt by caregivers in relation to individuals who increasingly regard incarceration as a last resort (Schetzer, 2016). Light, Kerridge, Ryan, and Robertson (2012, p. 591) noted the well-documented problems associated with deinstitutionalisation, also acknowledged by the Minister for Mental Health and Ageing, describing the “inadequate resourcing of community services and high rates of unmet need, disadvantage, homelessness, and imprisonment among people living with mental illness”. Capra (1982, p. 165) stated that “transcending the biomedical model will be possible only if we are willing to change other things as well; it will be linked, ultimately to the entire social and cultural transformation”.

3.3.3 Caregiving and Social Prejudice

Deinstitutionalisation has been broadly associated with widespread homelessness for people with mental illness (Henderson, 2004). In Australia, as elsewhere, MHS are synonymous with social and economic disadvantage, personal trauma, and community marginalisation of those with mental illness (Bowers, 1998; Stepping Up, 2007). Pilgrim et al. (2009) highlighted the two-fold disadvantage of primary mental health difficulties (resulting in stigmatization and social rejection), and high levels of historical and personal adversity (resulting in single lifestyles), affecting people with mental illness and their caregivers. For example, the Disability Support Pension now supports the majority of those with more severe mental illness in Australian (Stepping Up, 2007). Guerin (2004) found that economic contexts of exchange, such as the disability pension, often deter the formation of social relationships. Pilgrim and Rogers (1999) confirmed that residential ghettos have formed in the community to segregate mentally ill populations from mainstream society. As such, individuals with mental illness seldom participate in the labour market (Henderson, 2004), mirroring historical forms of discrimination associated with welfare assistance (Braddock & Parish, 2002). Caregivers of people with mental illness are also entitled to claim a State-Funded Carer Payment (Department of Human Services, 2015). These financial benefits only apply to individuals who care for a person with a recognised diagnosis (according to the APA and the ICD-10), and who receive psychiatric treatment from a mental health professional.

Concerning the effects of poor mental health on the community, Patel, Flisher, Hetrick, and McGorry (2007) noted that young people represent a particularly vulnerable group who are at increased risk of substance abuse, poorer sexual and reproductive health, and violence. Therefore, creating positive mental health outcomes among young people is significant for their personal ongoing opportunities, as well as economic productivity socially. Their study indicated that 75% of young people between 12–24 years, with early onset of depressive and anxiety disorders, including psychoses, substance use, and eating and personality disorders, will go on to experience them into adult life (Patel et al., 2007). Whiteford and Buckingham (2005) also found considerable unmet need and disability, with the largest sub-population of mental disorders involving anxiety disorders, mood disorders, and substance abuse.

As important social and public health priorities, Patel et al. (2007) proposed that an attitudinal shift from mental health care burden to more robust family and community networks may produce better mental health outcomes for young people by reducing the impact of social prejudice. Borg (2004, p. 157) emphasised the need for more accessible forms of therapy based on a holistic approach to mental illness involving community interventions that "respond to the community's specific needs". Herman (1992, p. 51) confirmed "traumatic events have primary effects not only on the psychological structures of the self, but also on the systems of attachment and meaning that link individual and community". Sullivan (1954, p. 297) thus described how "the depressive always hits the target and usually unhappily does this by self-destruction". Borg (2004) added that caregivers also experience self-blame, as well as community blame, concerning their failure to prevent the pain of mental illness:

> *"... from the interpersonal point of view, these problems are clearly linked to disturbances in real relationships with significant others, as well as to serious disturbances in the broader social, political, and cultural environments"* (Borg, 2004, p. 155).

Kahn (2013) suggested that thoughtful self-exploration and psychotherapy (and possibly medication), are practical therapeutic strategies that also have the potential to maintain social harmony and control over modern-day experiences of social angst and phobia. Kazdin and Blasé (2011) also pointed to the important role of psychotherapy in reducing the personal and social burden of mental illness and to address anxiety, depression, and bipolar disorder, as well as the stress associated with social, emotional, cognitive, and behavioural problems. However, Kazdin and Blasé (2011) did propose that a significant rebooting of the psychotherapeutic approach is required to meet the present need for services in society.

Therefore, in order to address social prejudice and increase the capability of people with mental illness, early intervention through psychoanalysis includes a working hypothesis about the impact of development upon life experiences (Capra, 1982; Orlinsky, 1989). Borg (2004) explained that psychoanalysis provides options that support personal agency by dealing with anxiety and the increasing complexity of life. Borg (2004, p. 150) added that interpersonal psychoanalysis and empowerment theory “stress the importance of paradox: the need to sustain, rather than foreclose, the tensions among opposing and conflicting points of view”. Caregivers therefore fulfil a vital purpose as the allies of psychoanalytic treatment (Orlinsky, 1989). In stark contrast to the potential of psychoanalysis to address social prejudice about mental illness, the literature describes the paucity of research in this area. Overall, the literature describes ongoing conflicts between the professional disciplines, and that access to psychoanalysis is placed beyond the financial reach of most people with mental illness, is rarely subsidized, and involves substantial waiting lists due to the high demand for services. Alongside self-referrals, an increased dependence upon expert knowledge and professional goodwill often controls the quality of support available (Henderson, 2004; Holmes, 1999). Consequently, the type of problems currently being addressed by clinicians may actively avoid the issues that caregivers often face (Orlinsky, 1989).

3.3.4 The Recovery Movement

During the 1980s, at the height of deinstitutionalisation in Australia, people with mental illness began to question the domination of psychiatric control over treatment. Pilgrim et al. (2009) therefore described the success of the Recovery Movement in reversing the obstacles regarding social integration and concerning individuals’ adverse experiences in human development. Independent informal groups and survival networks in the wider community were formed to achieve the collective goal of the attainment of individual autonomy. Similarly, the culture of self-determination, anti-psychiatry, and the Recovery Movement (O’Hagan, 2003) involved people with mental illness as experts of the ‘lived experience’ of mental illness, and called for them to define their own recovery and to rediscover their meaning and purpose in life (Repper & Perkins, 2003, 2012). Due to the grassroots success of the Recovery Movement, the WHO (2001), the Council of Australian Governments (COAG), and successive National Mental Health Policies embraced the ideology. Nevertheless, the literature reports that the role of peer support programs to provide genuine models of care within MHS services, while acknowledged, still has some way to go. Authors have reported that recovery has not been readily understood by mental health professionals, and that consumers continue to experience the 'institutionalising' influences of professional marginalisation (Davidson, 2003; Davidson, O'Connell, Tondora, Styron, & Kangas, 2006). Thus, thirty years later, the incorporation of 'lived experience' in MHS has been carried out with only variable success (Gomm, 1996; Slade, Adams & O'Hagan, 2012).

The association of failure with the recovery movement has subsequently allowed mental health services to protect themselves from further public scrutiny, as outlined below (Aldenderfer, 1993). Various attitudes and reactions toward recovery have highlighted inevitable conflicts in professional values and beliefs. Whiteford, Buckingham, and Manderscheid (2002) reported that local managers and mental health workers actively resist equal participation in the planning and delivery of services, thus reducing their involvement in *recovery-based services* to only 'tokenistic practices'. Discriminatory professional attitudes also include not treating people with mental illness as equal partners in the management of their disorder. Whiteford et al. also explained how mainstream disability services have limitations in accepting the episodic nature of mental disorders and the difficulties associated with psychiatric disability. They also declared "it is easier to change structures and increase funding than it is to change the values and attitudes entrenched in health professionals" (2002, p. 212).

Even so, Slade et al. (2014, p. 17) pointed to encouraging attitudinal changes involving MHS workers and caregivers as partners and social activists who challenge stigma and community assumptions “that people with mental illness cannot or should not, have the same citizenship entitlements as anyone else in their community”. Slade et al. (2014, p. 17) stated that the final challenge of recovery to full civic entitlement involves acknowledging that the MHS’s “treat-and-recover” goal that aims to re-engage the person with mental illness with life are “careless and toxic concepts which reduce hope and limit expectations”.

O’Hagan (2010, p. 9) added that the “mental health system was founded on values that are the antithesis to empowerment and equality”. Therefore, O’Hagan (2010, p. 9) identified that theoretical and ethical changes are necessary to value the crisis of mental illness “as a legitimate human experience”. Whiteford et al. (2002) also emphasized training and support for people with mental illness and their caregivers as being required if they are to effectively participate in recovery and to succeed as advocates. Likewise, Repper, and Perkins (2009) highlighted that caregivers also need to achieve recovery in their own lives by re-evaluating, accommodating, and adjusting to the changed values and meanings of their former relationships. Mental health services therefore play a significant role in facilitating caregiver recovery through enabling them to access new and valued opportunities to rebuild their caregiving relationships (Repper & Perkins, 2009).

3.4 Caregivers’ Need for Empowerment

Snow and Austin (2009, p. 184) argued that the decline in inpatient beds, and the increased focus on community care, human rights, and consumerism in mental health services has created the unavoidable truth that people with “severe persistent mental illness are living in the community without a corresponding response in community resources to meet their needs”. Snow and Austin (2009) further argued that the political and economic focus of deinstitutionalisation has impacted upon the wider communities' recognition of the contribution of informal caregivers, and therefore advocate that the ongoing issues of social and cultural inequality are affecting caregivers' health.

New forms of social and cultural discrimination have therefore become the focus of public health campaigns. 'Open Minds', promulgated by the South Australian Inclusion Board for example, emphasised greater recognition and equal opportunity for caregivers, families, and those with mental illness. The Carer Recognition Act (2010) similarly acknowledges those primarily responsible for the care of mental illness in the community. Lakeman (2008) described how the Carer Recognition Act needs to be universally acknowledged before caregivers' participation and inclusion can become standard practice in MHS.

3.4.1 Communication and Grief

As caregivers are at higher risk of exposure to crisis and experiences of secondary trauma, Ajdukovic (2004) stressed that broader-based relationships involving individual and caregiver interactions with, and for, the immediate community are essential for rebuilding trust and hope. Snow and Austin (2009) thus described the potential for positive outcomes regarding case management to closely monitor and coordinate caregiving in the community. To offer a fundamental insight into the present state of crisis in mental health services, caregivers' functional relationships and experiences of grief will be explored next.

Lindemann and Caplan (1948) developed a social model for community-based care to provide education and understanding about the need for early intervention and to restore a sense of control and autonomy to individuals and caregivers. According to this approach, grief-work increases caregivers' awareness about stressful experiences in four clear stages. Firstly, caregivers' acknowledgement of tension involves responses that restore homeostasis and problem-solving patterns. Secondly, a lack of acknowledgement increases tension and feelings of being upset about the continuing problem (Caplan, 1964; Darbonne, 1967). Thirdly, an identification of the problem and/or tension requires the use of (internal and external) resources to decrease the intensity of the problem (such as emergency coping techniques, new approaches, or goal relinquishment). Finally, if the satisfaction of the need or the problem is neither solved nor avoided, further tension will result in a major disorganization and an emotional break (Caplan, 1964; Darbonne, 1967).

‘Crisis Theory’, which arose from the work of Lindemann (1944) and his colleague Caplan (1961, 1964), specified shorter periods of treatment and a shift in focus to the group, the family, and the community in early mental illness detection and intervention (Darbonne, 1967). Snow and Austin (2009) added that early intervention and screening may also reduce mental health concerns by quickly de-escalating a crisis. Grief work and its four phases of problem solving involve both adaptive and maladaptive techniques for coping with trauma (Darbonne, 1967). Adaptive problem-focused strategies include the use of emotional and instrumental support, planning, positive reframing, acceptance, humour and religion, while maladaptive strategies involve behavioural disengagement and self-blame, self-distraction, denial, venting of emotions, and substance abuse (Carver, Scheier, & Weintraub, 1989).

Lindemann (1944) emphasised a novel context of dependency involving the success of grief-work that recognised the importance of attachment for achieving homeostasis and recovery. The need for belonging as the universal and complementary response of attachment involving caregivers has been highlighted by Valent (2007). Sullivan (1953) also describes the importance of attachment and bonding as biological and universal means of survival, noting the ‘psychophysiological regulation’ of food involving the caregiver. Scott (1989) added that protection, caretaking, and cooperative behaviours evolved to model inclusive fitness in human groups and populations involving a few hundred people.

Hence, caregivers’ perceptions about belonging, as a cultural construct, also reflect the current context of economic, political, and institutional power as forms of ideological control (Ajdukovic, 2004; Foucault, 1981; Huneman, 2008; Martinez, 2005). Making sense of the caregiving situation therefore poses important questions about the importance of attachment and bonding for caregivers and professionals, as those who share in the emotional burden and grief of the traumatized and who often facilitate the healing process (Herman, 1992). Rosenbloom, Pratt and Pearlman (1999) described caregivers’ psychological identification with care involving perceptions of loss relating to their safety, trust, esteem, intimacy, and control. Herman (2000) highlighted the responsibility of caregivers to help individuals experiencing trauma to complete the normal process of grieving, and to ensure that the traumatic reaction is not prolonged unnecessarily. Conversely, the prominence of the bio-medical model for treatment (with its lesser focus on interpersonal grief-work) has disadvantaged caregiver outcomes regarding interpersonal control and autonomy that are central to their psychological identification with care (Rosenbloom, Pratt, & Pearlman, 1999).

3.4.2 The Ideological, Political and Moral Duty to Care

Brophy and McDermott (2013) found that people receiving community treatment represent social groups that are largely subject to social discrimination and oppression, thus naturally being associated with caregivers’ experiences of stigma and marginalization. As a means of decreasing secondary trauma for caregivers, and to combat their experiences of stigma and social isolation within a community that does not understand, carer support organisations have focused upon providing information and empowerment. In a review of the literature by Saunders (2003), the perceived value of support groups as instrumental for families involved in caregiving for severe mental illness was noted. As a new social and cultural phenomenon, caregivers themselves also actively increase their knowledge of mental illness by pursuing activist roles and relentlessly advocating on behalf of those for whom they provide care.

Pilgrim and Rogers (2009) highlighted that the neoliberal approach to mental health care is particularly seductive for three main reasons: people with mental illness prefer an emphasis on citizenship and voluntary treatment; mental health workers seek the improvement of their clients; and, politicians and managers of MHS desire financial restraint and efficiency. By advancing social concepts as economic relationships, Teghtsoonian (2009) argued that caregivers indiscriminately confirm their civilian responsibilities by managing and understanding mental illness in their lives. Teghtsoonian (2009, p. 29) also described how caregivers have become innovative personalities and "rational, calculative actors" to further their own and their families' interests. Lemke (2001, p.201) also argued that:

> *The strategy of rendering individual subjects "responsible" (and also collectives, such as families, associations, etc.) entails shifting the responsibility for social risks such as illness, unemployment, poverty, etc., and for life in society into the domain for which the individual is responsible and transforming it into a problem of "self-care".*

As economic standards of costs and benefits, Teghtsoonian (2009, p. 30) argued that the new mental health care framework of support organizations and self-help may then "displace professional discretion as the basis for clinical decisions". By providing education, mentoring, and support to caregivers' and cultivating their knowledge and problem-solving skills to respond to the needs and challenges of mental illness, caregivers may also remain attentive to their own (genetic, lifestyle, and environmental) susceptibility to secondary trauma (Henderson, 2004; Teghtsoonian, 2009). Teghtsoonian (2009) added that these factors are aimed at reducing the critical need for services in the community and to detract from the government's responsibility to provide extra financial support to individuals and caregivers. She thus highlighted the contribution of Morrow, Hankivsky, and Varcoe (2004) who emphasised the increased vulnerability of women to neoliberal policies by insisting that individuals themselves secure housing, education, income, and work for people with mental illness “without public support or assistance” (Teghtsoonian, 2009, p. 34).

3.5 Summary

By exploring the difficulties that caregivers currently face, this chapter has identified the basis of their experience of secondary trauma with the overall development of community treatment for mental illness. This chapter has explored the emergence of post-modern caregiving by exposing the fragmented experience that has an impact on caregivers as individuals, and as members of the wider community. It has also explored caregiving as a form of economic organisation involving enduring stereotypes about mental illness based on current discourses about power. In addition, caregivers’ experiences of cultural change involving the concepts of mental health and mental illness, and concerning the institutional power of MHS and diagnosis have been illustrated.

This chapter has provided an overview of the current understanding of how mental illness is treated. By defining the treatment of mental illness, the chapter has also provided a review of the impact of political and social development affecting caregivers and MHS. In addition, a description of the social structures involved in care and the consequences of secondary trauma for caregivers was provided, with the increased need for professional and cultural education highlighted. Also highlighted have been some of the issues involved in community conceptualisations of self-care and caregivers’ increasing responsibility to advocate on behalf of those with mental illness. Consequently, this chapter has depicted participation in care as contributing to caregivers’ experiences of secondary trauma. The next chapter will therefore explore vicarious stress and secondary trauma as the specific context of this study.

CHAPTER FOUR

Vicarious Stress

4.1 Introduction

Chapter 4 explores the ways in which caregiving behaviours relate to vicarious stress. In this chapter, vicarious stress refers to specific responses and changes that occur in caregivers' awareness that affect their ability to cope with trauma. As previously explained in Chapters 2 and 3, the DSM-IV and DSM-5 describe particular vicarious responses to situations involving stressors that occur outside of caregivers' normal range of learning and experience, involving their exposure to traumatised individuals. This chapter therefore defines the secondary impact of traumatic events upon witnesses of trauma, such as close family members, friends, or caregivers who learn of such events (APA, 2013).

This chapter explores emerging concepts concerning three distinct manifestations, or types, of vicarious stress: vicarious trauma, compassion fatigue, and secondary trauma. Chapter 4 will explore the unique characteristics of each type of caregiver stress by describing their symptoms and their inter-relationships with each other. In particular, this chapter focuses on the inter-relationship between the symptoms of Post-Traumatic Stress Disorder (PTSD) and secondary trauma (Figley, 1999) involving the indirect transference (or osmosis) of PTSD symptoms to caregivers. Chapter 4 makes an original contribution to the knowledge in this area by exploring the association between vicarious stress and caregivers' cognitive and emotional behavioural interactions and responses to trauma.

This chapter will draw upon the available literature about mental health professionals and other MHS employees, to increase understanding about the specific characteristics of secondary trauma that contribute to conceptualisations about the relationships between the different types of vicarious stress overall. Chapter 4 will explore the potential implications of vicarious stress, as well as their relevance for, and impact upon, mental health caregivers.

Traumatology has emerged as a distinct field in the literature for the study of vicarious stress, examining how the conditions and circumstances that caregivers face create trauma. Figley (1999) highlighted the need for researchers to identify the dimensions of vicarious stress in order to understand what may be contributing to the development of specific symptoms and the nature of the interactions that occur between the dimensions. Table 4.1 outlines the dimensions as currently understood. They are explored further in this chapter.

Table 4.1 Dimensions of Vicarious Stress

Vicarious trauma	Self-concept; based on caregivers' recollections of care involving changes in cognitive outlook and approach
Compassion fatigue	Caregiving patterns of activity, involving experiences of emotional fatigue and chronic distress
Secondary trauma	Contagion or transfer of PTSD symptoms from individual to caregiver

To provide further clarification about the concepts reviewed in this chapter, Jenkins and Baird (2002) linked vicarious trauma to specific changes in caregivers' cognitive schemata; and compassion fatigue and secondary trauma to caregivers' socio-emotional symptoms. Four susceptibility factors for secondary trauma, identified by Figley (1999, p. 20) will also be explored in this chapter. Section 1 will explore the significance of self-concept for understanding how traumatic situations may trigger caregivers' memories of their own experiences. The concept of empathy will also be explored as a significant resource for caregivers. Section 2 will explore the relationship between socio-emotional symptoms and the caregiving situations that overlap with caregivers' prior experiences which result in distorted perceptions, generalisations, and assumptions about their caregiving role. It will also review the literature regarding the differences between compassion fatigue and burnout. Section 3 will discuss the specific context of secondary trauma, and the particular social and cultural issues facing caregivers. It will explore helplessness and powerlessness in relation to caregivers' increased susceptibility when exposed to vulnerable populations (such as traumatised infants and children). Finally, this chapter will conclude with an overview of the focus of the study and the research questions.

4.2 The Self, Self-schema, and Stress

In addition to the normal demands and physical challenges of caregiving, Figley (1999) explained how coping responses integrate stressful experiences as examples of successful vicarious learning that underpin caregivers' abilities to respond in crisis situations. Safran (1990, p. 3) added that the ongoing evaluation of one's self-concept provides humans with a general knowledge structure that directs both the processing of information and the way in which action is implemented. Sullivan (1956) also described how the self-concept is generalised though self-awareness and thinking patterns as a system that provides individuals with a psychological defence from the experience of anxiety. Herman (1992, p. 51) added that *care as a form of social conduct* involves a growing societal realisation about the inward and intrapersonal processes that define the elaboration of self-concept or self. Therefore, in order to understand how stressors are integrated into caregivers' self-concept, the literature identifies links between cognitive development and vicarious learning strategies.

In accord with evolving ideas about vicarious trauma, the literature demonstrates how the self-concept shapes the ways in which caregivers define their internal and external worlds. Markus and Kitayama (1991) described the central role of the self-system for *intrapersonal* regulation (based on relevant information, affect, and motivation), and *interpersonal* perception (based on social interactions and comparison). Markus and Kitayama (1991, p.

227) explained how the elaboration of the self-concept involves memories about the inner self (core conceptions, salient identities, or self-schemas). Consequently, the self-schema forms the self as a whole by interacting with the caregiver's social self, self-knowledge, and self-esteem. Markus and Nurius (1986, p. 954) thus suggested that the self-schema provides "a conceptual link between cognition and motivation" by incorporating individuals' ideas about what possible selves "might become, *would* like to become, *and are* afraid of becoming". Markus (1977, p. 63) added that, as such, schemas represent "cognitive generalizations about the self, derived from past experience that organize and guide the processing of self-related information, contained in an individual social experience".

Safran (1990) explained that theoretical models relating to the self-schema have become increasingly important as working constructs in psychopathology and psychotherapy. Subsequently, Craig and Sprang (2010) suggested that theorists' conceptualizations about the self-schema, and what it comprises, differ widely. Self-schema are described as including a number of different domains, including scripts that are central to communication, belief structures, and/or cognitive schemes that clarify how information is processed (Safran, 1990). Safran (1990, p. 89) defined the self-schema as "the generic cognitive representation which the mind extracts in the course of exposure to particular instances of a phenomenon". Subsequently, contexts of vicarious learning in caregivers' development are also linked to changes that occur in their cognitive schemata.

4.3 The Association between the Self-concept and Vicarious Trauma

Rosenbloom, Platt and Pearlman (1999, p. 67) described vicarious trauma as the accumulation of memories and the cognitive processing of indirect traumatic memories that gradually influence changes in the carer's worldview over a period of time. Similarly, McCann and Pearlman (1990) related the symptoms of vicarious trauma to the accumulation of memories about another’s traumatic material that affects caregivers’ views of the world. As such, vicarious trauma has been primarily associated with negative changes in one’s view of self, others, or the world, that may be profound and long-lasting, impacting upon caregivers’ development, personalities, and frames of reference (incorporating their world views, spirituality, identities, and psychological needs) (McCann & Pearlman, 1990). Pearlman and Saakvitne (1995, p. 280) also likened vicarious trauma to a system of communication that defines caregivers’ “physical presence in the world”. Consequently, the current literature about vicarious trauma seeks to ascertain what happens to caregivers’ schema when they are exposed to trauma.

Wilson, Lindy, and Raphael (1994) defined vicarious trauma as involving two main symptoms of PTSD, intrusive thoughts and avoidance behaviours. Jenkins and Baird (2002) also described the effects of vicarious trauma as including behaviours such as withdrawal, the depersonalization (of clients) and poor service, painful imagery, and emotional experiences associated with traumatic material. Similarly, Pearlman and Saakvitne (1995) compared the intrusive or avoidance symptoms of PTSD to caregiver strain. Wilson et al. (1994, p. 31) thus defined intrusive strain as the loss of boundaries, over-involvement, reciprocal dependency, and pathological bonding. Correspondingly, avoidance strain was defined by withdrawal, numbness, intellectualisation or over-reasoning, and denial.

Hunt (2003) also suggested that caregivers’ evaluations of strain and gain in the caregiving relationship may be independently related to outcomes. Subsequently, Lanzetta and Englis (1989, p. 545) argued that the “observer’s vicarious emotional response performs an empathetic function involving caregivers’ past associations concerning the displays of others, and affectively relevant outcomes for self”. Parkes (1994) thus indicated the importance of determining whether burden or gain was present in the caregiving role. Hunt (2003) described the positive impact of caregiver perceptions focused upon *gain* for regulating the relationship between stress, poor self-concept, and negative emotions (independent of *strain*).

Consequently, studies conducted by Batson, Fultz, and Schoenrade (1987) explored the different motivational consequences of distress and empathy. Fultz, Schaller, and Cialdini's (1988) study of vicarious affective responses to the suffering of others also described the factors that motivate helping behaviours based on empathy, sadness, and distress. For example, mental illness may trigger caregiver distress involving their personal feelings or thoughts. *Self-enhancement theory* compares the devalued status of people with mental illness to caregivers' own sense of justification about their worthwhile status (Crocker & Lutsky, 1986). As a safeguard from caregivers' feelings of vulnerability, *Just World theory* suggests that negative beliefs about people with mental illness were due to a "fundamental moral failure" on their part (Crocker & Lutsky, 1986, p. 102). Wilson et al. (1994) also linked caregivers' experiences of vicarious traumatization to empathic strain in relation to the permeable (absorption) disposition of caregivers that necessitates them attending to traumatic events. Valent (2002, p. 20) explained how empathy is vital during times of crisis:

> *"On the receiving side, empathy is the vehicle whereby helpers make themselves open to absorption of traumatic information. The absorption and subsequent impulse to respond may be lifesaving in ongoing traumatic events".*

4.4 The Sympathy and Empathy Continuum

The literature describes the difficulty associated with sympathy (*feeling for)* and empathy *(feeling with)*, due to their longstanding, interchangeable use. Further clarification about the contagion reaction, otherwise known as the *chasmal effect* (Kishur, 1984), involves the indirect transference of PTSD symptoms from individuals to caregivers. Consequently, Darwall (1998) described emotional contagion as a primitive form of empathy involving 'social referencing' (to imagine what the other actually feels) and 'joint visual attention', such as the ‘global empathic distress’ of children seeking comfort when they hear other children cry. Darwall (1998) thus argued that sympathy comes after empathy by initiating *felt* emotion (as afferent physiological feedback) to turn these ideas into felt impressions (such as the anxiety contagion experienced when exposed to anxious people). Lanzetta and Englis (1989, p. 554) added that, typically, empathy is considered to “arise from the observer taking the other's perspective or fantasizing about self in the actor’s situation”. Lanzetta and Englis (1989) therefore put forward theories of vicarious classical conditioning that involve human emotional responses that are similar, or identical, to that displayed by another.

Significantly, Darwall (1998) described how reciprocity (and altruism); imitate the original behaviour and provide a purpose for future behaviour. Darwall (1998) argued that well-being is irrelevant (as a first-person concept), as the desired benefits occur in the third-person (from the perspective of the person who cares). Subsequently, sympathy represents feelings from the first-person standpoint, *as if* one’s situation gives them a reason to feel that way, “warranted by features of the situation to which they apparently respond” (Darwall, 1998, p. 264). Caregivers’ subsequent motivation or ‘propriety’ to care about another’s feelings involves them first working out what *to* feel and then *seconding* the feeling (or similarly, dissenting from it) (Darwall, 1998). Darwall (1998) therefore focused on caregivers’ ability to appropriately ‘enter into’ the situation or else it would not be experienced and caregivers would ‘think it unwarranted’. Consequently, projective empathy *with* another is sympathetic cares about them (or for them) as a way of sharing another person’s feelings.

Darwall (1998) added that empathy allows one to become aware of the ‘idea’ as it is communicated or *caught* as the emotional state and feeling of another. Darwall (1998, p. 270) highlighted that “empathy without sympathy” engages with vicarious *experience* by considering “the other as the object of ‘objective attitudes’, instead of ‘participant reactive attitudes'". Darwall (1998, p. 270) added that empathy is "central for the formation of normative communities and like-minded groups who can agree on norms of feeling". Escalas and Stern (2003) pointed to communication research suggesting that while sympathetic responses ('I understand your pain') are significant for positive attitudes, greater influence is given to the personally felt emotions of empathy ('I share your pain'). Consequently, caregivers' self-awareness about empathy generates positive effects by allowing people to share emotions, facilitating similar goals and motives that encourage the performance of the caregiving role. Escalas and Stern (2003) therefore proposed that sympathy is a precursor to empathetic responses, as stages of experience in the hierarchy of drama (progressing from the cognitive [surface-level] sympathetic response to the more objective understanding, affectively felt and shared, as a [deeper-level] subjective empathic response).

Escalas and Stern (2003) explored the importance of narratives for sympathy and empathy responses through their studies of advertising. They described how the non-traditional narrative (involving changing scenes and different characters and events) was less likely to invoke emotional schemas because of a lack of comprehension (that otherwise would allow viewers to relate and lose themselves in the story). Alternatively, the classical form of drama evokes both sympathy and empathy by providing cognitive structures that stimulate the elaboration of responses, vicarious participation, and greater comprehension (Escalas & Stern, 2003). Escalas and Stern's (2003) findings consistently revealed that early recognition of portrayed emotions involving sympathy were the more easily achieved emotional responses, while absorption in shared emotions necessitated empathy. Importantly, Escalas and Stern (2003) identified that only people predisposed to empathy would continue along the sympathy/empathy continuum.

4.5 The Significance of Caregivers' Motivations

An understanding of empathy is important for research about vicarious stress because of the unique nature of the caregiving role and caregivers' exposure to various types of trauma. Goleman (1995) described how caregivers' coordination and attentiveness to the caring process serves as the basis of their knowledge. The German philosopher Robert Vischer (1873) also used the term *Einfiihlung* to describe empathy, to bring to mind an aesthetic contemplation of the world involving "humans' spontaneous projection of real psychic feeling into the people and things they perceive" (Duan & Hill, 1996, p. 261). Consequently, Gair (2012) described empathy as a helping terminology, indispensable to caregivers' perceptions about the lived experience. Craig and Sprang (2010) summarise various views of compassion fatigue, including Figley's description of empathic engagement as a conduit by which traumatic stress is transmitted from the individual to the caregiver. The original definition of empathy includes the shared understanding of common experiences and is derived from the Greek word *emapatheia* (Gair, 2012).

Batson, Fultz, and Schoenrade (1987) argued that caregivers' initial ability to witness another person's suffering is based on their own complex schema, which is then communicated as an empathetic idea through several aspects of interpersonal cognition and emotion. Therefore, Batson, et al. (1987, p. 20) described empathy as:

> *"(a) feeling any vicarious emotion; (b) feeling the same emotion that another person is feeling; or (c) feeling a vicarious emotion that is congruent with, but not necessarily identical to, the emotion of the other".*

Medical terminology about empathy is based on awareness as a learned skill, and physiological definitions include the processes performed by a part of the body not usually used for that purpose (Boulton, 1987; Gair, 2012).

4.6 Caregivers' Identity and Psychopathology

Caregivers' cultural and social identity, gender, and age are important factors for the transmission of trauma. The advantages and disadvantages of understanding caregivers' motivations involve identity and psychopathology (Valent, 2002). Rosenbloom, Platt, and Pearlman (1999) suggested that developmental experiences might play a role in caregivers' coping abilities concerning the relationship between their perceptions, actions, and events that parallel experiences of those in care. Porges (2001, pp. 142-143) found that early interpersonal communication and exchanges including "affective experience, emotional expression, facial gestures, vocal communication and dependent social behaviour (including facial features)", have been linked to behavioural symptoms (and psychopathologies), including autism, depression, aggression, post-traumatic stress, medical illness (senility, fever), when facing severe challenges (such as grief, rage, anger, and loneliness).

Figley (1995) suggested that caregivers' own unconscious stresses and traumas might evoke their experiences of trauma, as their compassionate reactions and cognitive clarifying processes interact with, and are relived as, experiences and needs. Young caregivers of older family members are clearly more susceptible to vicarious impacts. Pakenham, Bursnall, Chui, Cannon, and Okochi (2006, p. 124) highlighted the impact of caregiving on the development of young people, and in particular, those who care for a family member with a mental illness. For example, the intrapsychic strain characterized as *role captivity* refers to the "unwilling, involuntary incumbent of a caregiver role" (Pearlin, Mullan, Semple, & Skaff, 1990, p. 589).

The need for longer-term treatment in relation to caregivers' intrusive memories and experiences of distress was addressed by McCann and Pearlman (1990;1992), who developed the constructivist self-development theory (CSDT). As a framework for assessment and treatment, CSDT involves exploring how caregivers' unique histories affect their personality development, and shape and define their experience of events, including their adaptation to trauma. CSDT thus focuses on stabilizing symptoms and modifying caregivers' own expectations about their cognitive schemas and self-concept. Other mediating influences in care concern caregivers' own derivations of meaning in relation to the impact of traumatic experiences and other environmental factors upon development (Prugh & Harlow, 1961).

4.7 Compassion Fatigue and Secondary Trauma

Compassion is defined as deep sympathy and sorrow involving specific responses towards those in grief and those afflicted by suffering and misfortune (Oxford University Press, 2016). The Australian Oxford Dictionary (2006) also defines compassion as pity that inclines toward help or mercy. The relationships that exist between empathy, compassion fatigue, and secondary trauma therefore highlight how social learning processes and the socio-emotional symptoms of PTSD may affect caregivers. Figley (1999) thus renamed secondary trauma as 'compassion fatigue' in response to nurses' feelings about and perceptions of trauma.

The caregiver's ability to empathise with the person in care indicates the intensity of their feelings. Figley (1995) named 'compassion satisfaction' as one such positive indicator of caregiving that links to caregivers' adaptive coping and interpersonal capabilities. Valent (2002, p. 25) proposed that caregivers make adjustments or find alternative approaches to trauma by adapting their experiences, or by emulating maladaptive responses, such as those that occur between "caretaking/rescue; attachment; goal achievement/assertiveness; goal surrender/adaptation; competition/struggle; and cooperation/love". Valent (2007) therefore argued that caregiver responses may be relived and/or avoided in the environment as heuristically specific patterns that occur in understandable ways.

Valent (2002, p. 26) added that compassion fatigue is also associated with 'compassion strain', involving "severe anguish and intense guilt; associated with 'not having prevented, or having caused, harm or death'". Valent (2002, p. 26) thus associated caregivers' traumatic stress following traumatic events with a range of survival strategies, such as "*pity* for refugees (flight), *support* for the helpless (attachment), and *tenderness* for the abused (cooperation)". Similarly, rescue-caretaking involves saving or helping aspects for caregivers in traumatic situations where the victim could not be properly cared for or saved.

Compassion fatigue responses highlight specific types of negative feedback and psychosocial judgments following exposure to traumatic events, including "irresponsible and nascent meaning about one's poor role, failed expectations, and existential shortcoming" (Valent, 2002, p.27). Adams, Figley and Boscariono, (2008) and Craig and Sprang (2010, p. 322;) added that "the causal pathway between work-related stress and subsequent adverse outcomes in mental health workers may be modified by the exposure to secondary trauma". The literature indicates that the populations at highest risk of compassion fatigue include humanitarian aid workers, community mental health case managers, city trauma workers, child protective service respondents, and social workers (Craig & Sprang, 2010).

According to Kahill (1988), burnout links to aspects of motivation, but without the symptoms of PTSD. Burnout includes five categories of psychosomatic symptoms: physical, emotional, behavioural, work-related, and interpersonal. Other symptoms of burnout include callousness, pessimism, cynicism, problems in work relationships, and diminishing work performance (Figley, 2002). Figley (2002) also described a range of arousal symptoms associated with burnout, including sleep disturbances, headaches, irritability, aggression, and physical and mental exhaustion. Figley (2002) also associated burnout with frustration, powerlessness, and an inability to achieve work goals. Likewise, Craig and Sprang (2010) and Stamm (2005) described burnout as involving feelings of hopelessness, difficulties with work or workplace efficacy, and the gradual onset of the belief that one's efforts make no difference. The literature concludes that there remains a paucity of published and empirical research about the relationship between burnout and compassion fatigue.

4.8 Why Secondary Trauma is the Focus of this Research

Secondary trauma (or Secondary Traumatic Stress Disorder; Figley, 2002) involves behavioural and emotional reactions to exposure by traumatised individuals. Secondary trauma has been linked to a range of PTSD responses including: re-experiencing; avoidance; negative cognitions and mood; and arousal for more than one month (APA, 2013). Similarly, Figley (1995) described the re-experiencing of the primary trauma, avoidance of reminders and/or numbing in response to reminders, and persistent arousal. Zimmering, Munroe, and Gulliver (2003, p. 1) explained that, while the symptoms of secondary trauma are not found to be equal to a clinical diagnosis of PTSD, “indirect exposure to trauma through a firsthand account or narrative of a traumatic event, and subsequent cognitive or emotional representation of events, results in a set of symptoms and reactions that parallel PTSD”.

The literature also recognises secondary trauma as involving significant emotional, cognitive, and behavioural changes in the mental health of caregivers who treat the survivors of traumatic experiences (Craig & Sprang, 2010). Nelson and Wright (1996, p. 460) described caregivers’ responses in relation to war veterans: “ there exists a lessened ability to contain one’s emotional reaction when in close contact with a trauma victim”. Likewise, Viljoen’s (2001) study of South African police (during the change from apartheid) explained how the police “were convinced that they were not supposed to be affected by the horror they witnessed” (Section 1.1). Valent highlighted this response in relation to survival strategies:

> *... Powerlessness and loss of control are survival strategies that can result in trauma responses. Hopelessness can result in depression and despair. The social response to hopelessness is withdrawal and surrender, as the person is overwhelmed by the problem ...* (Valent, 1995, p. 33).

The literature highlights that secondary trauma is increasingly common, and more prevalent in the following environments: crisis emergency and trauma response teams (such as fire and paramedic service workers); those responding to natural, environmental, and man-made disasters; staff in trauma and emergency welfare services (such as rape crisis and welfare protection workers); and those working in clinical environments (such as nurses, social workers, and counsellors). Workers in remote communities, the spouses of Vietnam veterans, and teachers also describe the effects of secondary trauma more generally.

Craig and Sprang (2010) cited numerous studies focusing on the work-related and secondary trauma symptoms of PTSD in trauma workers to define how therapeutic practises may positively influence their conditions. Clinical supervision and training for new workers are processes thought to alleviate the possibility of secondary trauma. Valent (2002) confirmed that the intuitive placing (of boundaries) between caregivers and individuals allows those with mental illness to concentrate on, and safely express, their survival responses. Experienced clinicians were also noted to have increased their coping abilities by engaging in emotional separation and self-care strategies (such as social support) (Craig & Sprang, 2010). Lauder, Kroll, and Jones (2007) thus described the importance of health promotion interventions that target some point in the stress process, by including information and skill attainment that both improves and controls caregivers' perceptions about secondary trauma.

Teghtsoonian (2009) explained how policy analysts, academic, and community activists highlight the extensive social and personal costs of caregiving. Lauder et al. (2007) also highlighted the ways in which additional organisational stress and subsequent professional distress interface with mental health workers' personal histories and with their broader living environments such as in their own homes, and recur as mental health workers' return the workplace. Teghtsoonian (2009) argued that as current policies increase marginalisation and reduce public services, intensifying work schedules and high job insecurity contribute to the lack of control felt by caregivers, with negative effects concerning poverty, stress, and fatigue. Teghtsoonian (2009) also highlighted the particular effect of trauma upon diverse groups in society, with depression being twice as prevalent among women than men.

4.9 The Rationale for a Study about Secondary Trauma

This research proposes that mental health caregivers are a population worthy of further investigation, and therefore poses questions about the nature of the contexts that occur between the different types of vicarious stress, their particular characteristics and symptoms, and how these can be measured in mental health caregivers. Craig and Sprang (2010, p. 320) declared that "throughout the literature, the terms compassion fatigue, secondary traumatic stress, and vicarious traumatization are used to refer to similar conditions, [and thus reflect] … a lack of conceptual clarity regarding this phenomenon". Craig and Sprang (2010) also suggested that, due to a lack of data, pinning down this terminology definitively is premature. Research conducted by Sabin-Ferrell and Turpin (2003, p. 467) also suggested that the quantitative evidence about vicarious stress typologies is "meagre and inconsistent". Spinazzola, Blaustein, and Van Der Kolk (2005, p. 427) confirmed that "true advancement of the field will require a deliberate process of evaluation and adaptation of efficacious treatments, with less restricted more clinically representative PTSD samples". Craig and Sprang (2010) added that methodological design issues might also compromise important questions about PTSD transmission in caregivers.

A developmental approach, such as proposed by Sullivan (1954), might alleviate such concerns due to its emphasis on caregiving in human culture. Interpersonal Theory (Sullivan, 1956) also recognises the importance of the self-concept and personality development for understanding vicarious stress, as well as the interpersonal relationships of caregivers and those in care. Further, understanding the impact of trauma involves the cognitive, emotional, and behavioural dynamics of caregiving, including empathy. Figley (1999, p. 22) thus advocated for a new awareness that highlights the organisation's "duty to inform individuals of the hazards of working with trauma". Therefore, this research asks three main questions:

> *What is the impact of secondary trauma on care and caregivers?*
>
> *What is the impact of secondary trauma on recovery?*
>
> *How might strategies be identified to address secondary trauma*
> *in mental health caregivers?*

4.10 Summary

This chapter has explored the key concepts of vicarious trauma and caregiver stress involving the self-concept, as well as describing the typologies of vicarious stress as basic concepts that provide further insight about the interactions of compassion fatigue and secondary trauma. In addition, the chapter has explored how caregivers' particular susceptibility to secondary trauma involves their identity and psychopathology. It has also described the importance of empathy for understanding secondary trauma, and the relevance of learning constructs concerning caregivers' coping and experiences. Examples have been provided from the literature, as well as definitions of key indicators of vicarious stress.

This chapter has outlined and introduced caregivers' issues as the rationale and the focus of the research, and has proposed that heuristic learning experiences involving family and societal structures might further contribute to knowledge about secondary trauma, its relationship to development and the influence of social learning upon caregivers' anxiety responses as they are integrated into caregivers' personality. Thus, Interpersonal Theory and its methods and aims are the subject of Chapter 5.

CHAPTER FIVE

Methods

5.1 Introduction

Chapter 5 introduces the methods used in this *Caregiving and Stress* research. The chapter provides an explanation of the research procedures involved in the study, and an overview of how the researcher investigated secondary trauma in relation to indicators of vicarious stress. Interpersonal Theory was chosen to explore the participants' anxiety in the context of their unique individual and developmental caregiving experiences. This chapter makes an original contribution to knowledge by explaining how an empirical framework of exploration allowed the participants to both observe their own experiences of secondary trauma, as well as to describe their motivations and beliefs about caregiving.

Chapter 5 explains the data collection and mixed methodology processes involved in the four stages of the results, based on concepts provided within interpersonal theory. Potentially, this investigation increases the understanding of the interpersonal processes involved in vicarious stress and secondary trauma by reducing participants' distress when recounting their experiences. The Interpersonal Theory framework provided a gradual learning environment, informed by a deliberate and conscious reflection about caregiving experiences at each stage of data collection. The ongoing responsiveness of the participants to the data collection process involved an integration of their discussions and analysis about each stage (Dick, 2010; Wadsworth, 1998). This process gradually improved and established an awareness of secondary trauma. This chapter therefore explores the considerations involved in conducting four separate stages of data collection, and the purpose of the analysis for each stage which contributed to the rigour, validity, and reliability of the research.

5.2 Interpersonal Theory and the Exploration of Secondary Trauma

Interpersonal Theory offers a timely paradigm for research about secondary trauma through observing a course of events that gives rise to a wide field of data about participants' behaviour patterns (Sullivan, 1954). By defining specific developmental stages in the data collection process, interpersonal theory both guided the research questions and defined the areas for analysis. Four stages of data collection also provided efficacy in this research by potentially anticipating the harm caused by secondary trauma and promoting participants' personal agency (Bandura, 2001). Distinct stages in the data collection thus outlined specific developmental concepts based on participants' opportunities for interpersonal growth that could contribute to a greater theoretical understanding of secondary trauma (Sullivan, 1954).

A key component of the methodology for this research is informed by the researcher's role as both a participant and an observer (Sullivan, 1954). Participant observation emphasises processes of collaboration between the researcher and the participant to develop awareness of secondary trauma in relation to the care of mental illness. This research contains heuristic explorations about caregiving based on the formation of *building blocks* of enquiry, to establish a systematic review about the indicators of vicarious stress (Thomas, 2011).

An ongoing atmosphere of collaboration involved clarifying and verifying meaning about the researcher's and the participants' observations, as a new contribution to knowledge about secondary trauma (Morse, Mayan, Olsen, & Spiers, 2002; Wadsworth, 1998). Morse et al. (2002, p. 17) thus described *verification as* "the process of checking, confirming, making sure, and being certain". Achieving ongoing consensus about the participants' information and secondary trauma involved cycles of verification and highlighted (the naturally occurring) events in participants' lives that specifically related to experiences and symptoms involved in the management and care of mental illness (Sullivan, 1956). As Sullivan stated:

> *From such a standpoint, personality is taken to be hypothetical. That which we studied is the pattern of processes which characterize the interaction of personality's in particular recurrent situations or fields which "include" the observer* (Sullivan 1948, p. 106).

In this study, participant observation therefore revealed the important cultural and social factors associated with the caregiving role involving the self-concept and the personality. Hellawell (2006) described the insider/outsider continuum (in ethnographic fieldwork) as an important heuristic device that includes the researcher as a 'complete observer' and a 'complete participant'. Participant observation thus provided a vital link between the researcher and the participants' interpersonal interactions, thereby increasing understanding about how the participants' interpersonal schemas were integrated as cognitive and caregiving outcomes, thereby providing new perspectives on secondary trauma.

This research identified the specific issues that occurred for the participants by utilising two or more sources of information as part of a research dialectic involving both the researcher and the participant (Dick, 2010). This dialectic ascertained and explained the meaning of the participants' experiences of secondary trauma by considering exceptions as well as ambiguities (Dick, 2010). As participant and observer, the researcher facilitated the participants' insights into the research objective and analysis by incorporating their subjective interpretations as opportunities for interpersonal growth (Sullivan, 1956; Szasz, 1970). The research has remained open to sceptical challenges about these new interpretations which are useful to both theory and practice (Dick, 2002).

5.2.1 The Action Research Methodology

The action research used in this study involves processes used to obtain information about participants' lived experiences of caregiving based on successive stages of exploration of the self-concept and personality. As such, the exploration of the participants' self-system is influenced and shaped by their own character (Bandura, 2001). Action research allows the development of ideas about how care is embodied in order to clarify and confirm current concepts of vicarious stress. This research thus combines the social action of developmental psychology with the fieldwork of cultural anthropology (Dick, 2002; Evans, 1996; Sullivan, 1956). Sullivan (1948, p. 106), in *Towards a Psychiatry of the Peoples*, explained that:

> *The general science of psychiatry seems to me to cover much the same field as that which is studied by social psychology, because scientific psychiatry has to be defined as the study of interpersonal relations, and this in the end calls for the use of the kind of conceptual framework that we now call field theory.*

The specific aim of using action research is to evaluate and safeguard the relevance of the information about secondary trauma and to provide immediate benefit for the participants (Dick, 2002; Sullivan, 1954). The research also establishes mutual benefit and comfort in a specific sample group through deliberate and ongoing learning processes. The verification processes involved the participants' own reflections and predictions about their function as caregivers, and the consequent effects of other people's actions and beliefs on their knowledge outcomes (Bandura, 2001). By exploring different perspectives about secondary trauma, action research also provides further avenues for exploration that can positively influence change by generating knowledge and empowerment (Slade, Adams & O'Hagan, 2012).

Action research draws upon participants' own experiences and interactions and, in the case of this research, a conscious reflection on caregiving (Evans, 1996). Sullivan (1954, p. 7) added that "these experiences while individually unique contain those aspects of living that seem quite natural or normal, differing only in meaning provided information about specific or general interaction". The research questions therefore posed a working hypothesis based on the need to identify and learn about indicators of traumatic stress and their relationship to secondary trauma and PTSD (Figley, 1999; Sullivan, 1954). Action research therefore demonstrates coincidences in behaviour that result in accurate reports about secondary trauma (Sullivan, 1954). Any areas of uncertainty in the data were noted and clarified (e.g., those that did not agree with the previous interpretations of secondary trauma concepts and behaviour) (Dick, 2010). Data inconsistences also emphasised collaborative statements or evaluations relating to the cognitive comfort of the participants (Sullivan, 1954). For that reason, Dick (2002) explained how action research involves the testing of data through subsequent stages of research, noting early incongruities alongside later data that may explain disagreements and inconsistencies. Dick (2002) added that the analysis of stages of data collection permits a sceptical challenging of interpretations about secondary trauma useful to theory. The conceptual framework of action research also integrates social and theoretical contexts that permit the researcher to both observe and participate in caregiving values (Blum, 1955). Evans (1996, p. 178) stated that Interpersonal Theory offers a “systematic model for assessment and intervention … through an empirical approach to technique”. As such, this research involved participants’ contributions to four successive stages of the research.

5.2.2 The Four Stages of Data Collection

The study involved four stages of data collection that safeguarded the relevance of the information and the voluntary nature of participation by providing a clear context about the purpose of each of the research stages (Sullivan, 1956). The objective of Interpersonal Theory was to interpret and identify indicators of traumatic stress and how they relate to secondary trauma and care. A heuristic analysis of the data revealed ground-level interactions concerning secondary trauma, based on the participants’ own lived experiences (Sullivan, 1953). This approach also permitted the individual goals of participation in the research to vary (Wadsworth, 1998) by grouping similar data to provide varied perspectives on secondary trauma. According to Kleining and Witt (2001), the complete integration of the findings encourages maximum variation in the data, and subsequently increases the reliability of the research findings.

The qualitative heuristic analysis therefore involved gradual stages of data collection. The four stages of data collection were established from the initial research sample. The Stage 1 reception survey involved recruitment into the study. The survey questions generated basic demographic information and caregiving motivations (see Chapter 6). The Stage 2 reconnaissance interviews provided a developmental chronology of the participants' caregiving experiences, followed by an integration of the participants' analysis and feedback about the interview transcripts (Chapter 7). The detailed enquiry interviews opened with a discussion about the concepts outlined in Interpersonal Theory based on the analysis of the interview transcripts. Afterwards, a Detailed Enquiry involved a specific exploration of participants' self-organisation as outlined by Interpersonal Theory (Chapter 8). The final stage of data collection, the termination/ forum, presented a final summary of the research based on the researchers' analysis of the interview transcripts, followed by the results of the Forum presentation (Chapter 9). Figure 5.1 portrays the methodological stages and their relevance for data collection about secondary trauma.

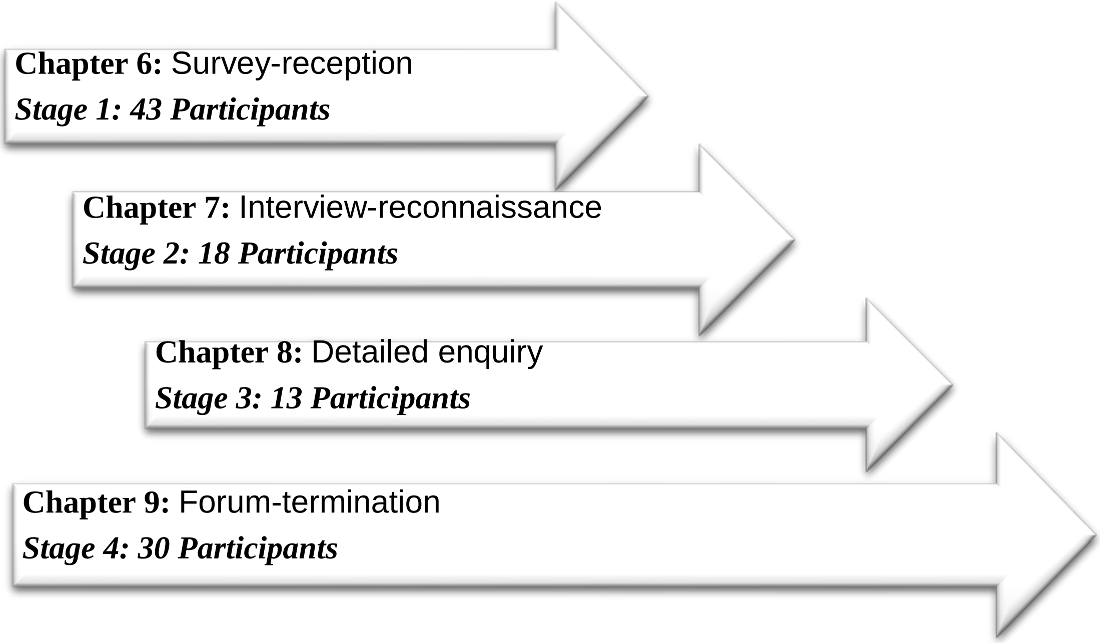


Figure 5.1 Methodological Stages of Data Collection

5.3 The Research Sample and Recruitment into the Study

To ensure that ethical standards were met, the study was subject to approval from the Flinders University Social and Behavioural Research Ethics Committee (project 5689; Appendix 1).

Selection of the research sample incorporated ecological validity by asking participants about their real-life, lived experiences of caregiving (Nastasi & Schensul, 2005). The research also incorporated interpersonal and cognitive theory regarding the influence of human adaptation and change (Bandura, 2001). The term ‘caregiver’ was used as the basis for recruitment into the study to ensure that participants could identify with the research outcomes. As caregivers are a traumatised population, recruitment was based on participants’ subjective evaluations of their own roles. The aim was to provide them with some measure of control over their immediate environment and their level of participation (Bandura, 2001).

Participants were recruited from organisations and support services recognised by caregivers of people with mental illness. The organisations were those that support informal caregivers of people with mental illness, and mental health employees. However, any of the latter who participated in this research also fulfilled primary informal caregiver roles. Initially, four organisations were contacted. A telephone call was followed by an email containing an information package. A Letter of Introduction (Appendix 2) and Information Sheet (Appendix 3) explained the aims of the research. The aims of the research and an outline of the research stages and procedures were provided. A number of organisations sought further clarification. For example, the researcher provided assurance assured that she did not require participants to identify the organisation they were recruited from. This was done to ensure that participation would be voluntary and anonymous, with participants’ details remaining confidential. A return email from the consenting organisations approved the researcher’s access to their members.

Consenting organisations then distributed the Caregiving and Stress Cover Letter (Appendix 4) and Survey (Appendix 5) to their employees/members by email (or in person) on the researcher's behalf. The recruitment process clearly indicated that the participants could withdraw from the research at any time without consequence. Participation was voluntary and unpaid so as to avoid bias in the data (Sullivan, 1956). Participants were also asked whether they wished to be involved in later stages of the research, in which case they provided contact details. If not, they were asked to refrain from identifying themselves.

Required changes to the recruitment and data collection process were undertaken and approved by the ethics committee. The initial four organisations were increased to ten, including four mental health service providers, a private caregiver support organisation, and a consumer health database (two of these organisations did not respond or required a lengthy application process). Table 5.1 outlines the final list of participating organisations.

Table 5.1 Final Sample

Community information resource centre
Community NGO – Education and respite service
Community NGO – Mental health support workers
Community NGO – Mental health support workers
Community NGO – Mental health support workers
Caregiver support association
Caregiver support association
Caregiver support association
Private carer/consumer network
Electronic database for carers and professionals

5.4 The Care-giving and Stress Survey

The reception stage (survey) was adapted from Sullivan's Interpersonal Theory as outlined in the Psychiatric Interview (Sullivan, 1954). The purpose of the reception stage was to establish a rapport with the participants based on establishing their perceptions of the benefits they could gain from the research. The survey also provided baseline data about the caregiving role of this particular cohort.

The actual survey was developed and refined through a peer review process and a pilot study. The research supervisors, other colleagues, caregivers, and other experts in the field tested the survey instrument through ongoing correction and revision of the survey questions. After six weeks, the final survey was approved by the majority of the reviewers, and was then submitted to the ethics committee (as a modification request).

The participants completed the survey in their own time and self-monitored their own levels of anxiety. Instructions about returning the surveys to the researcher were available by clicking a submit button to a confidential service provider (form-central). The survey asked a range of questions to facilitate the future stages of the research (Sullivan, 1954). There were nine demographic questions, while eight explored caregiver motivations and strategies (see Chapter 6). The surveys were stored in a secure database. The researcher accessed the surveys by downloading the responses. In order to maintain confidentiality, the contact details of the participants were only accessible by the researcher.

5.4.1 The Survey Results

Survey rounds were conducted over a 12-week period, with two requests approximately one month apart. After one week, 18 surveys had been returned. After two weeks, responses had waned and the five organisations previously added were contacted. After one month, the researcher extended the submission date by six weeks and conducted a second round.

Participating organisations were contacted (by telephone and email) seeking their permission to access participants for a second time. Seven of the eight organisations approved further access to participants. The second week (of the second round) availed another ten responses, with another five respondents coming from the original database. After a discussion with the research supervisors about the low response rate, the organisations suggested that the sample group had been over-surveyed and therefore had experienced survey exhaustion. A total of 43 returned surveys concluded the data collection for Stage 1 (see Chapter 6).

5.5 The Reconnaissance Procedures and Methodology

The Stage 2 reconnaissance interviews proceeded on the basis of the contact details of 20 Stage 1 survey respondents. These Stage 2 volunteers were contacted by email or telephone to organise an interview time. Each volunteer received the information package and a Consent Form (Appendix 6) via email. The consent form was returned to the researcher by fax or email prior to the commencement of each interview.

In total, 18 participants confirmed an interview time with the researcher. Participants from regional and rural areas also expressed interest for telephone interviews. The researcher discussed submitting a modification request to the Ethics Committee to accommodate this interest. Of the 18 interviews, 13 were conducted face-to-face and 5 were conducted by telephone. The semi-structured interviews took between one and two hours (average duration, 1 hour and 20 minutes). The interviews were audio-recorded to ensure that the data collection process was accurate and complete.

The reconnaissance interview stage (Sullivan, 1954) included key processes that explored the participants' relationships to caregiving based on their personal history and family background. This chronological review was based on the Interview Guide (Appendix 7) adopted directly from Sullivan's Psychiatric Interview (Sullivan, 1954). Each of the participants was asked the same questions in the same order. These questions allowed them to describe and directly relate their subjective experiences of caregiving. These questions also highlighted particular psychological states associated with the achievement of developmental milestones as outlined by Interpersonal Theory. By focusing on these specific developmental processes, interpersonal theory investigated participants' lifelong relationship with caregiving. The individual interview questions explored the participants' significant caregiving relationships and specific developmental periods, including infancy, childhood, juvenile, pre-adolescence, adolescence, late adolescence, and adulthood. These periods specifically highlighted the participants' interpersonal interactions with family, friends of family, relatives, school and community friends, teachers and role models, mentors, close and cherished friends, adult relationships, and partners (Sullivan, 1954). The interpersonal chronology of interactions involved exploring the participants' stressful experiences as potential precursors to secondary trauma. The data collection process highlighted the participants' qualitative responses about their caregiving beliefs and emotional patterns as developmental and interpersonal schemas to provide the participants with an insight into caregiving experiences that culminated with their current caregiving roles. By researching each participant's developmental background, the interview stage provided the framework for further interpersonal analysis and enquiry. These ideas are discussed in Chapter 7.

5.5.1 Analysis and Feedback about the Interview Transcripts

Following the interviews, the audio-recordings were transcribed by a professional transcription service, with signed confidentiality and anonymity agreements first forwarded to the Ethics Committee. The electronic recordings were placed in the Drop Box accounts of the transcription service. Initial delays in transcription necessitated the use of more than one service. Participants were informed of this delay in the attempt to minimise anxiety. When available, participants were forwarded their own transcripts. These contained analytical concepts from Interpersonal Theory that introduced the participants to the feedback process. The researcher highlighted sections of the transcripts during a preliminary analysis. Table 5.2 provides examples of identified concepts and evidence of these concepts.

Table 5.2 Examples of Preliminary Analysis

Concepts	Integration of interpersonal situations			Acts and ideals	
Evidence of concepts	Resolved needs (of care)	Continuing patterns (in care)	Coming to terms (with care)	What was done (in care)	What they thought should have been done (by care)

These feedback processes were outlined in the information sheet and verbally by the researcher at the commencement and conclusion of each interview. The feedback process also allowed the participants to reflect on their developmental experience of caregiving. The analysis of the transcripts therefore contained a holistic purpose involving both "retrospective and prospective" processes that formed the basis of the subsequent discussions (Thomas, 2011, p. 515). The participants also identified a number of themes that were either confirmed or modified through further discussion. The researcher encouraged the participants to make comments on, or changes to, the transcripts and to directly influence and contribute to the research findings before the transcripts were returned to the researcher.

The researcher contacted the eighteen interview participants by telephone and email to explain and verify the analysis process. This follow-up contact occurred on two occasions, one week apart. The researcher also answered any questions participants had about the meaning of the categories. The participants either confirmed or modified the researchers' tentative findings. All 18 participants provided feedback, with most responding positively to the highlighted sections of the transcripts. One participant made several changes, 10 made no changes, while two suggested that they needed more time to understand the coding and analysis. One of these participants subsequently made adjustments to the transcript and coding, while both agreed to accept the categories as they were and continue with the research. The remaining five participants, who did not respond by email, accepted the researchers' analysis during a follow-up telephone discussion.

5.6 The Detailed Enquiry

Contact to participate in the detailed enquiry stage was via two emails, sent one week apart, and a follow-up telephone call. Four interview participants (out of the 18) chose not to participate, while two suggested that the research approach did not adequately address the issues they faced as caregivers. The other two participants indicated that they were too busy with their caregiving to further take part. The remaining participants expressed their desire to continue with the research. Thirteen participants from the Stage 1 survey and the Stage 2 interviews participated in the Stage 3 detailed enquiry. Due to the reduced number of participants, the Detailed Enquiry stage was conducted as small group interviews.

According to the procedures adopted in the previous stages, the participants were emailed the letter of introduction, the information sheet, and a consent form explaining the research goals and establishing group norms. The researcher conducted interviews with 13 participants. All interviews were digitally-recorded and transcribed using the procedures outlined in Stage 2. The detailed enquiry stage opened with a discussion of the Stage 2 analysis and feedback. The subsequent clarification and verification of the participants' developmental milestones and relationships offered a working hypothesis about the indicators of vicarious stress and secondary trauma (Sullivan, 1954). The participants identified with their own interpersonal patterns as a plausible "conceptualisation that accurately describes indices of traumatic stress" (Figley, 1999, p.10). They also discussed their new awareness about their caregiving experiences based on the heuristic analysis. The particular purpose of the heuristic analysis in this research involved establishing notions about the causes of secondary trauma (including outlier examples) by “identifying common patterns” of the types of vicarious stress, and specifically focusing on the sub-type of secondary trauma (Thomas, 2011, p. 515).

During the second half of the interviews, the researcher asked the participants a number of questions adopted from the Psychiatric Interview (Sullivan, 1954) according to their relevance to the research (Detailed Enquiry Question Guide; Appendix 8). The detailed enquiry questions focused on the participants’ explorations of their personified self or ‘*I’,* based on their personal awareness (distinct from previously inferred information) (Sullivan, 1954). The participants explored the situations that increased their feelings of disadvantage or vulnerability. The researcher also asked participants about *security reserves*, such as whether they felt that they had lived a justifiable life (one that provided them with meaning and purpose), their exploration of faith or belief in a higher purpose or an understanding that has helped them in their caregiving role, and any feelings of shame and regret. The participants were also asked to reflect on behavioural changes and their efforts to *right or correct* these behaviours in their lives (Sullivan, 1954). The researcher also asked the participants about their sleeping patterns and their vocational and lifetime goals, as keys to understanding their overall self-organisation and interpersonal relations (Sullivan, 1954).

5.6.1 Detailed Enquiry Interview Feedback

The participants received their own transcripts according to the same processes outlined in Stage 2. This analysis of these transcripts explored three cognitive modes identified in interpersonal theory. *Being* explored the participants’ impressions of caregiving (protaxic); *doing* represented the subsequent communicated interactions (parataxic); and *knowing* stands for symbolic and conceptual understanding (syntaxic) (Sullivan, 1956). All of the 13 participants in the detailed enquiry stage confirmed the three modes alluded to above. These cognitive modes (*being, doing,* and *knowing*) are illustrated in Chapter 9 through 13 individual vignettes. Chapter 9 also presents the results of the fourth and final stage of data collection, the open forum.

5.7 The Open Forum

According to Interpersonal Theory (Sullivan, 1954), the fourth and final stage of data collection is termination, which was adapted as an open forum for this study to provide a summary, assessment, and overall interpretation of the data. The forum consolidated four aims of this part of the study which were to provide: a final statement about the research; a prescription for action based on the research findings; an assessment of benefit; and formal leave-taking (Sullivan, 1954) (see Detailed Enquiry Guide, Appendix 9). The forum was audio-recorded and transcribed according to the procedures employed in Stages 2 and 3. The researcher invited participants from any of the preceding stages of the research, including host organisations, interested parties, and stakeholders, to a forum presentation about the early findings from the 'Caregiving and Stress Research Project'.

Potential participants received an email containing an invitation, the Information Sheet, and a location map. Email responses were requested. The forum also provided an opportunity for people who were unable to participate in the research to nevertheless contribute to the findings. The forum was attended by approximately 30 people and was held at the Flinders University Victoria Square Campus in the Adelaide CBD. The format involved two 30-minute sessions, a PowerPoint Presentation (Appendix 10), and a Q-and-A discussion (Chapter 9). Morning tea and refreshments were provided during a 20-minute break.

The forum initially presented the participants with improved awareness and benefits resulting from participating in the research. The PowerPoint presentation about the early findings presented the participants with an opportunity to assess and validate the research. Secondly, the open microphone Q&A part of the forum raised and consolidated the significant issues facing caregivers of people with mental illness as well as exploring weaknesses in the data collection. At the close of the forum event, various participants expressed their desire to become involved in the research; however, the Flinders university Social and Behavioural Research Ethics Committee were informed that the data collection was finalised and complete, meaning that they could not participate further.

5.7.1 Forum Feedback and Final Evaluation

A small number of forum participants requested copies of the PowerPoint slides and discussion transcripts from the forum, which they received by email. Over the next few days, the participants were asked for their feedback about the forum. Two of the participants (who had also been involved in all the preceding research stages) responded that they had enjoyed the presentation and were happy with the transcripts. One organisation sought to publish the forum results, but this request was declined due to the forum representing a stage in the data collection process, and as yet the complete findings had not been formulated.

This study potentially reduced anxiety by generating an immediate benefit of participation through the Interpersonal Theory approach. Participants' awareness of secondary trauma was facilitated by their sensitivity to their own responses, beliefs, and emotional patterns (Dorsey & Jaffe, 2007). This study explored specific learning processes as well as the participants' assessment and feelings of vulnerability during each stage of the research. The participants examined their own consciousness and reflections related to conflicts in their motivations, values, and in the meanings of their caregiving role (Bandura, 2001).

A consensus on the data was reached through mutual verification about secondary trauma based on participants' communication with the researcher. This verification process ensured symbolically meaningful research outcomes that ultimately led to the empowerment of the participants (Wadsworth, 1998). The research environment increased participants' reliance upon social agency, providing vital opportunities for personal development and improved knowledge about their role (Bandura, 2001). Overall, this research allowed the researcher to explore a multiplicity of voices (about secondary trauma), and so, was able to avoid grand narratives (Lyotard, 1984; Stanford University, 2005). This research therefore utilised a counter-cultural paradigm while also incorporating a discussion about how Sullivan's concepts related to the types of vicarious stress outlined in the literature (Dick, 2010).

5.8 Validity and Reliability

This caregiving and stress research program aimed to explore the impact of secondary trauma on caregiving by investigating the types of coping strategies that the participants engaged in. The community caregivers involved in this study also provided their own interpersonal perspectives about adaption and change by incorporating a cognitive theory framework (Bandura, 2001; Nastasi & Schensul, 2005). Each participant contributed to the evaluation of the transcripts, the researcher's comments, and the tentative findings. An action research approach therefore ensured that the participants could derive direct benefit from their involvement in, and contribution to, the study. This research also encompassed a cultural discourse about actual situations that illustrates how carers should act, based on an understanding that develops from explaining how changes in behaviour occur (Dick 2010; Wadsworth, 1998). Therefore, this research has incorporated a range of processes that led to the immediate improvement of knowledge (Sullivan, 1954).

The mutual nature of the benefits and goals of this research were derived from participants' responsiveness to the consecutive collaborative stages of the data collection process (Sullivan, 1956; Wadsworth, 1998). This program has therefore identified observable patterns in participants' interpersonal development, relating their first-hand experiences of caregiving to their analysis of secondary trauma. The dialectic process (between the researcher and the participant) could thus compare similarities in the results across different stages of data collection (Dick, 2010). Chapters 6, 7, 8 and 9 thereby involve a heuristic replication of the data that confirms and improves understandings of secondary trauma (Dick, 2002).

The ongoing analysis of data collection remained accessible to the participants through access to the relevant documentation, such as the transcripts and accurate recordings (Morse, Barrett, Mayan, Olsen, & Spiers, 2002). This study has also established an overall coherence through a systematic and rigorous methodology that ensured the ongoing analysis and formulation of ideas though evaluative cycles of data collection based on systematic and consecutive stages of learning (Evans, 1996; Morse et al., 2002; Wadsworth, 1998). As a result, the participatory nature of this project involved the ongoing analysis and formulation of ideas about secondary trauma. The collaborative analysis of the data also improved the generalizability of the results (Dick, 2002). The active analysis and verification of the data provided new knowledge about interpersonal interactions by incorporating the current literature about vicarious stress (Figley, 1999; Morse et al., 2002; Sullivan, 1954). The replication and confirmation processes outlined in this research methodology will add to the growing awareness about secondary trauma, providing important knowledge for future research (Wadsworth, 1998).

5.9 Summary

The methods used in this research project established a practical and collaborative approach to the investigation of secondary trauma. The participants developed ideas outlined by interpersonal theory based on stage-specific discussions and the systematic assessment of their experiences of secondary trauma. This chapter has explained how the participants focused on the development of their understanding based on sound interpersonal concepts to accurately describe conceptualisations about traumatic stress. It therefore drew upon field research dynamics that were associated with real caregiving populations.

Chapter 5 has also outlined the interpersonal analysis of concepts concerning the integration of interpersonal situations outlined by Sullivan (1954). The methods described in this chapter therefore assisted in producing a theoretical understanding about stress and tension to explain interpersonal dynamics and to potentially define new knowledge about secondary trauma. The emphasis upon collaborative meaning and continuous corroboration between the participants and the researcher also contained a vital research dialectic that explored interpersonal tensions in the context of the self-concept and personality development. This chapter has therefore introduced the context of the four findings chapters that follow: Chapter 6 (survey/reception); Chapter 7 (interview/reconnaissance); Chapter 8 (detailed enquiry); and Chapter 9 (presentation/termination). These four chapters will be followed by Chapter 10 which presents a discussion of the entire research project.

CHAPTER SIX

Stage 1 Results - Caregiving and Stress Survey

6.1 Introduction

The development of the research to be described in the current chapter was based on an understanding of the impact of trauma on a potentially vulnerable sample group following the literature reviewed in the preceding chapters. In particular, an understanding of the significance of anxiety for the study of secondary trauma allowed the researcher to choose an appropriate method of investigation. To access participants for this study, it was imperative to directly avoid identifying the symptoms or immediate source of traumatic experiences because of the potential for undue distress or anxiety to be placed upon the respondents (Sullivan, 1954). Therefore, the researcher based her recruitment on the methods and research stages as defined by Sullivan's Interpersonal Theory (Sullivan, 1954).

6.1.1 Aim

The aim of the *Caregiving and Stress Survey* was to recruit respondents of similar origins and a common culture who identified with the caregiving role in the mental illness context. The survey was designed to increase respondents' comfort with the overall research program by establishing a clear statement about caregiving, thus encouraging their ongoing participation. Another goal was to collect background and demographic information about the respondents and their care-giving status. It was predicted that the sample information would identify the significant learning relationships and associations between the respondent's caregiving roles and their purpose. Furthermore, Sections 2, 5, 7 and 9 (see the following sections) were designed to tap a continuum of surface to deep engagement responses (approaches and strategies) in caregiving (Zeegers, 2002). It was proposed that surface responses would reflect anxiety while deep responses would characterise increasing interest and achievement.

6.2 Method

6.2.1 Participants and Procedure

This research program used the term ‘caregiver’ as the basis for recruitment into the study. While the goal was to identify potential participants who were caring for a person with mental illness, the use of the criterion ‘caregiver’ was indiscriminate both in purpose and meaning. Potential participants were targeted from relevant recognized support organisations in the South Australian caregiving community (e.g., Mental Health Services and Carer and Disability Professionals Information Services). The sample (outlined in Chapter 5) included informal caregivers of people with mental illness, of whom some were also mental health workers. Two survey rounds provided 43 respondents.

The questionnaires were collated by a confidential service provider (form-central) and stored in a secure databank that notified the researcher about completions by email. This ensured that the contact details of the respondents, provided voluntarily, could only be accessed by the researcher. The researcher then downloaded the surveys as an Excel document which was then translated into an SPSS data file for analysis.

6.2.2 Questionnaire

The goal of the survey was to survey the social influences of caregiving, and the demographic and emotional factors that contribute to cognitive perceptions and role expectancies (Shin, 2011). It was based on Sullivan’s (1954) Psychiatric Interview and the phenomenology of learning attitudes (Biggs, Kember, & Leung, 2001). Questions were also derived from Gratification Theory, Diffusion Theory and Expectation Confirmation Theory.

6.2.2.1 Demographic and Caregiving Details (Section 1)

Standard demographic details such as gender, age, education level, and current relationship status were initially sought. Following this, the nature of the caregiving relationship was sought, including whether the role was paid or unpaid. The participants were also asked if they considered themselves as the main caregiver, how many hours of caregiving was undertaken (per week on average), and how many years they had been a caregiver.

6.2.2.2 Personal Description of Caregiving (Section 2)

Five statements, each of which described a different characteristic of caregiving, were presented to the participants for their endorsement (e.g., ‘caregiving is personally satisfying’). Responses were sought using 5-point Likert scales ranging from ‘never’ to ‘always’. The five items were analysed separately, but were also summed to provide an index of surface to deep engagement. Scores ranged from 5 to 25, with higher scores indicating deeper responses.

6.2.2.3 Perceptions of Your Caregiving (Section 3)

This section was also comprised of five statements (e.g., ‘caregiving increases my sense of control’). Five-point response scales ranged from ‘strongly disagree’ to strongly agree’. In this instance, the items were only analysed individually.

6.2.2.4 Nature of Your Caregiving Role (Section 4)

Five items (e.g., ‘I follow a familiar routine’) were presented. Each was ranked according to 5-item scales ranging from ‘never’ to ‘always’ and were analysed separately.

6.2.2.5 Attitude Towards Your Caregiving Role (Section 5)

Section 5 consisted of five attitudinal statements, such as ‘I am motivated by my caregiving experiences’. Five-point responses (from ‘never’ to ‘always’) were analysed both separately and as a total score to determine surface to deep engagement. Scores ranged from 5 to 25, with higher scores indicating deeper responses.

6.2.2.6 Management of Caregiving Role (Section 6)

Section 6 involved a single question (‘how are you managing your caregiving role’) for which three responses were provided: ‘I often stay completely involved in the caregiving process’, ‘I switch off from my caregiving role whenever possible’, and ‘I can switch off completely and take time out for myself’. Respondents were asked to endorse only one of these responses.

6.2.2.7 Caregiving Role Practices (Section 7)

Section 7 comprised five statements describing caregiving practices (e.g., ‘I carry out my caregiving role independently’). Responses were sought using 5-point scales (‘never’ to ‘always’). The items were analysed separately and as a summative index of surface to deep engagement. Scores ranged from 5 to 25, with higher scores indicating deeper responses.

6.2.2.8 Important Issues in Your Caregiving Role (Section 8)

Section 8 asked the respondents to indicate any issues that they considered important to their caregiving role. Seven options were offered (e.g., ‘honesty’, ‘trust’, ‘recognition from others’). However, the participants were also free to suggest their own responses.

6.2.2.9 Learning and Caregiving (Section 9)

This section sought participants’ feelings about learning in relation to caregiving. Five statements, such as ‘I benefit from learning opportunities’, were presented, for which 5-point responses (‘strongly disagree’ to strongly agree’) were sought. Analyses of the individual items and a total index of surface to deep engagement (range from 5-25) were undertaken.

6.2.3 Statistical Analyses

All responses to the questionnaire were first analysed descriptively. Analyses then determined relationships between responses to Sections 3, 4, 6 and 8 and gender, age, education level, and time in the caregiving role.

6.3 Results

6.3.1 Sample Description

Completed surveys were obtained from 43 participants, of whom 35 were women (81.4%). The majority of the participants were in the 41-55 year old category. The full distribution of age groups is shown in Table 6.1. Approximately half of the sample reported a technical education qualification (Table 6.2), the predominant relationship status of the participants was ‘married’ (Table 6.3), and almost two-thirds reported that the person they cared for was their spouse or another family member (Table 6.4).

There were 21 participants (48.8%) receiving payment for their caregiving role, while 23 (53.5%) considered themselves as the main caregiver to the care recipient. The number of hours per week nominated by the respondents as the time they spent as a caregiver was highly skewed, ranging from 1 to 168 hours. The mean number of hours was 38.3 (SD = 45.2). The median (interquartile range, IQR) was 22 hours (8, 40). The number of years the caregivers reported being in the role provided a more normal distribution, with responses ranging from 1 to 37 years (M = 12.5, SD = 9.4, Med = 10.0, IQR = 5, 18).

Table 6.1 Age Groups of Survey Participants

	n	%
18 – 25 years	0	0.0
26 – 40 years	7	16.3
41 – 55 years	23	53.5
56 – 70 years	13	30.2
70 + years	0	0.0

Table 6.2 Educational Qualifications of Survey Participants

	n	%
None	1	2.3
TAFE / technical qualification	22	51.2
University degree	12	27.9
Post-graduate qualification	8	18.6

Table 6.3 Relationship Status of Survey Participants

	n	%
Married	21	48.8
Partner, defacto	9	20.9
Single	4	9.3
Divorced	6	14.0
Separated	1	2.3
Widowed	1	2.3
Engaged	1	2.3

Table 6.4 Relationship of Survey Participants to Care Recipient

	n	%
Spouse, family member	27	64.3
Friend, companion	2	4.8
Peer worker	1	2.4
Community health worker	8	19.0
Spouse & Community worker	3	7.1
Partner	1	2.4
Not answered	1	-

6.3.2 Personal Description of Caregiving

Responses to the participants' personal descriptions of caregiving are summarised in Table 6.5. There was modest endorsement that 'caregiving is personally satisfying', that it 'contributes to personal growth', and that it 'increases feelings of self-worth'. The 'personal caregiving role is well meaning' item was more strongly endorsed. Participants were relatively equally divided on whether or not they felt that 'caregiving was an obligation'. The mean response to the sum of these items was 17.2 (SD = 2.9, range = 9-22), suggesting that the majority of responses tended towards a deep level of engagement.

6.3.3 Perceptions of Your Caregiving

Table 6.6 summarises the participants' perceptions of their caregiving. There was strong endorsement that '*life decisions are influenced by caregiving',* that *'caregiving affects how I make daily choices',* and that *'caregiving involves time management skills'.* There was more modest support for the assertion that *'the caregiving role is rewarding',* and mixed opinions as to whether *'caregiving increases sense of control'.*

6.3.4 Nature of Your Caregiving Role

All statements were strongly endorsed (see Table 6.7). A minimum of 76.8% of respondents reported that they 'frequently' or 'always' engaged in the actions listed.

6.3.5 Attitude Towards Your Caregiving

Participants' expressed a strongly positive attitude toward their role (Table 6.8), with the strongest responses being recorded for 'knowing what my caregiving role is about'. The mean response to the sum of these items was 18.9 (SD = 3.4, range = 11-25), suggesting that the majority of responses represent a deep level of engagement.

Table 6.5 Personal Description of Caregiving

	Never		**Rarely**		**Occasionally**		**Frequently**		**Always**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Caregiving is personally satisfying	0	0.0	7	16.7	13	31.0	20	47.6	2	4.8
Caregiving contributes to my personal growth	2	4.7	5	11.6	15	34.9	13	30.2	8	18.6
My caregiving role is an obligation	9	20.9	6	14.0	12	27.9	10	23.3	6	14.0
Caregiving increases my feeling of self-worth	4	9.3	8	18.6	17	39.5	12	27.9	2	4.7
My caregiving role is well meaning	1	2.3	0	0.0	5	11.6	15	34.9	22	51.2

Note: %s have been adjusted where necessary to account for missing responses.

Table 6.6 Perceptions of Caregiving

	Strongly disagree		**Disagree**		**Neutral**		**Agree**		**Strongly agree**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
My life decisions are influenced by my role	0	0.0	5	11.6	6	14.0	15	34.9	17	39.5
Caregiving increases my sense of control	6	14.0	10	23.3	13	30.2	13	30.2	1	2.3
Caregiving affects how I make daily choices	0	0.0	2	4.8	10	23.8	19	45.2	11	26.2
Caregiving involves time management skills	0	0.0	0	0.0	3	7.1	20	47.6	19	45.2
My caregiving role is rewarding for me	1	2.3	3	7.0	16	37.2	18	41.9	5	11.6

Note: %s have been adjusted where necessary to account for missing responses.

Table 6.7 Nature of Your Caregiving Role

	Never		**Rarely**		**Occasionally**		**Frequently**		**Always**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
I make caregiving interactions easy to understand	0	0.0	1	2.4	8	19.5	17	41.5	15	36.6
I adapt my caregiving to the situation	0	0.0	0	0.0	2	4.7	15	34.9	26	60.5
My caregiving is guided by the person's needs	0	0.0	0	0.0	3	7.0	11	25.6	29	67.4
I discuss goals for caregiving with the person	2	4.7	4	9.3	6	14.0	11	25.6	20	46.5
I follow a familiar routine	2	4.7	1	2.3	7	16.3	19	44.2	14	32.6

Note: %s have been adjusted where necessary to account for missing responses.

Table 6.8 Attitude Towards the Caregiving Role

	Never		**Rarely**		**Occasionally**		**Frequently**		**Always**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
I want to learn more about caregiving	0	0.0	2	4.8	13	31.0	17	40.5	10	23.8
I just do what I need to do in my caregiving role	7	16.3	5	11.6	10	23.3	10	23.3	11	25.6
I know what my caregiving role is about	1	2.4	1	2.4	7	16.7	17	40.5	16	38.1
I am motivated by my caregiving experiences	1	2.3	7	16.3	9	20.9	15	34.9	11	25.6
I am improving my knowledge about caregiving	0	0.0	3	7.0	8	18.6	16	37.2	16	37.2

Note: %s have been adjusted where necessary to account for missing responses.

6.3.6 Management of Caregiving Role

The responses to the single item concerning how participants were managing in their caregiving role are summarised in Table 6.9, which demonstrates a relatively equally split between the three alternative responses.

6.3.7 Caregiving Role Practices

Participants' responses to how they were practicing their caregiving role are shown in Table 6.10. There was strong support for the notion of '*trusting my own experiences*', '*performing specific caregiving task*s', and '*fulfilling an essential caregiving role*'. Slightly lower endorsement was reported for '*learning from others' experiences*' and '*carrying out the role independently*'. The mean response to the sum of these items was 19.5 (SD = 2.6, range = 14-25), again suggesting a relatively deep level of engagement from participants.

Table 6.9 How Are You Managing Your Role?

	n	**%**
I often stay completely involved in the caregiving process	13	31.7
I switch off from my caregiving role whenever possible	14	34.1
I can switch off completely and take time out for myself	14	34.1
Not answered	2	-

6.3.8 Important Issues in Your Caregiving Role

Participants were asked those issues that were most important in their caregiving role. A number of options were suggested to them, but they were also invited to self-nominate issues. The data are presented in Table 6.11. Of greatest importance were '*trust*' and '*responsibility*'.

Table 6.10 *Caregiving Role Practices*

	Never		Rarely		Occasionally		Frequently		Always	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
I trust in my own experiences as a caregiver	0	0.0	2	4.7	2	4.7	28	65.1	11	25.6
I perform specific caregiving tasks	1	2.3	2	4.7	8	18.6	22	51.2	10	23.3
I fulfil an essential caregiving role	0	0.0	1	2.4	6	14.3	19	45.2	16	38.1
I learn from other caregiver's experiences	1	2.4	5	11.9	15	35.7	13	31.0	8	19.0
I carry out my own caregiving role independently	3	7.1	1	2.4	11	26.2	14	33.3	13	31.0

Note: %s have been adjusted where necessary to account for missing responses.

Table 6.11 Important Issues in Your Caregiving Role

Issue	**n**	**%**
Honesty	29	67.4
Trust	35	81.4
A caring environment	25	58.1
Good sense	28	65.1
Responsibility	31	72.1
Support and guidance	26	60.5
Recognition from others	8	18.6
Knowing limits, getting help	1	2.3
Knowing what to do	2	4.7
Rapport with care recipient	2	4.7
Faith	1	2.3
Adaptability	1	2.3
Integrity	1	2.3
Humour	1	2.3
Autonomy	1	2.3

6.3.9 Learning and Caregiving

Finally, participants' feelings about learning and caregiving are summarised in Table 6.12. The responses to these questions were overwhelmingly positive. Overall, there were no 'disagree' or 'strongly disagree' responses. Furthermore, very few respondents indicated that they were 'neutral' about these issues. The mean response to the sum of these items was 21.7 (SD = 2.5, range = 15-25), indicating that this set of statements demonstrated the deepest level of engagement of the entire questionnaire.

Table 6.12 Learning and Caregiving

	Strongly disagree		**Disagree**		**Neutral**		**Agree**		**Strongly agree**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
More research is needed	0	0.0	0	0.0	2	4.7	15	34.9	26	60.5
Certain things I want to know more about	0	0.0	0	0.0	7	16.7	26	61.9	9	21.4
Caregivers should be involved in research	0	0.0	0	0.0	3	7.1	14	33.3	25	59.5
I benefit from learning opportunities	0	0.0	0	0.0	4	9.3	20	46.5	19	44.2
I want to learn more about common issues	0	0.0	0	0.0	5	11.9	21	50.0	16	38.1

Note: %s have been adjusted where necessary to account for missing responses.

6.3.10 Analyses by Gender

The results of the gender analyses are presented in Tables 6.13 to 6.16 for Sections 3, 4, 6 and 8, respectively. For Section 3 (Perceptions of Your Caregiving), mean ranks and results of the Mann-Whitney U tests (converted to z) are shown in Table 6.13. No gender differences were evident. Table 6.14 presents the results of similar tests for Section 4 (Nature of Your Caregiving Role). A single gender difference was noted, with males significantly more likely than females to endorse ‘I follow a familiar routine’. A single χ^2 analysis tested the difference in gender proportions shown in Table 6.15 for Section 6 (Management of Caregiving Role). There was no significant difference ($\chi^2_{(2)} = 1.18$, p = .553).

Table 6.13 Perception of Caregiving by Gender

Perception of Caregiving	**Females**	**Males**	***z***	***p***
My life decisions are influenced by my role	22.1	21.7	0.08	.934
Caregiving increases my sense of control	22.9	17.9	1.07	.286
Caregiving affects how I make daily choices	21.5	21.4	0.02	.986
Caregiving involves time management skills	21.8	20.2	0.34	.734
My caregiving role is rewarding for me	22.5	19.8	0.58	.559

Table 6.14 Nature of Caregiving Role by Gender

Nature of Caregiving Role	**Females**	**Males**	***z***	***p***
I make caregiving interactions easy to understand	21.5	18.5	0.65	.516
I adapt my caregiving to the situation	22.3	20.7	0.38	.703
My caregiving is guided by the person’s needs	21.5	24.0	0.61	.544
I discuss goals for caregiving with the person	22.5	20.0	0.53	.594
I follow a familiar routine	20.2	30.1	2.15	.031

Table 6.15 How Are You Managing Your Role? by Gender

	Females		**Males**	
How Are You Managing Your Role?	**n**	**(%)**	**n**	**(%)**
I often stay completely involved in the caregiving process	12	(35.3)	1	(14.3)
I switch off from my caregiving role whenever possible	11	(32.4)	3	(42.9)
I can switch off completely and take time out for myself	11	(32.4)	3	(42.9)

Finally, a series of Fisher's Exact Probability Tests (Table 6.16) were conducted for the core response options of Section 8 (Important Issues in Your Caregiving Role). The number of participants who endorsed each option is shown. A greater proportion of males than females endorsed 'honesty' as important. No other significant results were found.

Table 6.16 Important Issues in the Caregiving Role by Gender

	Females		**Males**		
Issue	**n**	**(%)**	**n**	**(%)**	***p***
Honesty	21	(60.0)	8	(100.0)	.039
Trust	28	(80.0)	7	(87.5)	1.000
A caring environment	21	(60.0)	4	(50.0)	.701
Good sense	22	(62.9)	6	(75.0)	.692
Responsibility	25	(71.4)	6	(75.0)	1.000
Support and guidance	21	(60.0)	5	(62.5)	1.000
Recognition from others	5	(14.3)	3	(37.5)	.153

6.3.11 Analyses by Age

For Section 3 *(Perceptions of Your Caregiving;* Table 6.17), the mean rank for each age group is shown, along with *Kruskal-Wallis* results expressed as z. No significant effects were evident. Table 6.18 presents the results for Section 4 (*Nature of Your Caregiving Role*), with no age effects noted. A linear-by-linear χ^2 was used to examine the association between age and Section 6 (*Management of Caregiving Role;* Table 6.19). It was not significant ($\chi^2_{(1)}$ = 0.37, p = .543). Finally, age effects for each of the Section 8 options *(Important Issues in Your Caregiving Role;* Table 6.20) were also examined using linear-by-linear χ^2. A single significant effect suggested that as age increased, 'responsibility' decreased.

Table 6.17 Perception of Caregiving by Age

Perception of Caregiving	**26-40**	**41-55**	**56-70**	χ^2	***p***
My life decisions are influenced by my role	18.3	21.6	24.8	1.43	.490
Caregiving increases my sense of control	23.4	23.7	18.2	1.81	.405
Caregiving affects how I make daily choices	22.1	20.9	22.2	0.12	.941
Caregiving involves time management skills	27.4	17.9	24.9	5.61	.061
My caregiving role is rewarding for me	27.9	20.9	20.8	2.13	.344

Table 6.18 Nature of Caregiving Role by Age

Nature of Caregiving Role	**26-40**	**41-55**	**56-70**	χ^2	***p***
I make caregiving interactions easy to understand	22.6	21.1	19.8	0.27	.873
I adapt my caregiving to the situation	21.7	22.1	22.0	0.01	.996
My caregiving is guided by the person's needs	19.4	19.7	27.5	5.21	.074
I discuss goals for caregiving with the person	27.4	21.2	20.7	1.61	.448
I follow a familiar routine	19.7	22.3	22.7	0.32	.851

Table 6.19 How Are You Managing Your Role? by Age

	26-40		41-55		56-70	
How Are You Managing Your Role?	**n**	**(%)**	**n**	**(%)**	**n**	**(%)**
I often stay completely involved in the caregiving process	2	(28.6)	8	(34.8)	3	(27.3)
I switch off from my caregiving role whenever possible	2	(28.6)	6	(26.1)	6	(54.5)
I can switch off completely and take time out for myself	3	(42.9)	9	(39.1)	2	(18.2)

Table 6.20 Important Issues in the Caregiving Role by Age

	26-40		41-55		56-70			
Issue	**n**	**(%)**	**n**	**(%)**	**n**	**(%)**	χ^2	*p*
Honesty	5	(71.4)	16	(69.6)	8	(61.5)	0.25	.614
Trust	6	(85.7)	17	(73.9)	12	(92.3)	0.42	.517
A caring environment	5	(71.4)	14	(60.9)	6	(46.2)	1.30	.255
Good sense	6	(85.7)	14	(60.9)	8	(61.5)	0.82	.366
Responsibility	6	(85.7)	19	(82.6)	6	(46.2)	4.74	.029
Support and guidance	6	(85.7)	13	(56.5)	7	(53.8)	1.47	.225
Recognition from others	5	(71.4)	1	(4.3)	2	(15.4)	5.70	.017

6.3.12 Analyses by Education

One participant, who indicated '*no education'* (see Table 6.2) was removed prior to these analyses. Analyses for Section 3 (*Perceptions of Your Caregiving)* are shown in Table 6.21 and demonstrated no associations with education (*Kruskal-Wallis tests).* A single significant Kruskal-Wallis test was found for Section 4 (*Nature of Your Caregiving Role*; Table 6.22).

Participants with a basic university education were more likely to endorse '*I make caregiving interactions easy to understand*'. As with previous variables, a linear-by-linear χ^2 demonstrated no effect between education and *Section 6 (Management of Caregiving Role;* $\chi^2_{(1)} = 1.31$, p = .253; see Table 6.23). Similarly, there were no linear-by-linear associations between education level and role credibility options (Table 6.24).

Table 6.21 Perception of Caregiving by Education

Perception of Caregiving	**TAFE**	**University**	**Post-graduate**	**χ^2**	***p***
My life decisions are influenced by my role	21.0	21.0	23.5	0.29	.864
Caregiving increases my sense of control	19.6	23.6	23.6	1.23	.541
Caregiving affects how I make daily choices	21.7	19.1	22.0	0.50	.778
Caregiving involves time management skills	19.8	22.7	21.6	0.56	.755
My caregiving role is rewarding for me	19.6	24.2	22.6	1.31	.520

Table 6.22 Nature of Caregiving Role by Education

Nature of Caregiving Role	**TAFE**	**University**	**Post-graduate**	**χ^2**	***p***
I make caregiving interactions easy to understand	17.9	27.9	17.2	6.92	.031
I adapt my caregiving to the situation	18.7	26.7	21.4	4.40	.111
My caregiving is guided by the person's needs	19.9	23.0	23.6	1.18	.554
I discuss goals for caregiving with the person	18.0	25.4	25.3	4.19	.123
I follow a familiar routine	21.3	22.8	20.1	0.30	.863

Table 6.23 How Are You Managing Your Role? by Education

	TAFE		University		Post-graduate	
How Are You Managing Your Role?	**n**	**(%)**	**n**	**(%)**	**n**	**(%)**
I often stay completely involved in the caregiving process	8	(40.0)	3	(25.0)	1	(12.5)
I switch off from my caregiving role whenever possible	7	(35.0)	2	(16.7)	5	(62.5)
I can switch off completely and take time out for myself	5	(25.0)	7	(58.3)	2	(25.0)

Table 6.24 Important Issues in the Caregiving Role by Education

	TAFE		University		Post-graduate			
Issue	**n**	**(%)**	**n**	**(%)**	**n**	**(%)**	χ^2	***p***
Honesty	16	(72.7)	6	(50.0)	6	(75.0)	0.08	.781
Trust	18	(81.8)	9	(75.0)	7	(87.5)	0.03	.868
A caring environment	13	(59.1)	6	(50.0)	5	(62.5)	0.00	1.000
Good sense	14	(63.6)	6	(50.0)	7	(87.5)	0.67	.413
Responsibility	17	(77.3)	7	(58.3)	6	(75.0)	0.19	.664
Support and guidance	14	(63.6)	5	(41.7)	6	(75.0)	0.02	.894
Recognition from others	3	(13.6)	2	(16.7)	3	(37.5)	1.78	.183

6.3.13 Analyses by Years in the Role

The final analyses examined associations between Sections 3, 4, 6 and 8, respectively, and the number of years participants reported filling the role of caregiver (Tables 6.25 to 6.28). For Section 3 (Table 6.25) and Section 4 (Table 6.26), Spearman rho correlation coefficients were calculated. No significant relationships were noted for either set of variables. The mean rank of years in the role for each response to Section 6 is presented in Table 6.27. A significant *Kruskal-Wallis* test was obtained ($\chi^2_{(2)} = 9.07$, p = .011) which indicated that participants who had been in the caregiving role longer were more likely to endorse '*I switch off from my caregiving role whenever possible*'. A series of Mann-Whitney U tests (expressed as z) were conducted for the core responses to Section 8 options (Table 6.28). The mean rank (years in the role) is shown for participants who did, or did not, endorse each option. Participants who endorsed 'support and guidance' were significantly likely to have been in the role for a shorter time. There was also a trend (*p = .058*) toward less experienced caregivers also endorsing 'responsibility' more than longer-term caregivers.

Table 6.25 Perception of Caregiving by Years in the Role

Perception of Caregiving	***rho***	***p***
My life decisions are influenced by my role	.26	.093
Caregiving increases my sense of control	-.26	.094
Caregiving affects how I make daily choices	.20	.219
Caregiving involves time management skills	.24	.127
My caregiving role is rewarding for me	-.20	.201

Table 6.26 Nature of Caregiving Role by Years in the Role

Nature of Caregiving Role	***rho***	***p***
I make caregiving interactions easy to understand	-.02	.894
I adapt my caregiving to the situation	-.23	.145
My caregiving is guided by the person's needs	.02	.899
I discuss goals for caregiving with the person	-.09	.578
I follow a familiar routine	.102	.519

Table 6.27 How Are You Managing Your Role? by Years in the Role

How Are You Managing Your Role?	**Mean Rank**
I often stay completely involved in the caregiving process	21.9
I switch off from my caregiving role whenever possible	26.5
I can switch off completely and take time out for myself	13.4

Table 6.28 Important Issues in the Caregiving Role by Years in the Role

Issue	**Ticked**	**Not ticked**	***z***	***p***
Honesty	20.9	22.8	0.47	.640
Trust	20.8	24.6	0.79	.432
A caring environment	19.2	24.6	1.40	.161
Good sense	20.6	23.2	0.67	.503
Responsibility	19.2	27.2	1.90	.058
Support and guidance	17.9	26.8	2.30	.022
Recognition from others	14.8	23.1	1.72	.086

6.4 Summary

The caregiving and stress survey provided an introduction to the research program by establishing a clear opening statement about this particular caregiving sample. The survey represented the first stage of the research, and aimed to increase the respondents' levels of comfort, and to encourage their ongoing participation. The survey also indicated any anomalies in the data that could potentially be explored in the next stage (2) of data collection (the individual interviews). This chapter makes an original contribution to knowledge by presenting the respondents' basic caregiving profile, as caregivers for people with mental illness in the South Australian demographic. The quantitative statistics described in this chapter included information about the respondents' demographic status; their perceptions and descriptions of their caregiving role; the nature of their caregiving attitudes; and information about their management practices and learning goals.

The results of this survey presented important findings about the caregiving sample by mainly depicting an older middle-aged demographic. The majority of the respondents were from 41-55 years old and female, and most were married. Nearly two-thirds of the survey respondents identified as caregivers for a spouse or other family members. On average, the respondents spent 22 hours per week in their caregiving role over a period of 12.5 years, and identified trust and responsibility as the most important issues in their caregiving relationships. Male respondents were more likely to endorse familiar routines and honesty, while less experienced caregivers highlighted their increased need for understanding about their caregiving responsibilities, as well as support and guidance**.** The results of this survey also indicated that as the respondents' age increased, the importance of responsibility decreased, suggesting that the increased life experience of the older demographic sample may have played a role in these findings.

In terms of the respondents' educational attainment, 50% reported having a technical education qualification, while the respondents who reported having a basic university education indicated an improved understanding about caregiving interactions overall. Subsequently, a range of caregiving approaches and strategies were compared analytically across the sample based on the respondents' age group, gender, level of education, and number of years spent in the caregiving role. Importantly, the results indicated that (instead of anxiety responses) most respondents showed a sense of achievement and increasing interest in the caregiving role. This caregiving and stress survey also found that caregiving role models were important for younger caregivers in the community. While the survey sample acknowledged a cultural bias towards female caregivers generally, it also pointed to the value of the lived caregiving experience. Further discussion about the Stage 1 survey results will be provided in Chapter 10.

This survey has established the first stage of data collection and introduced an outline of the subsequent research processes involved in this research project. As such, this survey chapter has provided a clear opening statement about the respondents' caregiving status and that they gained a sense of familiarity with the overall research aims in preparation for the next stage of data collection. The results of this survey also highlighted the need to explore caregiving as an overall concept. The next chapter therefore asks participants' important questions about their own experiences of caregiving and the ways in which caregiving has potentially influenced their identity and life career. Again underpinned by Sullivan's Interpersonal Theory, Chapter 7 makes a reconnaissance into the caregiving role, by exploring how the participants' cognitive and life span development has influenced their learning and coping skills. Chapter 7 presents the results of the reconnaissance interviews based on the participants' reflections about their interpersonal experiences of caregiving and their developmental background from early childhood until the present.

CHAPTER SEVEN

Considering Secondary Trauma through Individual Interviews

7.1 Introduction

Chapter 7 reports on interviews conducted with 18 individual participants. The (Stage 2) interview questions made a reconnaissance into each participant's family background and personal history to form a chronology of caregiving in their lives. The results of this chapter follow the initial recruitment of Stage 1 (Chapter 6). The question guide for the exploration of secondary trauma outlined in these results was adopted directly from Sullivan's 'Psychiatric Interview' (Sullivan, 1954). Each participant was asked the same questions in an identical order, with the average duration of the interviews being 1 hour and 20 minutes. The interviews were audio-recorded and professionally transcribed upon completion.

The methodological concepts described in this chapter outline the basic developmental and interpersonal schemas that relate to caregiving themes. An original contribution to knowledge is the exploration of how participants' specific developmental milestones have influenced their later caregiving roles. These specific milestones included infancy, childhood, the juvenile period, pre-adolescence, adolescence, post-adolescence, and adulthood. The interviews also explored the important caregiving relationships that accompanied each specific developmental period, including those with family, relatives, family friends, school and community friends, teachers and role models, mentors, close and cherished friends, adult relationships, and partners. This chapter reveals how these interpersonal milestones and relationships contributed to the participants' later coping skills, trauma, and care.

7.2 Learning to be Caregivers Throughout Development

The participants for this study (N = 18) are identified by the pseudonyms listed in Table 7.1. The majority of the participants involved in the interviews were aged between 40 and 70 years. Three were primarily family caregivers, although they also worked in the MHS sector. The following reflections describe many of the particular issues experienced by this generation. The first three developmental stages (and approximate ages) presented in this section include: Infancy (0-2) - (the first self-personifications); Childhood (3-5) - (the beginning of verbal communication); and the Juvenile period (6-8) - (the learning and correction of interpersonal interactions).

Table 7.1 Pseudonyms of participants

Male Participants	Ian, Peter, Robert, Adam, Matt
Female Participants	Kate, Sam, Sarah, Kim, Lisa, Chris, Janet, Leah, Mel, Kelly, Ann, Louise, Nadia

7.2.1 Family Issues as Early Concepts about Care

In interpersonal theory, ***infancy*** represents the earliest personifications of care developed with, and through, the primary caregiver. Accordingly, infants' first cognitive constructs and empathetic experiences involve three main aspects of learning and esteem: approval (good me); instruction (bad me); and dissociation (not me) (Sullivan, 1956). The following findings describe the participants' early observations and perceptions about their primary caregiving experience. These observations were then compared to their families' expectations about caregiving overall. This section explores the following themes: immigration; extended family; communities; sibling relationships; responsibilities; and bonding.

Eight of the eighteen participants were directly affected by the migration of their family to Australia. These participants described the importance of their primary group to provide family cohesion in their new country, and to strengthen fragmented ties. The participants' early dependence upon family as their primary source of socialisation also highlighted their early experiences of social isolation. ***Lisa*** described how visiting family members overseas helped to overcome distance and separation. She then described how her parents preserved their sense of belonging and identity by caring for her grandfather.

> *... We migrated from [country] in 1963 ... the privilege of being able to go back ... throughout our childhood to visit relations ... every 7 odd years ... occasionally their offspring came out and stayed with us ... all my mum's family have now died ... I'd seen my parents ... look after ... my grandfather ... they organised ... help for him ... so ... he was near and we used to visit him quite regularly.*

Ann also described how immigration had impacted upon her family and the extra responsibility it placed on her parents. Her early observations were heavily influenced by her parents' ongoing struggle to make ends meet and to provide adequate care.

> *... My dad worked a lot ... though he was brought to Australia, because they said they needed carpenters, he couldn't get work ... and my mum was left in a hostel with five children ... It was probably extremely difficult for my mother ... having a sick son and then dealing with my illness ... I see care giving ... as ... an experience of someone being a carer for someone from quite early on really ... from birth.*

According to Interpersonal Theory, **childhood** begins once a person begins to communicate verbally and achieve social integration through cooperation and approval. The participants' early childhood experiences highlighted the success of their early caregiving/bonding experiences with immediate family. They also learned to communicate with people outside of the family by meeting and forming new friends at school. The participants explained how their current caregiving orientation, and their first concepts (ideas) about empathy, stemmed from the issues they experienced during their infancy and childhood.

For example, the participants' ability to *delay gratification* was essential for achieving two important cognitive processes: the transfer of information to experience (*sublimation),* and the maintenance of interpersonal security from anxiety and disassociation (*selective inattention)* (Sullivan 1956). ***Lisa*** clearly described her first learning experiences based on the life skills taught to her by her father. Her ability to cooperate established her subsequent personality development and contributed to her interpersonal security. ***Lisa*** described how learning these early life skills prepared her for her current caregiving role.

> *... in my inability to be able to understand ... I didn't speak until I was 2 and a half ... I remember going to a lot of child psychologists and speech therapists ... about 15 years after I left school ... I ... sat for tests and they ... said, "Oh yes, by the way you've got dyslexia."*
>
> *... Most of my presents ... as a child ... were hammer ... saws - ... Dad, because he was an only son, he just ... said, "Well if she can't [read] ... she can't do it, so don't harp on it; let it flow, pick on her strengths instead". ... He'd ... take me out to the garage and we'd make something ... he said, "Well let's go out and just look at it and work out how we can do this without relying on the book". And I think, in a way that gave me more life skills ...*

Sarah described her childhood relationship with her mother and her experiences of delayed gratification involving early observations of caregiving for her severely disabled sister. She subsequently explained how her transfer of information to experience was affected by her ongoing inability to communicate with her mother.

> *... I was expected to grow up very, very early and ... my mum's said that to me since then ... she's sort of told me lots of things about her and how it was for her. I know I felt really excluded ... she still manages to ... get things mostly from her own perspective ...*

Likewise, ***Adam*** and ***Leah*** highlighted how their primary caregiving relationships were important for achieving cooperation and approval. The significance of their immediate environment to provide them with sustainable interpersonal opportunities and interactions was clearly evident.

Adam

> *... I have 3 older [siblings] I was the baby of the family ... even now I have a sort of distant relationship with my mum ... We never really bonded ... but [caring] seemed to be quite normal as a child I guess ...*

Leah

> *... it ... came predominately from my aunt ... the sort of care that you could do no wrong and you had that in-shakeable approval and love from her ... I always knew my aunt ... whatever happened I could never do any wrong and I'd go out of my way to make her very pleased and proud of me. ... Whereas my mother ... you could never really please her ...*
>
> *... The most outstanding factor ... in care [was] looking and seeing how people, when they became ill, how a family member took the place of ... their mother ... that aunt looked after her brother ... they never married ... they were brother and sister, and sharing the same house.*

The presence of **grandparents and extended family** strengthened the participants' social networks and their optimism about interpersonal growth. These early social networks were important influences that also shaped later caregiving values. The participants' highlighted their greater communication skills and successful social integration. ***Ian's*** extended family provided the most significant opportunities for his interpersonal development. He described how his grandparents defined his self-concept during early childhood.

> *... I do know that as a young kid ... because my father was either at work during the week or at weekends ... I wouldn't see a lot of him ... so my main ... care growing up prior to going to school was through my grandparents ... I was never really cared for by anybody else ...*

The participants emphasised the importance of their parents and primary caregivers in gaining an understanding of caregiving. ***Ian's*** early perceptions of caregiving clearly influenced his early childhood behaviours and self-esteem.

> *... not saying I was neglected as a child or anything by my parents ... I don't think my dad was around as often as I would have liked ... what I'm told and I think that might have had some influences on me during school ... when I first started ... because I used to run away ...*

Sam described her childhood socialisation experiences with family and friends. Her recollections of her grandparents provided her earliest caregiving memories. She also emphasised the role that her local community played in defining and shaping her identity.

> *... I saw my father with his mother living across the road from us ... and became very close to my grandmother ... more so than my own mother ... my [grandfather] had ... a heart condition ... we'd eat apples together and things ... I was sort of keeping him alive ... that's my earliest recollections ... of anything ...*
>
> *... My father had a base of friendships and people to replace siblings he never had ... his [twin] sister died at birth ... there were no other children ... [so] my father's mother was very conscious ... the house was full of people ... Sunday night ... was always like a party night ... my dad built a tennis court in our backyard and soon that was full of everyone as well.*

The following participants described how their childhood activities impacted upon their later personality development. Most of the participants agreed that their early ideas about caregiving were deeply influenced and shaped by their immediate environment. **Local farming communities**, in particular, had strong cultural expectations about caregiving, which were primarily associated with farming and earning a living from the land. ***Kelly*** described the importance of her environment for care, and her observations about caregiving in the wider community.

> *... I had one sister and we lived ... on a farm ... during the 50s and 60s ... it was [a] ... protective type of environment ... we were always quite well fed ... well clothed, we tended to have ... an exciting, adventurous time ... we were pretty self-sufficient ... there weren't neighbours next door ... so it was only when you went to school that you talked to people ...*

Kate also described how the farming culture influenced her early self-concept and her perceptions about caregiving. The caregiving responsibilities were predominantly focused on her mother and the sibling relationships. Her immediate family also represented the overall needs of her social network and defined the context of ***Kate's*** childhood socialisation.

> *… Granny ... if I'd come home from school ... she'd give me lollies ... sort of 'someone's home' ... whereas my parents were worn out ... from their physical work on the farm ... being baby number five ... they were just tired emotionally ...*
>
> *... I'm one of a twin and we were born last in the family, so my parents were busy working and I received quite a bit of care from my eldest [sibling], who is ten years older than me ... I can remember my [sibling] being around a lot but my mother was the main carer ... Sundays it was a drive to aunties and uncles when we were younger. On Sundays it was off to church.*

This social environment led ***Kate*** to group her childhood friends according to their social activities and socio-demographic status. ***Kate's*** development was subsequently reinforced by maintaining her social connections with her childhood peers during her later development.

> *… The farm kids ... went to the local church outside of the main town ... the town kids ... there was no crossover ... because they were farm kids, just like I was. ... we didn't hang around after and play in the school yard ...*
>
> *... I went to a very small school where we had the same teacher for 26 children for the same seven years, my twin sister [was] in my direct grade ... we knew all the other 27 children ... when we became teenagers ... some of us had moved on to high school but we came back to this youth group.*

The participants' childhood socialisation focused on the social activities and connections that were important to them. This ensured that they learned about, discerned, and accepted social differences in their immediate communities. ***Nadia*** described how her early social interactions defined her later caregiving identity and self-concept.

> *... You'd have school friends that were sort of lower socio-economic ... it was their friendship that you fell in with ... nothing else was considered back then ... and a few neighbours ... they all had young kids and we all went to the local school ... I can't remember ever being frightened or not wanting to go to school. School was pleasurable for me ...*
>
> *... One girl friend ... she had a disabled ... sister ... that was my first introduction to disability ... we got along like a house on fire ... she'd be round at my place and I'd be round her place ... we all went to the local little primary school and she was there.*

All the participants reiterated the importance of moral learning for their later caregiving values. ***Kim*** described how her mother's caregiving attitude positively defined her early self-concept and worldview. ***Kim's*** family encapsulated the type of care that provided her with understanding and interpersonal security in the world.

> *... I suppose it was Mum and Dad, and ... you don't even think about it as care. You just think of ... we just looked out for each other and that's it really.*
>
> *... I think my mum was very much a caregiver to everyone ... if anybody needed a place they would end up at our house ... and dad. ... I think it's just something I just accepted ... looking back on it now it was normal. I just accepted it as is. ... I felt secure as I was growing up ...*

For most participants, the caregiving role was influenced by their rural environment throughout primary school. This specific cultural background clearly defined their early expectations about caregiving interactions. The participants openly accepted the interpersonal boundaries that defined their normality as children. They also described enjoyable childhood experiences, even when facing particular challenges and issues in their immediate environment. ***Leah's*** early observations of caregiving contributed to her later acceptance of, and stability in, the world.

> *... you'd walk to school or ride your bike ... most of the kids you knew ... neighbours ... school was good. ... The friend that I had when I was almost 5, is still a friend ... they had fairly big property ... Her grandmother ... and grandfather lived in the adjoining part of the house ... there were chooks ... and we'd do really naughty things with gun powder ... (laughing) it's awful, yeah, awfully good.*

Participants' parents often ensured that older siblings took part in, and were responsible for, **the care of their younger siblings**. ***Janet*** described the stress of her childhood caregiving role, explaining how she learned to cope with and manage her parents' trauma. This experience defined ***Janet's*** self-concept, interpersonal security, and later caregiving role.

> *... Being the second oldest child, there were three younger siblings below me ... I was often put in a place of protecting them ... I know at the age of four trying to make my younger sister a bottle. I recall changing nappies and things like that for my younger brothers, three years old I was ... my caring started at a very young age ...*
>
> *... Being the product of a hard-working ... but also an alcoholic father ... and a mother who suffered immense emotional and mental trauma at the hands of my father. ... I was usually the caregiver because my mother was very scared. She used to often run away ... Occasionally my aunty would come out to the property to help my ma out. ... my dad would sort of turn on my aunty too.*

Janet described how her early caregiving responsibility was crucial for maintaining the family unit. Her caregiving role was also reinforced within her immediate environment by her childhood activities. These activities ensured that she continued to provide a *normal* caregiving experience for her siblings.

> *... [at] five ... caring for and raising fifteen baby lambs out of twenty-four during a three-year drought on my parents' sheep and cattle station ... We lived 65 miles out of sight of the town ... I do recall on occasions ... at the age of eight trying to get the car ... from town ... to get ... my drunken father and to my younger siblings ... home safely because Mamma had run away by then.*

Matt described the social disadvantage that affected his family. During his childhood, caregiving for his siblings and good teamwork contributed to the stability of the family.

> *... I grew up with an older [sibling] and a younger [sibling] and we were a very close-knit family. I was the middle, the son in the middle and I think my older [sibling] was very supportive of us ... We kind of looked after ourselves quite a lot ... I think the three of us, we all worked together, we all sort of went out of our way to just co-operate and support our mum ...*

Chris highlighted how her early caregiving environment was defined by a sense of respect for her mother's morals and values. Her immediate family relationships provided ongoing opportunities for socialisation and maintaining vital family connections, and shielded her from the trauma of her dad's mental illness.

> *... I'm the middle one of five so I looked after the younger two in tying shoelaces and walking to school with them ... we had quite a bit of contact with a couple of aunts ... we were raised to have care for one another ... with mum's philosophy ... you'd be there for each other ...*

Sarah described how the concept of the modern nuclear family defined her early caregiving responsibilities. She highlighted how gaps in her own interpersonal development often exposed her unresolved need for care and attention. These ongoing caregiving patterns deeply affected her as a young child. Subsequently, ***Sarah*** explained how her childhood integration defined her interpersonal situation in her later life.

> *... I'm the oldest – my next youngest has all sorts of difficulties ... I was only like 19 months old when she was born ... I knew that my sister ... she's intellectually*

> *and physically disabled ... she had hospital ... operations ... so … my perception of care would probably be that other people receive it and I don't ... I think probably maybe I felt caring ... was somehow my job, even at that age ... and probably didn't want to do it ... except for animals ... I think it ... was a fairly gaping hole ... the whole concept that anybody would actually take care of me ...*

The participants' increasing family and caregiving responsibilities not only impacted upon their worldview, but deeply influenced their learning potential and later development. ***Louise*** explained how she was primarily occupied with the care of her father during her childhood. Consequently, she was mindful of the role required of her, as well as her mother's reactions to coping with the ongoing management of serious health issues.

> *... My father ... has alcohol dependency issues ... my ... caring ... started from early childhood ... he's got really severe health complications ... monthly ... getting the ambulance ... monitoring his vitals ...*

As the oldest child in the family, ***Robert*** also described his adjustment to extra caregiving responsibilities and their impact upon his emotional development.

> *... I'm the eldest of four, so I had to look after my two younger [siblings ...] [who] were born ... when I was a teenager, so ... I also looked after everybody whilst they were little children ... Well I remember running away looking for another family really [laughs].*

In Interpersonal Theory, the **juvenile stage** commences with the formation of the first independently-formed peer relationships outside of the family unit. In these first peer relationships, juveniles co-operate and compete for approval from adult authority figures. The participants' highlighted their relationships with the friends of their families, school teachers, and other adult mentors, who facilitated their ongoing adaptation as well as the correction of left-over development issues from infancy and childhood.

Ann highlighted how migration played an ongoing role in her juvenile development and school education. While she described being *quite good at school*, she also strived for social inclusion and to achieve a sense of belonging in order to support and identify her opportunities in future life.

> *... I can remember my teachers ... but it's ... like my schooling started at nine years old ... though I was quite good at school ... I just couldn't wait to get out … Yeah it was very strange really that no-one bothered ... and I was so behind ...*

Lisa described the ongoing role of dyslexia in her personality development. As her successful social integration required adequate literacy skills at this stage, she described the impact of her learning difficulties on her schooling and her overall esteem in relation to her sister.

> *... I have dyslexia and it wasn't diagnosed until I left school ... I had a lot of anger, resentment and frustration going through school ... although my parents cared for us ... I had a lot of, slightly resentment that I wasn't more like my sister.*

The fulfilment of caregiving responsibilities during the juvenile stage also pointed to the wider economic and cultural issues affecting participants' parents. Sole-parent families were primarily focused on preventing further social fragmentation. ***Mel*** described the escalation of caregiving responsibilities in her family and the impending strain experienced by her mother.

> *... Very disjointed family ... I used to look after my younger [sibling] quite a bit because he was seven years younger ... My mother and father separated when I was 14 and back in those days there were no pensions ... so mum always seemed to be taking in ironing ... until it got too much for her.*

Participants also described their increasing awareness of personal disadvantage and social isolation. Some sought to establish their own standards of approval and interpersonal cooperation in peer relationships. ***Janet*** described the challenges she faced as a juvenile and the social stereotypes that influenced her self-concept and later personality development.

> *... after my father died ... without a will, we were actually placed into those homes ... but we used to go to a normal school ... I was a trustee at the girls' home ... I was the first ever girl in that home that actually become a prefect at the local primary school ... not only was I a prefect but ... I was captain of the girl prefects ... and that stood me in good stead.*
>
> *... two months after we were returned home to my mother, I heard my grandmother and my ma talking ... "they're going back into the home ... we can't keep on being overcrowded."*

The researcher asked participants about the give-and-take nature of their early friendships. Some participants' recalled the intimacy and closeness of their **juvenile** relationships, fondly remembering their friends' faces and names. These recollections provided them with solid representations about what was good and right about life, and often included their friends' developmental welfare along with their own. ***Sam*** explained how she continued to cooperate with her parents in order to have the opportunity to develop her juvenile relationships.

> *... We were not allowed to go and play at other children's houses ... the caring role of my parents ... that protection, that security ... "we'd rather have you here, but bring your friends here" ... I just didn't question that ... we could have anyone we wanted to come to our house ... I don't recall ever challenging my parents on any decision thinking that I'm hard done by, because my friends can go out and play and walk up the street or go to the local shop but I can't ...*

The participants' ongoing interpersonal relationships now formed the basis of their peer group. ***Chris*** pursued social activities and friends outside of the family unit that encouraged positive personality development. While she learned to cooperate with her mother's caregiving and her father's mental illness during her childhood, her juvenile development highlighted her concern about the situation and its impact upon her younger brother.

> *... Just being aware of being careful of what tripped dad off ... I learnt to look for that and head off ... either out of the house or, to my room. ... I remember ... my*

> *younger brother coming home and finding my dad trying to gas himself ... he was probably about the same age I was when my first experience came through ...*
>
> *... Just knowing that the friend was there to fall back on and how comfortable it was and safe ... there was more of her relaying her family situation to me ... there were times where it was [reciprocal], yes ...*

The participants' **cultural and social perceptions** of family also emphasised their ongoing need for interpersonal security. They highlighted their interpersonal vulnerability when discussing the types of relationships they shared with their families. ***Adam*** reflected on his experiences of family life that led him to question his overall sense of identity and belonging.

> *... Mum and Dad's friends ... we used to go to their houses for meals ... they were in a more loving arrangement. The mother and the father had a better relationship so it ... seemed like a home atmosphere ... you could feel the difference ... you could feel the love between the family members ...*

The family unit also influenced the participants' overall outlook on life. For ***Matt***, respectful communication in family relationships both confirmed his self-concept and his worldview about the importance of caregiving for human interactions.

> *... I don't think our home environment was as stable as most other children. But it was certainly not volatile, in the sense that there were crises ... I would kind of compare that with ... perhaps my other friends ... who didn't show that level of respect ... I would never talk about my family like they would ... I ... held my close ones in a more of a higher regard.*

7.3 The Impact of Self-concept on Personality Development

The last section emphasised that the participants *learned how to be caregivers* based on their understanding of their immediate environment and their relationships with family, relatives, family friends, and peers. These early caregiving experiences integrated the participants' self-concept and personality. This section explores how the participants' ongoing development linked to the important interpersonal milestones of pre-adolescence and intimacy, adolescence and group relationships, and post-adolescence and community integration. This section describes the importance of how the participants' interpersonal development helped them to embrace cultural and social diversity.

Pre-adolescence (approximately 9 to 11 years) provides the first experiences of intimacy, with increasing interpersonal awareness. During this stage, socially constructed gender differences and similarities create intimacy between pre-adolescents of the same gender. This reflects the participants' first experiences of genuine interpersonal love defined by the pre-adolescent's perception of their friend as an absolute equal (worthy of the utmost care). The love experienced by pre-adolescents differs from family love (to achieve interpersonal security) and transforms the juvenile relationship of learning (cooperation and competition). A clear majority of participants indicated that they felt 'alone' during this period.

Ann recalled having a serious illness during her pre-adolescent years. Her unfulfilled opportunity to achieve interpersonal intimacy with her peers and friends during this stage was paralleled by her extraordinary courage (to overcome social isolation) and her survival in later life (as a primary caregiver and mental health advocate).

> *... I remember my dad ... bringing all my brothers and sisters ... I was just so excited, but ... they didn't bring my mother ... just sitting and crying, saying I thought mum would come. ... so we all went back on the train to visit her ... then dad had to take me back ... to the hospital again ...*

Kim's opportunity to establish intimacy in her peer relationships was threatened during the transition from primary to high school. However, ***Kim's*** parents attempted to restore friendships for their daughter to ensure that her opportunities for intimacy would continue.

> *... we were separated when we got to high school into different groups ... I don't think we were ever as close again ... so that bond is broken I think. ... I was*

> *distraught at the time ... I can remember the parents going up to the school ... and we were trying to get over to the other class ...*

Leah provided an example of pre-adolescent intimacy involving her social peer and friend, who also met with her father's approval.

> *... she was good and there were a lot of things in her character that I liked ... her saving grace was that she was a really good pianist and I liked music and my dad did, but we used to wag school ... we used to smoke ... I still see her, would you believe it? ... when I go home ... that means a lot to me that we're connecting.*

Similarly, ***Kelly*** described how her earlier farming environment supported intimacy and facilitated opportunities for socialisation and personality development with peers.

> *... I always knew ... I was going back to the city, to school ... it was developing the relationships with the other girls in the boarding house ... we supported each other because most of us came from country-farm type ... when things were difficult ... we cared for each other which made it ... really good fun.*

Janet defended her understanding of interpersonal intimacy by explaining how she faced the socio-economic conditions of her pre-adolescence. She described the particular cultural and social circumstances that shaped her later identity and caregiving role.

> *... That was actually in Year 7 when I went to the girls' home ... because you know, we were homey, scumbags, nit bags, don't go near them. Hey look out, here come the homeys ... Oh look out, they got nits again; they got DDT in their hair, whatever ...*

The participants often maintained respect for their primary group relationships during this stage of their development. ***Nadia*** described the trauma that influenced how peer intimacy was perceived during her pre-adolescence. This collective family experience came to define ***Nadia's*** later identity and caregiving role.

> *... Of course after dad was killed we were Legacy children* **...** *so we would have legatees coming in to check on us and make sure we were ok. But mum was fiercely independent and I guess that's where we've all got our own independence from as well ... pretty well all self-sufficient ...*

Likewise, ***Adam*** described the enormous transition he made during pre-adolescence, as the youngest of four children (and baby of the family), to fulfilling a primary caregiving role for his brother. ***Adam's*** unfulfilled need for intimacy during this stage suggested a much earlier disruption in his development concerning his inability to bond with his mother.

> *... my brother when he hit about 16, 17 just went crazy, he's got bipolar ... I ... did feel that I had to look out for him, not knowing back then, but I would've been probably 12 ... when he started to present ... and just felt the need to look out for him more than I guess you normally would, I felt obligated. It's really hard to explain ... it just sort-of happened ...*

In Interpersonal Theory, the stage of **adolescence** (approximately 12 to 15 years) is heralded by puberty. The initial intimacy of pre-adolescence now involves the formation of two groups comprised of at least two pairs of adolescents. Sullivan (1956) described how these young groups or gangs establish opinion leadership by identifying one peer leader among the group. Adolescent peer groups enable long-term social adjustment and facilitate the learning of interpersonal boundaries in relation to the integration of lust and intimacy between the different genders. Therefore, interpersonally, adolescent individuals are concerned about finding and establishing intimacy with a person fundamentally different from themselves. Subsequently, Sullivan (1956) added that adolescence presents an opportunity to appreciate and develop empathy towards social differences based on adaptation and tolerance.

Matt described how his early peer-group relationships involved two pairs of friends (a small gang) that emphasised opinion leadership based on their mid-level social status. ***Matt's***

adolescent experiences highlighted the natural and easy bonds that occurred between group members as well as his emerging personality and sense of responsibility.

> *... And ... became friends with a good group of people ... A lot of people would see me as the one that did his homework ... not irresponsible ... there was ... a core ... middle ... group. We weren't cool, we weren't dorks ... You could come and go as you wish ... it was a good place to be.*

During adolescence, ***Sarah*** described her ongoing struggle to achieve intimacy as the older sister of a person with high care needs. The arrest of her adolescent development was deepened by her illness during high school. ***Sarah*** pursued ongoing cooperation and approval from her peers by forming two groups with people she perceived as needing her care.

> *... That was my rebellion year ... I used to go out a lot with my friends and I still had my horses [animal refuge] ... my most important thing ... it was kind of up to me to look after everybody, so particularly as I got older, by the time I was sort of 13, 14 and my friends were 15, 16 and they were typical 15, 16-year-old, stupid people ... I sort of took it on myself to make sure that they were okay and to look after them ... probably even cultivated friendships ... with people who may ... have been more needy in a way too ...*

> *... I went from someone who basically got honours certificates in everything in first form to not doing terribly well in fourth form because basically I'd just had enough ... I ended up with glandular fever when I was 16 and ... just basically said 'right that's it' ... I thought 'stuff it; I'm just not going to go back to school; what's the point?' ...*

Robert also described how his adolescent development stopped short of the two-peer group relationship. ***Robert's*** new identification with the caregiving role satisfied his need for intimacy and peer leadership during this stage.

> *... We were having inoculations ... and the government caravan was there and this boy comes up to me and says 'I don't like getting an injection' ... 'will you hold my hand?' and I said 'yeah, whatever. If that makes you feel safe I'm happy*

> *to do it' so that when I first encountered my first caregiving role ... I was about 15 years old.*

Louise linked her adolescence to her ongoing concerns about her parents' well-being. She described providing care for her mother through support and encouragement. ***Louise's*** consequent ability to cope with serious health issues and alcoholism deeply influenced her later choice of employment and her overall worldview.

> *... That's why it was so hard for my mother ... to make that decision fearing that if something is going to happen to him being on his own ... and I helped her ... encouraging and ... supporting her and letting her know that if something happens nobody will blame her ... because there was a guilt feeling for her ...*

Louise described how the two-group relationship contributed to her problem-solving skills and formed the bedrock of her social identity, by allowing her the time to cope with her caregiving responsibilities. She also compared her personal family experience at this time to a greater appreciation of what a healthy family should be.

> *... Well my brother ... with him moving out of the family ... I took it as if he left me alone there ... I always just left the house, I always knew that when things are bad, I'm just going to make plans, we're going to go meet up with friends, grab a coffee, go out and that was my escape. So even though I didn't share, that was a place where I could ... stop thinking about it, get it out of my system, get it out of my head and obviously come back once, but ... at that age we did a lot of sleepovers and stuff like that so I could actually get out for some time, for even a couple of days if I really had to. ... I think it became a little bit more difficult as I was ... growing up. Towards the age of ... 17-18-19 ... I started building my own relationships and ... realising ... that is not a healthy relationship at home, start seeing what a healthy family looks like.*

Post-adolescence (approximately 16 to 18 years) reflects the final stage of interpersonal development prior to adulthood. The integration of lust forms an integral dynamism for the achievement of interpersonal satisfaction with the opposite sex, and for responsible interaction within society. Experiences such as anxiety are regulated and interpersonal communication occurs according to social and cultural norms. Importantly, complex problem-solving skills are generally conceptualised at this stage (Sullivan, 1954).

According to this stage of development, the researcher asked the participants about the importance of **role models** for their development**.** The participants' often related their early adult role models to their concepts about **achievement** in society. ***Kate*** described how her geography teacher both improved her self-esteem and influenced her career in later life.

> *... I had the strictest English teachers in high school ... they really got me into shape ... They taught me to be dignified and to express myself ... I thought 'yes, I can do this' ... they showed me beauty ... I had a great [male] geography teacher ... it was just this whole new world ... I wanted to know more ... I guess that was the early beginnings of wanting to travel.*

Based on her earlier peer group integration, ***Kate*** described her ongoing connection with her early rural environment. Her subsequent adolescent development occurred within a familiar caregiving environment and continued through her ongoing relationship with her mother.

> *... I didn't do Year 12 because I didn't need it, I went straight into nursing ... the local doctor said ... 'I've got a position for you here' ... then I returned to live at home basically ... and became a lot closer to my mother ...*

Louise also described a male role model and teacher at high school, who provided vital opportunities for her early adult development. She subsequently described her increased self-esteem and confidence to pursue her life career.

> *... In high school I had a teacher who is probably the reason I ended up where I am, very much believed in me, and always reinforced me to do well and ... it was after being in his class that I decided to ... start learning ... not because of my academic performance but because of my self-esteem ... this is where he really helped me.*

The participants' growing social networks also provided avenues for personality development during early adulthood. While ***Ian's*** grandparents contributed to his childhood development and self-concept, the acknowledgement of his high school peers during adolescence also provided him with further opportunities to develop and fulfil his personal goals.

> *... there's no incident that I can sort of pinpoint and say ah that's what I modelled my caring role on ... because I cared for my wife's mother ... they say that it's very rare for someone, why is that? ... I guess probably the values that I've got in growing up and I don't like to fail at things ... I've always been ... introverted and shy and not overly confident in myself ... leading up to high school ... I was probably a little bit scared of going ... what gave me more confidence was ... being Dux of the school ... something that I'd never expected, or never recognised that I was probably doing as well as I was ...*

Sam described a senior staff member at her college as an important role model that positively influenced and shaped her leadership role and career in later life.

> *... I went to a private business college when I left primary school and the next 4 or 5 years ... the principal of the day ... I saw as a mentor ... and I ... followed in his shoes ... it gave me a head start ... to pick up the family business ... that made me decide I wanted to be a teacher ...*

Finding important role models during post-adolescence also increased the participants' opportunities to socialise with like-minded people. ***Robert*** described the positive guidance of his schoolteachers that helped to define the rules and additional responsibilities of his adulthood. His ability to satisfy his interpersonal needs also involved learning how to discern his own situation and his future.

> *... a few teachers I suppose I idolised ... I remember talking to one of the teachers ... I was getting better guidance from them than I was off my own mum and dad. I knew a few things, like what some of the teachers were up to but I never told any of the students ...*

7.4 The Total Environment

This section describes how the participants' **adult** (approximately 18 years+) circumstances have helped to stabilise their previous trauma experiences. The following results highlight how caregiving expectations were shaped by the participants' immediate learning environment and self-concept. Overall, this section explores how the social expectations of the participants' parents later affected their ability to cope with increased stress and experiences of disadvantage in their lives, as well as how they coped with broader discrimination and stereotypes about mental illness in society.

Matt described the economic and social disadvantage that affected the welfare of his entire family. He explained that, as a male role model, his emerging caregiving role involved meeting the specific social and cultural needs of the stolen generation.

> *... When my mum moved out from my dad ... they'd bought a house together ... Mum always tells me that ... the public ... legal assistance ... never really fought hard enough for her and she got ... half of what the property was purchased for ... as opposed to half of what it was worth ...*
>
> *... My sister called around some mental health person and mum wouldn't ... accept any help from anyone ... my sisters both left ... my older sister ... only recently been married ... and my younger sister ... found it all too stressful ...*
>
> *... I had this old car ... and we were sleeping in the caravan park ... Mum ... felt that was safe. ... We were almost on the run ... Friends of our family for years ... and people in our church ... had noticed the difference. ... Mum's still not the person she used to be ... that was a very big role that I took on looking after her.*

Likewise, ***Kate*** explained how social discrimination and gender-based stereotypes influenced her own expectations about motherhood and caregiving, describing how the important issues of belonging and control determined her choices in later life.

> *... I was doing the academic stream ... otherwise you had to do the commercial course in those days ... Even in high school girls were looking for their husbands ... some of them did get married young ... my own sister got married at 18.*
>
> *... I couldn't blame my mother because ... my father gave my mother no say and she never owned a cent. ... I always thought ... it a good lesson but you didn't want to learn that way and 'I'm going to take care of myself' sort of thing.*

Differences in values also created social divisions in families. ***Kelly*** described interpersonal tensions that subsequently shaped her learning environment and later life experiences.

> *... I think my mother ruled the roost ... because she'd come from the city and lived in other cities ... she had a more ... worldly view of things ... which probably reflected how we saw things a bit more too ... while my father ... lived in the same area all his life ...*

The participants described the importance of their neighbourhoods, cities, and towns for their sense of belonging. The researcher asked the participants if their concept of caregiving emanated from *family* or *community* (in the total environment). Most participants described their family and close relatives as the main sources of their caregiving values. Increased feelings of social alienation and loss of trust in community highlighted the other important social issues affecting the participants. ***Peter*** described how accepting and learning from *others* in the community both created and sustained his caregiving values.

> *... Community in general; you've got to be looking after your neighbour ... when you have a fairly tight-knit rural community everyone sort of knows each other. You care for each other. You remember that someone a month ago was crook and when you see them next time, 'how are you going?' ... You get a city-based scenario people don't know who the hell their neighbour is and you walk in the street and – they're crazy ... no recognition.*
>
> *... And you not only care for people, you care for their belongings ... you really notice this in the station country where people just park their vehicle and don't even bother locking it up and everyone respects those belongings. ... You get a*

> *city situation, you come back to pick it up and the bloody thing's probably not there ... and I think that's that caring base coming through because you're caring for the other person in a total environment.*

Kelly also described how her farming environment established clear expectations about caregiving in her social group and her community.

> *... I think country people are more straightforward and in the main ... they tell it how it is ... you get to know where you stand fairly quickly ... you also get to know people well because there's not so many people, so you can't actually put on a front ... In a small community you get the whole gamut ... you get the people that are not doing so well ... who are doing quite well ... the ones in-between ... everybody else knew their strengths and weaknesses ... people were accepted for what they were ... they had to stay in their little roles ... in that way you were cared for ... If something did happen ... neighbours came round ... made meals ... or brought meals over ... even though they weren't close.*

A sense of belonging was also important for establishing the personal boundaries that maintained the participants' interpersonal security. ***Nadia*** described the diverse social roles that ensured the safety of the whole community and provided her with interpersonal security.

> *... Being a country town ... there was this strong sense of community ... a strong sense of family ... whereas ... today ... it's ... all alienated. ... When we were smaller, we knew every neighbour in the street ... that neighbour across the road used to sew our dresses ... the neighbour up the road used to look after us when mum was out ... the neighbour next door, we used to go in there and feed his birds when he was away; our homes were always open, they weren't locked, so there was a real sense of freedom as well ...*

7.5 Introducing the Current Caregiving Situation

This section illustrates how the participants' development and understanding of caregiving culminated in their current situation. It describes the participants' current roles and explores the different contexts of their caregiving relationships that led to their participation in this research project. The findings revealed that most of the participants would have preferred to have been free of their former family responsibilities. ***Ann*** compared her hopes for her future adult life and fulfilment in marriage, to her current caregiving role for mental illness.

> *... We had a good life, my husband and I had our first trip ... the kids were old enough to look after themselves ... members of the family were keeping an eye on them ... that was the beginning of a whole new life ... it was ... a fantastic feeling ... but a year later both my sons became unwell, and our lives totally changed ...*

Matt's previous caregiving responsibilities for his family transferred across to his marriage and defined his current caregiving role and situation.

> *... I was attracted to her and we got married about two years later ... [my wife] got pregnant and she had a perfectly normal pregnancy ... but the labour and what happened after was what led to the current situation.*

Kate highlighted the ongoing correlation between caregiving and motherhood/independence and control. She explained how her social and cultural circumstances led to her current caregiving situation.

> *... my son is 30. They're only ... 15 months apart ... [My daughter] sort of crumbled a bit and became very quiet. She was never naughty but just a bit distant and preoccupied, but happy and loving and all that. ... I can't remember how ... my daughter got stuck ... she fell through the cracks ... she got bullied [at school] ... she couldn't keep up with ... [the] girls ... she was coming home late ... she had a ruptured appendix. ... She'd already been treated for depression at high school ... and then she flipped out at 17, and was then diagnosed as bipolar, and that was the first of her hospital admissions. ... and it was the scariest thing in my life, visiting her in a psychiatric ward and that started the real mental health journey for me, as ongoing support carer ... ongoing involvement with the medical, doctors, everything*

Janet described how as an adult and caregiver, she continued to seek approval though her caregiving role. She explained how her developing adult identity was based on her past expectations about caregiving and survival.

> *... Extremely bad post-traumatic stress disorder ... I felt needed once again ... age seventeen ... I couldn't make him better, could I? ... I married him because I thought I could make him better ... He was a screwed up ex-Vietnam vet ... however, I did fall in love with him ... there was also the risk of becoming co-dependent on his behaviours too. ... Hence, when he shot me through the leg, I had to go to the local hospital that I was nursing at and lie ... I had to flee ... leave my home ... leave my family ... I took off under a DV protection order. ... with my oldest son. He was seventeen months old ... I finished my nursing ... when I couldn't get employed ... I used to do ... anything ... manual work, didn't matter. If I could get work, I'd get work.*

Janet then described her personal struggle with grief for her two sons and her husband. Her current caregiving role followed her daughter's mental illness.

> *... It was in my second year of nursing ... I had two sons ... my oldest son committed suicide ... my second son ... died ... seven weeks later of SIDS.*
>
> *... I met a man ... he come over to [place] and he found me. Now I wanted ... another child. I didn't want a husband; I didn't want all the dramas that went along with that bullshit. And I got pregnant and I ended up marrying him and moving to [place] where I spent ... many years of my life.*
>
> *... He died two years ago [from an allergy]. ... To that marriage, I had two daughters. Thirty-one ... [and] ... one of them is 29 and I'm her carer ...*

Similarly, ***Leah*** described her grief over the loss of her son. The traumatic events that led to her current caregiving role and situation highlighted her continuing need for approval and acceptance as a woman.

> *... it was the thing to do ... we had one boy and then three years later (I lost a child in-between) and I had a daughter, and then we had another son ...*

> *.... the son that had schizophrenia, he had a diving accident ... it would have been about 6 weeks ... then he came home [from hospital] and eventually he went back to school the following year ... there's been a very close bond with this particular child, well he's an adult now.*

> *... my husband ... didn't cope at all ... I think a lot of our marriage problems started ... (I thought) that it was just ... for him to shape up and I did all the visiting ... and stayed with people and stayed with (son) in the hospital ... that's dominated a lot of my life ... I mean, mothers do that don't they?*

7.5.1 Recognising the Breakthroughs

In Interpersonal Theory, the stage-specific developmental milestones ally with specific cognitive and emotional schemas that are important for achieving breakthroughs. The transition periods between each stage, therefore contain vital opportunities for interpersonal recovery and personal transformation (Sullivan, 1953). The following findings highlight the circumstances that put the participants at further risk of secondary trauma and made them feel unsafe. The participants described specific areas of difficulty in their caregiving situations that also potentially contained valuable opportunities for resolution and interpersonal growth.

Moving away from everyday family life to the caregiving role meant that the participants often needed to come to terms with mental illness. While ***Chris*** outwardly accepted her first marriage, striving to make the most of the situation led her to consider her own mental health outcomes. Accordingly, in her second marriage she became a caregiver for her spouse.

> *... it was a way out of the house ... I believed I was in love, but whether or not I was or was just looking for a substitute or I don't know. ... He was twenty-one ... I think I became a substitute mum ... we ended up adopting a child after waiting ten years ... there was quite a bit of ups and downs in the relationship ... my mother-in-law would refer to [my son] him as her son ... We were coming up to our 25th wedding anniversary and I realised things were not what they should be and hadn't been for a long time ...*

Sarah's current caregiving role followed the traumatic events that affected her daughter. Her caregiving interactions highlighted the tensions she experienced as a single mother and her desire to ensure that her daughter would regain her health.

> *... Her best friend was killed in a car accident when she was six ... She had a lot of problems going to school and being with people ... I think the Asperger's probably runs through everybody ... she had times where she didn't go to school ... by the time she was 11, I pulled her out completely and we home-educated her. ... There was a lot of pressure ... I was actually issued an ultimatum ... this was a [type of] school where I would have expected a lot more tolerance ... but her teacher said that either she starts going to school ... or I look for something else. ... I'd rather have our situation ... there's a lot of really good things ...*

While their earlier environment shaped the participants' caregiving values, the integral nature of their interpersonal and family relationships facilitated their ongoing personality development. ***Sarah*** referred to her double caregiving identity, as a younger person and as an adult; and the ongoing demands of the caregiving role upon her personal resources.

> *... I was always my mum's ... counselling person that she talked to ... pretty much her only one for a long time. It's really hard to define the difference between being a mum and a carer ... it's only like 12 months ago that I ... had it whacked through my thick head that maybe I was actually a carer; not just 'this is what you need to do' ... the bigger part of it happened ... about 17 ... years ago ...*

Sarah continued to describe how anxiety has played a significant role in her current caregiving situation. She defined clear interpersonal needs that related to her earlier experiences of trauma which now affected her coping abilities.

> *... It has actually sort of orientated me to understand what's going on for me, because I had believed things ... that actually aren't true, and so ... someone from [support organisation] ... pointed out to me that a lot of my problems are actually involved around caring ... the fact ... this has been going on all of my life ... My anxiety is actually relevant ... it's not just [what] goes on in the minds*

> *of the self-indulgent mentally ill ... excuse my fury ... Sometimes I ... think ... 'Oh just have [a mental illness].*

Sarah also described how her current trauma experiences clearly indicate the need for extra financial and practical support.

> *... financially things are terrible. My house needs an enormous amount of work ... we've got absolutely no space ... I feel really desperate again ... when we've been really, really strapped ... we ... had enough ... only because [Mums] re-mortgaged her house to kick a bit of extra money over.*

Sarah also defined how her real caregiving needs arose in addition to her personal needs, highlighting how the current political framework and government services treat caregivers. She called for an adequate acknowledgement of the real-life issues facing caregivers.

> *... if you happen to be fairly well-educated, reasonably intelligent – you're not a drug addict or any of these sorts of things ... you don't fit into any of the categories and you just fall through the cracks ... probably not ... [seen as a real person] to a degree.*
>
> *... I don't think any of us really are ... on the government ... level the services that are provided just don't really fit ... the real difficulties are just incredibly difficult to get over. That's financial, time, energy, just the real basics of life ... being absolutely fed up ... with ... the whole system.*

Importantly, many participants reiterated these same themes. ***Sarah*** clearly identified how the similar needs of caregivers may facilitate foresight about their crisis and their need for community support. Consequently, she made a clear distinction between her caregiving role, being a mother, and the similar needs of caregivers who face their crisis alone.

> *... And there's times where I have felt like, you know, the light at the end of the tunnel has been ... a train that's then run over me and how the hell do I ... cope with this? ... I'm 54 years old, when am I actually going to get a break?' ... it was probably sort of the end of 2008, when my health absolutely fell in a heap, and [my daughter] ... was suicidal ... I just thought 'help' ... but it just goes on.*

Similarly, ***Nadia*** identified the issues she experienced in her carer role and place of employment, highlighting the impact of long-term respite work upon her mental health.

> *... caring for kids with disabilities in the respite situation for eight years ... I have become physically tired, and emotionally tired, and I think if there's such a thing as compassion fatigue ... I've got it ... I think there's a use-by-date for carers ... I'm up to mine or I'm I've past it ... I have been in another situation just recently working for the same agency in a different house ... every other weekend for eight years ...*

Nadia's employment responsibilities and caregiving role necessitated her creating her own respite and, if possible, re-establishing opportunities for intimacy and family support.

> *... I usually work twelve days on, two off ... that includes all holidays as well ... since my mum died; my sister and her daughter ... [we] take seven days out of the holidays ... we go away somewhere ... that's what I look forward to every year ... that's the only thing I've got to look forward to.*

Janet highlighted the impact of iatrogenic illness from her daughter's ongoing psychiatric treatment. Coping with these additional tensions in her caregiving role, increased ***Janet's*** concerns about the transmission of trauma.

> *... and when I say pretty hard calls, my daughter has got severe drug and alcohol abuse problems along with mental illness, which I believe her health, her mental health is impacted by the psychiatric medication regime that she's on.*

7.5.2 Accessing Respite

The researcher asked the participants if they had accessed respite services. ***Sarah*** described her difficulty in achieving real caregiving outcomes, when explicit caregiving stereotypes and typecasting dominated the approach of the respite and support services.

> *... Me personally? [Gesture] ... Well I see a psychologist, which I've done off and on for support ... I mean the support that's out there is just useless, it's all like the carer's support ... which I've joined carers ... like 'let's get together with*

> *other ... some of us ... just are really tired ... like is there any chance of support?... to have a bit of a rest or something? Can someone else take over some of this? ... but oh no, they can't take people to appointments and they can't do this and they can't do that ... they can't take people in cars. [Just now] I'm really frustrated ... I'm probably much angrier about the whole situation as well.*

The participants emphasised the social ignorance and denial surrounding mental illness that triggered both their prior and current traumas, as well as their concerns about their own well-being. ***Adam*** described seeking information that identified caregivers with similar needs and highlighted the context of his particular concerns and responsibilities.

> *... There's a special referral support service ... an intensive support ... short-term thing, but hopefully it'll help me get a better grasp on autism and why things are the way they are and how I can deal with it, and approach it maybe, from a different perspective than I do now.*

The participants also explained how they constantly adjusted their activities and behaviour patterns to the demands of their caregiving roles. ***Matt*** described his personal dilemma while continuing to provide care and needing to explain his situation to others.

> *... It's had a big impact on my work ... to the point that I would prefer that my employer see me as ... not a carer ... I had to tell them about it, and I've even had to have time off ... I get multiple phone calls on any day ... it was actually my wife calling me at the start of this interview ...*

Matt explained that providing suitable caregiving outcomes often involved considering the accompanying circumstances and his ability to cope with his collective responsibilities.

> *... originally (spouse) was a bit reluctant to use my mum to help out, but then when things sort of came to the crunch ... she started calling on my mum a bit ... because ... the way [my wife is] now, my sisters have admitted to me that they can't connect with her, and my younger sister, when I had this disagreement with her about ... putting in ... and making an effort with my wife ... she said look, I just don't like her personality.*

> *... One of my close friends, (who's a close friend to my wife as well) ... he's very frank, and he just said to her 'look you are a bit full on' ... 'you are very intense' ... because I'm so easy-going, I kind of don't get upset about the fact that (my wife) is tense ... maybe that's why we've survived ... unless she can talk to me about all the stuff that's on her mind, she's carrying all the stress ...*

Similarly, the participants described how their need for recognition, autonomy, and choice, were generally misunderstood by the wider community. ***Matt*** described the predominant social stereotypes and gender roles surrounding male caregivers.

> *... There is some good, support ... there's a male support worker ... I know that the help's there ... I haven't really wanted to do that at the moment. I've talked to him a little bit and he offers ... men's support groups ... on charter boats fishing and ... away for a night here and there. ... It's not really the sort of thing that would work ... I'm just needed at home ... the thought of me going away - to my wife is probably a bit daunting ...*

Matt explained how greater understanding and flexibility from carer support and respite organisations involved recognising the particular context of dependency in the caregiving relationship and the individual responsibilities of caregivers in relation to mental illness.

> *... I really give them credit ... [Organisation]; around respite ... I've explained to them ... it's not going to work for me. ... my wife's going to have a problem ... I can't just go off ... and ... forget all responsibility, can we go as a family? ... they are ... more than happy to pay for a couple of nights ... wherever I choose ... that's been a huge help ... getting away from the stresses of caring at home ... taking my wife and my son with me, they're very supportive ... three, maybe four times a year, we can look forward to ... help with the financial side ... that's been structured very flexibly and they've been always really quite understanding.*

7.5.3 How the Reconnaissance Feedback Informed the Next Stage

Upon completion of the individual interviews, the digital recordings were transcribed by a professional transcription service (as outlined in Chapter 5). The analysis and feedback process involved the researcher highlighting five main analyses in the transcripts, in two parts. The first part highlighted (by colour-coding) three main interpersonal integrations of tensions: *resolved needs; continuing patterns;* and *coming to terms.* The second part highlighted the participants' accounts of their own situation: *what was done (in care) and what they thought should have been done (by care).* The feedback process was explained to the participants prior to the interviews and in the information letter. The transcripts were then returned to the participants by email or post (upon request). The researcher encouraged the participants to read through their transcripts and to make any comments or changes they thought necessary. These analyses form the first section of Chapter 8, the Detailed Enquiry.

7.6 Summary

This chapter has explored how the caregiving role functioned for participants throughout their lives. Caregiving concepts were defined by exploring what it is to be a caregiver, and the participants' own reflections about their developmental experiences were described in relation to the ways in which they both created and fulfilled their current caregiving roles. The findings of this chapter provide a unique insight into the social and cultural construction of caregiving. As well, the application of research questions from Interpersonal Theory remained sensitive to the participants' experiences of anxiety and distress.

Finally, this chapter has made an original contribution to knowledge by exploring the relationship between the participants' developmental milestones, interpersonal trauma, and their caregiving experiences. Chapter 8 therefore presents the participants' feedback about the interview transcripts, as well as the next stage of the research involving a detailed enquiry into the participants' current circumstances.

CHAPTER EIGHT

The Detailed Enquiry

8.1 Introduction

The Chapter 8 findings emerged from the specific research aims and analytical processes outlined in Sullivan's Interpersonal Theory, which allowed the participants to familiarise themselves with their caregiving experiences and secondary trauma and to minimise their experiences of anxiety (Sullivan, 1954). This chapter presents the Detailed Enquiry, Stage 3, of four methodological stages in the data collection process for this study. Stage 2, the Reconnaissance stage (Chapter 7), presented the participants' caregiving backgrounds and an analysis of significant milestones in their interpersonal development. Stage 1, Reception (Chapter 6), offered the basis for recruitment and provided a demographic survey and analysis of the research sample. The results of the Detailed Enquiry in this chapter will be followed by Stage 4, the Termination stage (Chapter 9), which presents an analysis of the participants' cognitive modes and the findings arising from the Caregiving and Stress Forum.

Chapter 8 presents the findings of the interview transcript analysis (as outlined in Chapter 5, Methods). The first analysis involved the three main interpersonal tensions involved in caregiving situations; *resolved needs, continuing patterns,* and *coming to terms* (Sullivan, 1954). These tensions will be discussed in relation to the key typologies of vicarious stress outlined in the literature: vicarious trauma, compassion fatigue, and secondary trauma. The following analysis presents the participants' own accounts of caregiving, and a comparison of caregiving acts (*'what is and what was done'*), with caregiving ideals (*'what should be and has been done'*) (Sullivan, 1954, p. 92). The second section of this chapter presents the findings of the Detailed Enquiry Question Guide (Appendix 8), in relation to the following topics of discussion: personal esteem, vulnerability, righting or correcting behaviours, reserves of security, and lifetime and individual goals (Sullivan, 1954).

This chapter makes an original contribution to knowledge by exploring and explaining the relationship between the three main interpersonal tensions involved in caregiving situations: *resolved needs, continuing patterns,* and *coming to terms* (Sullivan, 1954), and the three key typologies in the literature: vicarious trauma, compassion fatigue, and secondary trauma. Detailed enquiry interviews were conducted over an average time of 1 hour and 20 minutes. Ten females and three males were interviewed (see Table 8.1). Only three interviews were face-to-face, held at the Flinders University campus located in the Adelaide central metropolitan area. Others were by telephone due to logistic constraints. Confidentiality was established as a norm and consent forms were signed before the data collection commenced. Two participants chose to adopt pseudonyms during the discussions to further safeguard their personal anonymity.

Table 8.1 Participant Interviews

Female enquiries (10 participants)	*Kate /Sam* *Sarah /Kim* *Lisa /Chris* *Janet /Leah* *Mel /Kelly*	**Male** enquiries (3 participants)	*Ian* *Peter* *Robert*

8.2 Participants' First Impressions

The following results demonstrate the participants' increased awareness of secondary trauma based on the methodological analyses of 18 interview transcripts. The benefits of the research were articulated by most of the participants, who shared their new understandings of how they have integrated their interpersonal tensions throughout their development. ***Janet*** described gaining a new perspective about her caregiving role, despite her current situation.

> *... Oh yes, things not thought about – that you just don't think about were sort of brought to the forefront and it ... helped me to rethink and to look at the resolution, if that is at all possible ... stuck in the situation type thing ... because you do, you become very stuck; well, I feel that I do.*

Sam described how she had rediscovered herself and the significance of her life journey. She also gained insight by rethinking her approach to her caregiving role.

> *... I found it [the analysis of the transcript] tricky initially ... just even going through this again ... it's a purer perspective for me and I can better understand how it was developed and its use, which I think really is quite amazing.... I felt at the conclusion of it, it was ... a good start of doing my own biography ... it is an introspection of your own self in the world you had to operate ... I thought this is something I really haven't had to think about before ... so for me, it's been a bit of a challenge just coming to grips with it all.*

Kim also expressed how the analysis had increased her awareness of her self-concept and the importance of gaining a new perspective. She also described gaining insight into her past understandings and their relevance to her caregiving role, coping skills, and cognitive approach.

> *... I thought it was going to be a lot more of ... the current situation, about what was happening with the caring role rather than ... my history, which really surprised me. ... You hadn't thought of things in a certain way prior to doing it, so it was a good insight to ... look at things and not even realise that you've kind of thought those things. ... I think it helps piece together about how you deal with things, how you have dealt with things ... from what's happened in the past.*

Some of the participants had formulated an understanding of secondary trauma based on their past caregiving approach. ***Ian*** explained how the methodology increased his understanding about his caregiving experiences and his consequent behaviours.

> *... I guess going back so far, and looking more at me and my background, wasn't what I was anticipating the questions to be centred around ... What was I expecting? More questions around the impact on myself ... like me giving care ... What the impact of that has been on me, rather than looking back at my history. ... Having gone through the process and those questions and reflecting on it, you can begin to understand how your own upbringing and events in life may impact or have some sort of relevance to how I deal with things now ...*

Lisa also described how the analysis confirmed her ability to adapt to her situation, her understanding of her identity, and her ongoing fulfilment in her caregiving role.

> *... Some things are a little bit clearer but I wouldn't say new ... it does give confirmation and ... certainly understanding, and a surety, that that was the right thing and that's why we are who we are.*

Chris also described how the analysis had complemented and improved her own concept of caregiving and her understanding of secondary trauma.

> *... certainly affirmed or confirmed what maybe I'd already known ... it's just there in the background ... it's given me more understanding.*

The participants also discussed how the analysis provided further clarification about their coping abilities. For ***Kate***, the unexpected direction of the research enabled her to assess the overall impact of caregiving on her ongoing interpersonal development.

> *... I thought it was great. I was surprised how much came up going back to early childhood days and care. I thought that was quite insightful for me and it sort of gave me quite a bit of insight into my sort of coping skills or resilience ...*

Mel also explained how the analysis increased her understanding of her developmental background and caregiving. In developing this new awareness, she explained how she had previously overlooked the ways in which caregiving had informed her worldview, and her subsequent ongoing ability to consider the needs of other people before her own. ***Mel*** therefore identified her increasing awareness of her self-concept.

> *... just having to ... think back so long ago, things that I've never considered for many, many years and couldn't recall them even. ... it just really made me ... stop and realise how much I'd either pushed behind me, or else totally forgotten about ... I felt like I was caring most of my life anyway. There were always others that were considered first ... but I hadn't put it in perspective along the line of being caring at that stage.*

Leah carefully unpacked the emotional processes that accompanied her previous caregiving experiences, through identifying the importance of her lived experience for understanding her caregiving role, and the subsequent empowerment she experienced when sharing her life journey.

> *... Very interesting and very well done. I really enjoyed it actually. ... I was surprised at the depth of emotion that rose to the surface three-quarters of the way through the interview and it takes more to unravel me now, but I did feel at one or two stages of the interview that I could have unravelled ... yes, I feel there's been a resolution with my caring ... and ... from ... seeing ... other people's caring roles as well ... I think everything that you've said that I've been able to drag along with me on this journey of life; I feel it could never be any more powerful than it is right now.*

8.3 The Integration of Interpersonal Tensions

The following sections present the participants' analysis of their own interpersonal tensions. The analysis of these findings is based on the *theorem of reciprocal emotions* outlined in Sullivan's Interpersonal Theory (Sullivan, 1954). In the following sections, the participants discussed and reflected upon how their *complementary needs* (were resolved or aggravated); how their *reciprocal patterns of activity* (were developed or disintegrated); and how their *satisfaction and foresight was facilitated* (by similar needs, or rebuffed).

8.3.1 The Resolution of Complementary Needs

The Detailed Enquiry first explored how participants' integrated and resolved their complementary needs throughout their development, and the possible relationship between the self-concept and vicarious trauma. Significantly, participants' discussions about resolved needs confirmed their relationship to their self-concept. They highlighted how their primary interactions with family both formed the basis of their self-concept, and provided significant learning relationships that led to, and facilitated, the development of their coping skills.

These early coping skills highlighted how particular interpersonal processes contributed to the participants' well-being and protected them from experiencing ongoing anxiety. They described the specific challenges that affected their self-concept and their ongoing personality development. This section presents these findings under the following three sub-headings: Self-concept and social fulfilment in society; Self-reliance and resilience; and Independence, achievement, and recognition.

8.3.1.1 Self-concept and Social Fulfilment in Society

The notion of self-concept had a different meaning for each participant, based on their hindsight. ***Mel*** and ***Kelly,*** in particular, relied upon their hindsight about their caregiving role and their subsequent coping abilities to interpret their responses to the research question. They also depicted their own, and other caregivers', situations along a lifetime continuum of learning. ***Kelly*** described how her own caregiving journey had defined her overall position.

> *... can I just say, stepping back say 10 years when I first started caring for my daughter, I would be answering a lot of these questions completely differently, right? ... From what I've seen when talking with other people who care for different people, people are in different spots and some people don't move on ... it's not just a straight line, it's up and down and it's a scale, and we go backwards and forwards ... but it's where you're caught on that caring journey, is how you might answer or give emphasis to some of the questions.*

Likewise, ***Mel*** described how she had benefited over time from simply learning how to accept the increased tensions of her caregiving situation.

> *... Mine's just been non-stop for years with different situations ... I would face things entirely different now than what I would even 10 or 20 years ago. ...it taught me to accept things more perhaps after something had happened a second time, rather than beating myself up trying to work out how to find an answer or how to solve a problem and that sort of thing ...*

The participants experienced increased interpersonal security and satisfaction when they felt that their complementary needs in care had been resolved. Their ideas about **self and security** highlighted their emotional relationship with their families in the context of their primary caregiving group and culture. Their self-concept (or self-system) integrated their extended and intergenerational family relationships as interpersonal resources that "*went a long way"* towards reducing their experiences of anxiety. ***Kelly*** explained how ongoing interpersonal security during development contributed to her overall self-concept.

> *... it just made me start to think about maybe elements that were important in my early life that impacted on my caring role ... maybe it isn't so much about relationships and social capital ... If you have a lot of supports or if you have a good family relationship when you're young, it makes you feel better ... because you've got that sort of capital there, or that support. Then, as you go through life, you draw upon it at different times and it helps you, sort of cope basically.*

For ***Mel,*** the research questions meant investigating exactly what was resolved during the process of her development. She described the need to develop positive recollections and outcomes about caregiving to meet future needs.

> *... Whereas mine's totally different ... I didn't have the support then, and haven't got it now ... my mother was a support up until she passed away a couple of years ago, even though she was in a nursing home. I sort of reflect back on her, but none of the others.*

The participants described how an understanding of self-concept was necessary to cope with unanticipated and unexpected events in life. ***Kate*** reflected upon how her early caregiving activities and responsibilities had developed her self-concept. These complementary needs both ensured the overall well-being of her family and resolved the later challenges associated with ***Kate's*** caregiving role in adult life.

> *... Looking back on my earlier life, I already had challenges and disappointments, so when I became a carer, I realised there were skills there that I could ... call on, or that I sort of had a bit of confidence to face the future, even though that wasn't in my plan, to have a family member in those circumstances. I guess the early discussions [about resolved needs] showed me that I already had resolved some difficult things in my life, so this was just another part of it ... it was frightening but I felt that we could all survive as a family, as a family unit, meant a lot to me.*

Looking back over longer periods of interpersonal development provided the participants with the opportunity to openly, and objectively, exchange ideas about their self-concept. For ***Leah***, developing an overall caregiving and coping strategy both complemented her resolved needs and redefined her personal boundaries.

> *... I felt that resolved need equipped me better at a later stage and I was more equipped to not unravel ... I can remember the time when I'd be at arm's length and I thought that was okay. ... there is something to fall back on ... I got fairly close to not having any reserves at times, I can recall that.*

Robert highlighted how the gaps in his own interpersonal development defined the difficulties he experienced in his later caregiving relationships and interactions.

> *... When we go through life, we have our ... like, Maslow's hierarchy of needs, that you get a disproportion – some of them are fulfilled, your shelter and things like that, and your food and your accommodation and stuff, and clothing ... But, there's the ones ... when you get to ... relationships, they're a bit more difficult to manage and to get fulfilment out of ...*

Sarah also recognised how she *missed* her self-concept and struggled to define her own interpersonal fulfilment. She described how the unresolved complementary needs of her childhood had resulted in missed opportunities for a meaningful and purposeful life.

> *... when I was a child, anything that I didn't fulfil myself, didn't really exist so ... at a fairly deep level ... my physical needs were met, but certainly not ... [emotional] ... It's been a long and [is] becoming [an] extremely tedious battle ... I feel like I'm just not getting anywhere with anything. ... actually just a sense of achievement in myself, that I've managed to do something that's worthwhile to me, I really struggle with.*

Subsequently, most participants' described how they needed to leave their knowledge of self behind when faced with the additional interpersonal tensions of their caregiving situations. ***Kim*** described how the loss of her self-concept subsequently affected her identity and caregiving role. Following the migration of her young family to Australia, ***Kim*** described how she increasingly detached her self-concept from her increasing parental responsibilities.

> *... I tend to not think of me as an entity, I just think of myself as an appendage to the other people. ... That – because I think the caring role is just so integral ... that I don't think of myself as me. I got lost somewhere there, which I think is not a good thing.*

The participants' notions of interpersonal security also illustrated the long-established expectations about caregiving for family that contributed to the formation of their self-concept. ***Kim*** continued to describe how the acceptance of caregiving in her immediate culture maintained a sense of *normality* and family stability, and promoted healthy responses to stress.

> *... I've just been brought up like that, and that's just how things are ... it's because my mother was a very caring person and so I ... accept that to me ... is just normal ... isn't that just like normal patterns of behaviour?*

Most participants expressed that they were happy about caregiving and potentially realising the happiness of the persons in their care. The participants' desire to achieve interpersonal satisfaction through caregiving both safeguarded their own sense of security and their interpersonal resources. These interpersonal resources were also developed through maintaining their distinct caregiving values. ***Kim*** described the specific coping strategies and caregiving goals she adopted to both satisfy and fulfil her own mental health needs and the overall mental health of her family.

> *... as far as my own needs ... I need to be well to be able to look after the other members of the house as well ... you have to look at it as how you can do the best good for the most people, so sometimes you have to ... stand away from the person that needs the most care ... not remove yourself from them, but just see ... you might have to reduce your level of care for them a little bit to get yourself well to look after the others.*

Mel discussed how her own self-concept also provided an example of *resolved needs* in her family and fulfilled her expectations about 'caring and sharing'. She thus described how she facilitated the ongoing development of specific caregiving values, behaviours, and activities that culminated in her caregiving identity.

> *... Whether that means I recognise that things were tough and I've ploughed on regardless ... it's sort of taught me that ... okay, the upbringing didn't equip me for the skills that I required, but along the way, I sort of taught myself that the caring, the sharing, and the openness, and looking after your own needs, sort of came together.*

Janet also highlighted the importance of guarding her own self-concept, by developing specific behaviours that enabled her to both find herself again and to establish future opportunities for reciprocal activities.

> *... l think the arm's length behaviour, if you can call it that ... that worked really well for me and I think it's a lot of things ... If you're getting too involved, arm's*

> *length is a way to employ that strategy and backing off ... Yeah protect yourself; that's a really good way of putting it.*

However, most participants described feeling estranged from their personal support networks and the identity and security they had previously found in friendships. Some of the participants relied on their notions of their self-concept to resolve their social needs. ***Ian*** defined his new self-concept and caregiving identity by becoming increasingly self-reliant. His self-reliance also typified his earlier caregiving experience and the role-models provided by his grandparents and extended family.

> *... I've had friends that have kind of been close, but a small, close knit group ... I haven't necessarily relied on them strongly, which is probably why now, having drifted away from them a little bit, doesn't necessarily affect me as much ... often you feel like you're left out on your own in that caring role, because there's probably so much going on, you don't have time for that friendship side.*

For most participants, the need to maintain their self-concept involved interacting with like-minded people (other caregivers) to build and support their dwindling interpersonal resources. This adaptation to *resolved needs* also recognised new forms of dependency on social networks to provide participants with the ongoing and collective courage to face their individual and daily difficulties. ***Lisa*** described how accessing social networks in the community increased her interpersonal security.

> *... I knew that if I didn't have that security ... of having someone or something ... that I wasn't going to cope ... so I just went out and found it.... Knowing that makes those difficult times ... easier ... You know that you have got support and you know that it's a phone call away or the people around the corner, that you can go when you need to, if you need to ... that knowledge, it just gives you that ... security blanket.*

8.3.1.2 Self-reliance and Resilience

The participants' frequently compared their personal resilience to their concepts of self-reliance. Self-reliance was considered as being vital for the ongoing development of their coping skills. ***Chris*** described how she adapted her *resolved needs* and proactively developed her caregiving role in order to provide better support for the person in care. ***Chris*** thus identified her ongoing ability to function with her self-concept.

> *… You find that base within yourself to find top-ups for yourself ... it's not a hassle ... I can self-rely ... and still give care and support ... one is self-reliant or confident ... because that's where we've been placed, and one adapts because of where we've been put ... so, we know that there's two ways to go. ... We either sit down and stick our heads in the sand, or we say 'right, well, okay nobody's going to do it for us', so we just get on with it. ...*

Similarly, ***Chris*** discussed how she coped with unresolved grief and loss. She defined her resilience through her ongoing ability to achieve caregiving outcomes and to resolve the enduring interpersonal tensions she had experienced as a daughter and a mother.

> *... I'm aware that I should have stood up for myself more, but being me, I just glossed over it and put it into a box and left it in a corner, because that's how I deal with things ... That was just a once-off feeling that maybe I could do it and it didn't work, so you learn to recognise that caring is what's going to be.*

The participants also defined their susceptibility to vicarious trauma based on the level of personal empowerment they currently experienced as caregivers. ***Sarah*** described how her upbringing was primarily focused on providing caregiving for a sibling; therefore, she developed her self-reliance early in life. ***Sarah*** described a gap in her complementary needs and in her ability to communicate and successfully translate information to experience to achieve positive long-term outcomes.

> *... it depends on what level you're looking at need at, too.... I mean, that goes back to the first thing ... resilience, because I mean honestly, I don't think that's*

> *helped my needs, my own personal needs, in any way whatsoever; it's caused me damage more than anything ... if anything [resilience] ... actually worked against my true needs rather than for them, in a lot of ways ...*

Sarah described how resolving her complementary needs was still integral for developing a new self-concept and personal identity. Therefore, her efforts to understand the source of her aggravation were constantly undermined by her ongoing caregiving role.

> *... It's not so much that I'm not me ... over the last couple of years, that's become more difficult to work out what that actually means ... because I'm changing what I think's important and my values ... I get a lot of feelings of anger and frustration because of, in a sense, not being allowed to express that – me.*

Lisa also compared her 'resilience' to her self-reliance and with her ability to both reciprocate and develop her coping skills. ***Lisa's*** new definition of self-concept involved achieving personal outcomes and satisfaction in her caregiving role.

> *... I think with one's own ... my resilience and my ability to be independent, self-sufficient, all those sort of fully independent words, I can see in the various areas what needs to be done ... if it didn't come to that, I just made sure that that changed and that it did come about, so that ultimately, there was still the success or resolution to what was happening and just being able to – yeah, just getting on with it ... being there, being on top of it and getting it done.*

Lisa also focused on developing her self-reliance to build her self-confidence and to address her social isolation in her immediate environment by increasing her feelings of social inclusion and belonging.

> *... Self-reliance gives you confidence and [the] ability to say 'yeah I can do this and I can do this very well and I'm very good at it' ... or you find that sometimes you may be a little bit more isolated and sometimes you need to look for things ... and read things and find people ...*

8.3.1.3 Independence, Achievement, and Recognition

The participants' abilities to achieve broader social recognition for their caregiving role were related to a range of self-care and support issues. ***Chris*** reflected on her achievement as a caregiver through her ongoing development of coping skills and through identifying the circumstances that safeguarded her from further trauma.

> *... I think just recognising achievement, so one day better than another, or one hour better than another, and reflecting on it and feeling good about it.*

The participants highlighted the importance of understanding their own caregiving motivations. Positive experiences in their early development contributed to both their self-concept and their subsequent choice to fulfil a caregiving role in their lives. Their significant caregiving interactions therefore involved realizing their collective identity over generations, and resolving the complementary needs that occurred in their current interpersonal relationships. ***Sam*** described how she prioritised the well-being of a family member before her other responsibilities in life.

> *... I mean, just being the firstborn straightaway says that you're going to have to be a leader within the family, because there's an expectation and that then, just sort of tended to link with other areas of my life which became very important and that's, of course, the area of caring and the caring wasn't just for one person, it's been over generations.... I gave up my professional life deliberately to become a carer ... it was a personal decision I made ... in order to do the best I could for the person I was caring for... as I felt was needed at that time, when the crisis was ... very high level.*

The notion of 'duty of care' was also added to the participants' ideas about the self-concept. For example, most of the participants identified that their ongoing ability to cope with setbacks in life depended on the way they managed their self-concept and their stress. ***Kate*** described the type of survival strategies she adopted in order to cope with the stress.

> *... I did sort of step back and have a look ... I use the word 'compartmentalised' some of my life, [it] just helped me to survive it all, to sort of put that, in that category ... that's what that is, and now I'm dealing with this ...*

The participants also recognised the importance of maintaining personal autonomy for the person in their care, describing how they managed to build social capital and create social interactions for them by increasingly exposing their immediate family and close friends to the truth about mental illness. Both ***Kate*** and ***Sam*** emphasised their need to create a *normal* caregiving environment by openly recognising and accepting their situation.

Sam

> *... I feel it's more acceptable then when ... the person I care for ... in the presence of my friends and colleagues from time to time ... it is important that it be made public, irrespective of whether you've got denial or pain or whatever you might feel, that's just part and parcel of what happens when these situations come into your life ...*

Kate

> *... I went into sort of denial for a couple of years and then, when I thought 'well, yeah, we can manage this ... regardless of the diagnosis' ... I think not including the person you care for in ... family situations or even from social situations is quite demeaning to them.*

8.3.2 Developing Patterns of Activity in the Rest of the Personality

In the last section, participants' ideas about their complementary interpersonal needs and self-concept were clearly seen to be influenced by their current needs and the needs of the persons in their care. Their different descriptions of their self-concept confirmed the fundamental role of interpersonal communication to achieve integration and resolve their personal needs. In this section, the participants described how communication both safeguarded their own needs and determined the type of care required for their ongoing role. They frequently separated their understandings of their self-concept from their notions of personality by questioning these concepts. These specific activity patterns helped the participants to define their current caregiving roles and to provide insight about their choice of adaptive coping skills.

The following section focuses on the development (or disintegration) of reciprocal patterns of activity within the personality in relation to compassion fatigue (Sullivan, 1954). They are presented under the sub-headings of Ongoing adjustment and adaptability, Family and culture as patterns of behaviour, The caregiving personality that integrates tensions, anticipating personal autonomy, and Empowerment, marriage, satisfaction, gender, and foresight.

8.3.2.1 Ongoing Adjustment and Adaptability to Stress and Trauma

In their ongoing patterns of behaviours and activities, the participants became more aware about the ways in which they perceived the person(s) in their care. The participants' ongoing stamina in their caregiving role related to their ability to adjust to the needs of others and to empathise with, and understand, their experiences. ***Robert*** (a mental health nurse and personal caregiver) described how he maintained a stream of communication for his clients at work, to create a non-judgemental and safe environment.

> *... It helps me appreciate ... more ... where they're coming from ... in their shoes so ... I can see it from the other side ... from the carer's side then ... the client's side.... I look at it like that and [often] different ways ... to communicate and be able to open up and talk freely ... like ... in the work situation ... they [clients] assume that they are able to talk to me about their needs and what they're going through. Whether they want help or not is another story; [laughs] but they're certainly able to come here [service].*

While ***Robert*** linked his own recollections of his self-concept to his experience of vicarious trauma, his subsequent ability to adjust his ongoing caregiving activities to his situation involved developing a new worldview based on compassion.

> *... There are times when I become tired and I don't function at my best. ... in your emotional energy and [being] able to deal with different things that happen....*

> *It's very much a sort of like an ebb and flow ... things ... remain unanswered and unfinished ... You have to take it on its merits ... you're not able to truly ... express yourself ... so ... you're boxed in. ... Sometimes it is a thorn in your side ... when you try and help people through things ...*

Likewise, the participants' interactions with family and significant others highlighted their ability to integrate their interpersonal tensions and adapt to ongoing trauma. ***Kim*** explained how her continuing responsibility for caregiving often involved taking the harder road.

> *... I always try and look at everything from every angle and I play devil's advocate and say 'well, if this happened or if this happened' and try and work out the best way to deal with this, rather than just naturally go for possibly the easy way or things.*

The participants' highlighted how the current integration of their caregiving situation often occurred outside of their immediate awareness. ***Leah*** described how she integrated the expectations of her extended family/culture into her current caregiving role. She then reflected on her ability to develop compassion by reciprocating patterns of activity in her personality that improved her coping skills.

> *... I was surprised looking at my life how those continuing patterns arose and you're unconscious of them, of that side of your – or developing personality and yet it's really alive, and well, and it's probably still happening in a form today at the age I am ... And it's to the betterment I think of – the dramas that come from caring and the stretching of yourself as a person and as a developing person make you a better person in the end, better to cope ...*

Sarah described her ongoing and interpersonal struggle to define her self-concept and personality. She described how her awareness of her self-concept was based on her observation of the changes that had occurred in her personality over time.

> *... as far as a sense of self, it's an ongoing process to discover what is real and what's not, which I guess goes into personality too. ... I've changed a lot over the*

> *years, so a lot of the stuff that we talked about in the interview, I would probably do quite differently or feel quite differently about now than then. I think that the whole personality thing is just a – it's a chipping away in a sense of what's real and what's not.*

The participants discussed how patterns in their personality enabled them to improve their coping skills and adapt their behaviour to their new situation. ***Robert*** outlined the limitations of empathy involving his (intrapersonal) childhood responses and (interpersonal) adult caregiving role.

> *... I think you have to ... reason about these things that have happened to you ... to look back at these things and say 'well, I reacted back then as a kid but now I can ... react to it as a child or I can react to it as an adult' ... other times, you're encountering new things as an adult, so therefore you don't have ... that response ... in reserve ... depending on how severe it is ...*

The participants also adapted their earlier traumatic experiences to continued patterns involving their caregiving behaviour. ***Janet*** thus reciprocated the caregiving activities she learned in early childhood by successfully transferring that information into her current caregiving role. ***Janet*** described the difficulties she experienced when continuing to measure her personality development through her increased compassion for others.

> *... It's more of your self-*worth being measured in - *you know, I feel good if I'm helping somebody else. It's like a lift, that's how I feel good. I'm trying to relearn other ways of feeling good, and maybe I will, but I don't know because I've lived like this for so long that ... I don't know how ... to change it but, yeah, ... it is hard ... for me personally.*

8.3.2.2 Family and Culture as Patterns of Behaviour

The participants discussed how their families' expectations about caregiving were developed into interpersonal resources. The participants' abilities to reciprocate the generosity, caring values, and unique cultural environment of their development also defined their later caregiving activities. ***Kim*** described how her family's caregiving culture influenced her life and came to represent normal patterns of behaviour.

> *... a lot of other cultures ... look after their elderly relatives ... if they've been brought up like that ...*

Sam described how she developed a broad range of interpersonal resources for her caregiving role by integrating her earlier self-concept with her ongoing personality patterns.

> *... I didn't suffer from having to get my parents' or family approval ... because ... my parents died early, and then I sort of moved away from the family home and traditions ... although it left me on my own, I felt that some of the ... skills I learnt by seeing how other families live have helped me ... the influence of my parents, particularly my father in my early life, is still part of me now.*

Sam also demonstrated how her current caregiving role has continued to develop broad acceptance of, and compassion about, her son's illness.

> *... I'm sure I do have a special relationship with my son for whom I care, and the mere fact that he is in no hurry to leave here, even though he probably could. We could make it happen for him, but he feels and wants to be part of the family right here, in the family home.*

Like ***Sam,*** some of the other participants benefited from learning about other cultures, particularly in relation to their acceptance and tolerance of humanity. The cultural perspective broadened the participants' interpersonal skills and increased their range of activities. ***Kate's*** marriage integrated cultural diversity with a new sense of belonging. These ongoing patterns in ***Kate's*** personality development, both increased cultural tolerance in her family life and supported her personal acceptance of mental illness.

> *... And I think how other people view caring and extended family. I sort of recognise that 'oh this is quite different from how my early upbringing was', so yeah, I've been grateful for the multicultural aspect in my life. It gave me another source to draw on and that it wasn't shameful.... I actually felt ... even other*

> *cultures go through this ... our Western society expects us all to ... come out perfect, whereas other cultures, it's such a mix of acceptances ... probably ... fairer ... it's like ... different is fine because ... so our way is not the only way. ... that it's not all black and white ...*

Kate also developed her own identity and intellectual independence to overcome the female disempowerment she had observed growing up.

> *... I broke away from some earlier childhood beliefs and patterns and I felt ... I've got a collection of things to draw on now because I've travelled widely and ... I went back and did extra study ... on top of that, [there's] been this huge learning situation ... I'm not quite sure where it's going to lead me. ... I haven't come to that crossroad yet.... I'd say my personality has got me through a lot by being independent ... to assist my daughter in being independent was such a big thing for me ...*

Most participants described how they had developed zero tolerance towards discrimination and concerning the depiction of mental illness and disability in society. These reciprocal caregiving patterns were developed through new activities that demonstrated strong non-judgemental positions. ***Kate*** described how she incorporated new behaviour patterns to advance and promote culturally-appropriate values about mental illness.

> *... I find I'm probably a better person for having been through this sort of lived experience of mental health ... it's so widespread and prevalent in a lot of people's lives, but they themselves don't recognise it. Even if it is a person in the family with bad depression, they seem to gloss over it, but it can be quite a debilitating psychiatric issue. ... it's very hard to ... be of assistance without being judgemental to some other families or other people ... but I find if I talk about it ... you've just got to scratch the surface and every family seems to be having something to cope with ...*

The participants increased awareness about the stigma of mental illness highlighted their ongoing struggle to overcome discrimination. Many participants described how changes in their cultural expectations and caregiving values had occurred over time, and had contributed to their compassion about trauma. They described how these changes in their personalities required new interpersonal skills and increased their discernment of their environment.

Chris

> *... If people don't see my point of view or are completely opposite or whatever, and that's their choice and they have the right to do it. I don't tend to try and push my view ... it's made me more tolerant.*

Kate

> *... patience is something that I've always been fortunate to be able to hold. ... I guess it's perhaps not quite as good these days. Then again, in retrospect, some things have happened and I think well, if I wasn't patient, it would have a magnitude ten times worse ...*

8.3.2.3 The Caregiving Personality that Integrates Tensions

The participants described how they coped with the increasing frustration they experienced in their environment, by engaging in supplementary caregiving processes. They explained how they modified their expectations about their caregiving role and their ability to cope. ***Robert*** described the different processes he adopted to assist him to cope with increasing tension and trauma.

> *... as you grow up, you find patterns that ... help yourself to cope with things ... both interpersonal and in work relationships ... they're a bit like Old Faithful. ... otherwise you get yourself into quite a bit of trouble. ... [you] try and be like a chameleon ... sometimes situations that weren't very palatable or very nice ... adapting and coping to deal with those ... or end up somewhere else ... you've just got to move on ... sometimes you've got to let it go ... its own way ... other times, when you haven't been able to adapt, those sorts of things ... play on your mind 'how did you deal with it before?'*

Similarly, participants described their inability to cope with their situation and overall dissatisfaction about their caregiving relationships. They were increasingly affected by the personality changes they experienced, and struggled to cope with personal trauma. Thus, they described their ongoing ability to maintain their core values, at the expense of their personal values and their overall situation. ***Ian*** explained how the subsequent disintegration of his interpersonal situation occurred when his reciprocal caregiving activities failed.

> *... I guess you just get to a point where you're almost ready to give up on the whole thing because you can't keep enduring that same situation day in, day out. The person with the mental illness, they're living with their illness day in, day out, but once it becomes part of your life as well, you're living with the mental illness too ... that does become tiresome, because you think you're not suffering, or you don't want to think that you're suffering from anything, but eventually it rubs off on you ... probably for most people, the easiest way out, is just to remove yourself from that situation altogether and ... push it away ... it does push you to the wall and it's whether you're prepared to continue on with it or just let it go ...*

Many of the participants also learned how to predict their own personality patterns, as well as the patterns that occurred in the personalities of the people they cared for. They discussed how their own motivation issues played a role when a particular behaviour or caregiving situation demanded their attention. ***Lisa*** described how a range of behaviour patterns changed her immediate circumstances and ultimately influenced her ongoing caregiving activities.

> *... Sometimes behaviour can be predicted by a pattern. ... I know with the person that I'm caring for, that there's a particular pattern that happens and if one's alert and acute and ... senses it, one can change the direction of a pattern by knowing the pattern.... And if one misses the pattern or misses the cues ... there can be a different outcome to the one ... if you're on top of the ball and work out what's going on before it happens. It's sort of about values as well, but it means that sometimes, because we have to accommodate, things do change and the patterns tend to be the ones that sometimes dictate what changes.*

Lisa confirmed how the general misunderstanding and spread of misinformation about mental illness in society made extra demands upon her role. She emphasised that caregivers' particular personality types compensated for this shortfall in the wider community.

> *... We as caregivers tend to be the one that has to be flexible ... because generally ... we provide the care for ... the ones that aren't flexible, and we're the ones that are always there. We're the ones that are strong; we're the ones that say 'okay, let's just get on with it'. We're the ones that flex around the inflexible ... not due to selfishness, but just because there has to be give somewhere, and it's better for us to take it or to do the give, or to have to give, than for them to have to give ...*

Culturally-embedded values about mental illness in society also established specific caregiving behaviours (and coping mechanisms) that confirmed social stereotypes about *sick roles*. ***Janet*** described how she preserved and maintained the status of the person receiving care in her role as a nurse and personal caregiver.

> *... in the nursing profession too, you have to accept things that maybe weren't part of your belief or value system, but you accepted them ... it was the person you were looking after, not their values, not their thoughts ...*

The participants' increasing tolerance levels and interpersonal skills also ensured that their own caregiving knowledge and compassion for others continued. They made ongoing adjustments to their coping behaviour to better manage their treatment of mental illness. ***Janet*** described the particular patterns of activity she had developed in her efforts to understand the person in her care and their experience of mental illness.

> *... at the same time, that person's still alive and they're turning into somebody that you don't know, that you don't understand and it's really hard ... at times, if they're there doing their tantrums, it's hard to be firm and to use the behaviours you do know are productive ... to just stand your ground ... but at the same time, to keep yourself safe because you're not dealing with that person that you love, you're dealing with this mental illness that's getting out of control, and just to maintain a non-threatening and a non-harassing or whatever type of thing ...*

Subsequently, the participants' understandings of their own self-concept automatically overlapped with their individual behaviour patterns and personalities, resulting in the cultural embodiment or personification of caregiving values. ***Chris*** described how these cultural values were established and reciprocated in her caregiving role. She explained how she merged her essential obligation to fulfil a caregiving role with her personality, so that human needs and rights would increase through her activities.

> *... I guess learning to establish where other people's needs do need to come before yours, and where your needs need to come before theirs. ... I think core values are there, but the value that everybody has a right to lead a healthy life and do whatever; as a carer with somebody that's not able to do it, you learn well, not every life is not what you expect it to be.*

Due to the unpredictability of mental illness and personality change, the participants made every effort to understand and inform themselves about the potential impact of their own behaviours on the persons in their care. They greatly assisted their caregiving role by ensuring that they developed reciprocal patterns of activity involving the persons in their care. ***Ian*** described how he intentionally improved his awareness about mental illness to both facilitate and enable positive outcomes in his situation.

> *... Well, it's that growing awareness. I mean seven years ago, I didn't have a clue about mental illness but, being me, I need to discover things and not take things at face value and try and understand them and come to grips with them. I'm nowhere near understanding mental illness yet, but at least I've made the effort to begin to at least become aware of it ... and even though none of us probably really understand it ... it's about being aware and attempting to learn more and making the effort because you can see the – well you have a goal. In my case, I have a goal around ensuring my kids' future is secured ... which is the reason why I've stuck at caring for my wife for so long and endured so much ...*

Sam explained how her increased awareness about mental health issues developed over her lifetime. For ***Sam,*** these activities clearly demonstrated her ability to reciprocate caregiving patterns based on her growing compassion and knowledge about mental illness and disability.

> *... I've often said to myself [my development] that was preparing me for the role that I finally had to take without knowing that was going to happen ... that's the pattern my life has taken ... like pre-destination ... probably it goes back to when I worked in rehabilitation for many years before my son became ill ... when I'd work with soldiers ... from Vietnam who were totally traumatised ... [and]then ... with ... every other disability ...*

8.3.2.4 Anticipating Personal Autonomy and Empowerment

The previous section explored how the participants learned how to adapt to, and cope with, caring for other people's needs. Thus, they pursued new caregiving approaches to address the unresolved problems of the past. The participants' caregiving knowledge (in ongoing patterns) primarily focused on their adaptive coping mechanisms in order to prevent further social disadvantage and anxiety. Most of them expressed their desire to achieve personal balance in their role and explained how they often felt like they were walking on a tightrope. ***Sarah*** described how her prior experience of caregiving contributed to her personal deterioration and influenced her ongoing role.

> *... I think that I was definitely sort of heading towards the rescuer archetype for a long time. ... I've been aware of that for like 20 years ... and attempting to unpack it basically, so that it's not what I just automatically do. ... I don't know about recovery ... I suppose in a way maybe I would hope to be able to inspire that in others, but I'd also like to be able to inspire it in myself, which is incredibly difficult.*

Sarah described the increasing tension and frustration she felt in her caregiving role, explaining how her susceptibility had affected her sense of self and her overall well-being.

> *... a large part of the stress ... the peripheral stuff that has been very chaotic ... has probably been more a force; and then trying to stay centred ... to have some semblance of life, have been ... really eroded and very difficult to do. ... I've ... found it exceedingly difficult to really sustain anything ...*

To maintain the balance between sense of self and well-being, the participants described how they developed supplementary caregiving processes as their own particular responses to increasing frustration. The following participants, ***Leah*** and ***Janet***, depicted the activities that redefined their interpersonal and caregiving environments.

> ***Leah*** *... I can pinpoint ... times in my life, ... it would take me straight back to issues where you step up, and episodes where you just have to act, and a lot of it's just going on gut feeling and sometimes it's an overreaction, I guess, and you learn that as you go along as well.*
>
> ***Janet*** *You learn tact, don't you? And to back off? And sit, stand and roll over when you're told to. You're doing it because you think and you know, or you feel and you have to do it, yeah? ... You're doing it because you think, oh well, no-one else is doing it, no-one else – or the flipping thing's going to fall to bits, unless, someone comes in with the glue ... and I've got the glue ... You know, it's really, really difficult, because often we're thrown into this and we're doing it, not even knowing what we're doing.*

The participants highlighted their leadership potential through their ongoing responsibility and by achieving positive caregiving outcomes. Their increasing frustration with their caregiving role in the community highlighted the inadequacy of formal support systems and mental health services to respond to ongoing mental health crises. ***Peter*** explained that while broad sympathy for caregivers may occur in the community, a clear definition of needs is required to prepare the way for true understanding and to develop compassion and empathy.

> *... You can't achieve what you need to achieve, and you know that's the right thing to achieve. So, which way do you come at it to attack it again (to actually achieve that) is not a straightforward thing. When you can actually have a goal in*

> *mind and just go straight to that goal ... and you move to the next page, that's good, but when you're ... on the same page all the time ... because too many other people are actually pulling strings, and changing results for the worst, yeah, that's when the stress comes in.*

Most of the participants were very conscious about the role that stigma and discrimination played in the care of mental illness. Their greater understanding and lived experience of these issues often deprived them of the opportunity to hand their caregiving responsibility over to mental health services. The consequences of this rebuff called for supplementary caregiving processes to conceal the participants' increasing anxiety, and to reassure and protect their self-esteem and ongoing satisfaction in the caregiving role (Sullivan, 1954). ***Sam*** described how she developed a loud and clear political voice in the community, in order to define her needs as a caregiver of a person with mental illness.

> *... One of the biggest barriers that I've had ... is working with a bureaucracy who does not have lived experience, but who is going to make fairly significant decisions that impact on we as carers, and also those persons for whom we care ... you have to always be proactive ... in order that things happen the way you want them to happen, and if you discover that it's happening here, at point A but not at point B, I've just learnt to be outspoken about these things and question why, until I'm given a suitable answer. ... The regular answer is, they say 'oh we didn't know what they're doing'.*
>
> *... That's why it seemed early on that we as carers could capitalise on that, because it then allowed us the freedom to speak on behalf of the whole system in terms of going to the minister or to the press or anywhere else. And for the first time in my life, I actually felt empowered to say 'I'm not on anyone's payroll' because that then gave me freedom to say it as I saw it and, I guess I have done that from time to time ...*

The participants' extra responsibility in providing positive outcomes for the community reflected their objective and pragmatic attitudes about caregiving in an overall sense. Their greater need for political empowerment and independence also highlighted their increased social isolation as caregivers. ***Leah*** described how she pursued advocacy roles and lobbied relentlessly for 20 years to achieve supported accommodation for her son.

> *... I've been advocating for (person) for 20 years and this concentrated effort with politicians and lobbying and relentless pressure and the public advocate and then to finally – (we just can't believe that this burden of what's going to happen has been lifted). ... the change that came in our lives, in our family lives and the person we're caring for, is once we were able to get (person) into rehab, and that's been life-changing for all of us ... (the person has) been able to get the supported accommodation unit ... where (the person is) independent [and] ... there's a 24 hour presence ... that's what we've been hoping and praying for – ...*

8.3.2.5 Marriage and Gender: Satisfaction and Foresight

The participants had much to say about *marriage, care, and ascribed gender roles*. The exploration of this topic demonstrated the influence of Western cultural values. The participants' discussions about gender issues highlighted the deeply entrenched cultural stereotypes in society that caregiving is based on the nurturing, obligation, coping abilities, and responsibility of the female. The participants' increased ability to provide care also increased their responsibility to fulfil a caregiving role for their community. ***Kate*** explained that the existing social expectations about women's caregiving roles and nuclear families were directly developed and reciprocated through her own caregiving activities.

> *... My caring role sort of came along when I was a single mother, and seriously, there was just this vacancy of parents or extended family around me and I shielded my son or a few people from the impending sort of diagnosis that was sort of looming up ...*

The participants thus described how their perceptions about the differences that occur between the male and female gender created additional social and cultural challenges. ***Chris*** noted the various cultural expectations that had influenced her self-concept and clearly identified her role as a female caregiver in society.

> *... the first point I jotted down ... was 'raised to care and support one another'. Of course, 'do not upset dad. Be diligent in your work, supportive of friends'. The marriage breakdown, separation and being on the outer of my ex-husband's family. Being practical and a rock and a person to go to ...*

The female participants continuing ability to cope with the demands of their caregiving roles broadened their definitions about gender stereotypes. ***Janet*** described how she developed her own identity as a woman to free herself of society's behavioural and activity patterns.

> *... she forgot who she was. She was 'Mrs Somebody' then. I now pronounce you man and wife, Mr and Mrs, and then you've got to take their bloody last name as well, and it's like 'come on'. Found out years later, that's tradition. That's bullshit.*

Many participants faced the trauma of marriage breakdown, separation, and child-rearing by marshalling their determination and courage to adapt and go it alone. ***Janet*** responded to the researchers' comment about her decision to continue caregiving, as being *heroic*.

> *... When I hear people say that, you know, to me it really wasn't. It was - yes, it was but ... I didn't know nothing else. I had really not a lot to compare it with ...*

This theme was echoed by ***Leah*** who noted that women's overall contribution to caregiving should no longer be taken for granted.

> *... that's not a word that describes women all that often is it? And we are heroic.*

Equally, a woman's caregiving role was culturally acknowledged for communicating and reciprocating emotions. ***Sam*** described how as a woman she was able to talk about mental illness to transform community beliefs and social expectations.

> *.... it's not seen to be terribly manly, I don't think, to be caring for one of your siblings. ... it's not talked about publicly, whereas I talk about it very publicly because it's helped me to cope ...*

Sam also associated her womanhood with her ability to cope with stress through satisfaction and foresight about her role. She described how she upheld social expectations about male responsibility by reciprocating the emotional tensions of the whole family.

> *... that brings its own stresses with the family when all you're trying to do is have a cohesive group of people living together ... It takes the female and ... presumably the carer in the family to try and make this happen ... it's just innate ... that there are differences in the genders. ... The female values and roles ... is inherent in their background ... as opposed to the males ... I have a spouse who thinks that the time will come when the person I care for - we care for - will be all better again and life will just get back to normal. Well that was 20 years ago ...*

Male participants described their ability to care in the context of maintaining their family connections. These reciprocal activities developed flexibility in their personality patterns and reinforced important emotional memories. ***Ian*** described how caregiving for mental illness had strained his marital relationship but galvanized his ability to cope with ongoing change.

> *... marriage is just a label ... to a situation; the situation is a relationship and the family ... the piece of paper doesn't give it any strength ... it's how strong the connection is underneath it, which has ... been a bit strained, but it's how you perceive it underneath and how willing you are to allow that to move ... it's not always 100 per cent perfect, it sort of fluctuates between one per cent and 99 per cent ...*

Ian thus highlighted how he needed to refocus his attention upon his self-concept to maintain his ability to reciprocate caregiving activities in relation to his spouse.

> *... you put so much attention onto others ... you actually forget about yourself ... if you're not in a good place, then the rest of it falls to pieces ... it takes extra effort to remember to care for yourself as well ...*

Increased female disempowerment and oppression also stemmed from growing socio-economic and demographic disadvantage. Participants described the additional stresses that compounded their social isolation. ***Sam*** explained how gender politics and the perpetuation of female stereotypes in society contributed to economic inequality and social control.

> *... I don't think there is such a thing as liberation for women ... when the changes first starting occurring ... I was still only receiving 75 per cent of the male wage ... I think life for women became doubly difficult when we were supposedly offered equality, because we not only had to do what we'd already been doing, we're suddenly doing a lot more in order to do what our male counterparts were doing ... and I really worked doubly hard ever since ... I thought that I was liberated; what a joke ... I had to resign when I got married.*

Fulfilling social expectations and the extra responsibilities of caregiving also involved ongoing patterns and tensions in challenging economic inequality in society. ***Leah*** described the increasing strain on her marriage and business career.

> *... I guess what wasn't so good was when the marriage failed ... it all became needy and extraordinarily demanding and soul-destroying ... It's like a peak, everything ... for the whole family, it was like a crescendo ... and then boy, did everything come tumbling down ...*

Leah's ongoing struggle to achieve an individual and autonomous identity involved increasing her awareness about her own disempowerment as a woman. She described the behaviours that she observed in herself and in other women, and the significant patterns of activity that provided new opportunities for social and cultural empowerment.

> *... I felt most empowered because I did leave the marriage and I was making choices for myself and not having a hindrance and feeling reasonably fulfilled ... all that came crashing down as well, but ... that really gave me a bit of footing ... I thought I knew what was happening and I could see it happening around me and it did happen to me. Disempowerment, especially with other women and seeing how they coped ... the coping mechanisms ... By the same token ... it ...*

> *empowered other women as well. That's where I think women have got the greater strength, when they can get something going and empower each other; it costs nothing.*

Similarly, the culturally-accepted circumscription of women's caregiving roles highlights male contexts of empowerment. These contexts are overwhelmingly shaped by ongoing socio-economic development and day-to-day power politics that establishes marginalised and traumatised populations in society. ***Leah*** described how gender stereotypes surrounded women's self-concept and subsequently defined how they obtained and accessed interpersonal resources.

> *... It's acceptable for females because the gender stereotyping kicks in. It's unnatural for men to do it so; yeah they'd face a dilemma wouldn't they? ... The stats really – they just show up such a high percentage of female carers ... I think there's another perspective of all that thrown in that really clarifies and clouds at the same time, is the feminist movement and how women became empowered. It all came rushing to our door and mental illness and then we had to sort through that and choices that we made on the crest of that wave ... there's not a lot of women, or there weren't a lot of women making the choices for women on a political level. There were a few radicals ... but generally, it was men that were putting in place things that made the need for women to accept this role.*

The male participants also described how increased social discrimination and cultural prejudice had affected their caregiving role. Overall, the male participants were expected to fulfil their role as the main financial providers in their families. The following assessment of the male personality by ***Ian*** was reiterated by the other male participants. ***Ian*** highlighted the cultural misnomer and misunderstanding that surrounded his caregiving role when seeking support from caregiving organisations and recognition in the wider community.

> *… It's not so much with being a male, but it's probably personality.… I can't compare it to a female, but it's been tough and I'm sure that it's tough for both sexes. Probably for me as a male ... my communication skills aren't great, so I'm*

> *not an outward sort of person, open person, so I tend to naturally keep things to myself. ... for me, it's always been hard and I think as males we tend not to share our emotions and things as much. We like telling fishing stories ... (if you're a fisherman) ... with your mates, but talking about your wife who has a mental illness and all the things that go on with that, probably is not something that you'd talk about, even if I had the opportunity to. And just trying to find - opportunities to find new groups of friends ... with friends being scattered and living different lives and ... not really connecting, I've found it hard to develop new friendships and circles of friends.*

8.3.3 Coming to Terms with Caregiving Tensions

This section explores the impact of increasing tension and frustration on the personality in relation to participants' supplementary coping processes and disassociation. In *coming to terms*, participants described how their coping experiences increasingly resulted in secondary trauma because of the disintegration of their ongoing patterns in interpersonal relationships (Sullivan, 1954). In their efforts to decrease anxiety, the participants increasingly associated and identified their experiences of anxiety with other caregivers and *normal experiences*.

The participants highlighted how they facilitated foresight about their caregiving role by establishing similar needs through their shared experiences of care for mental illness, and through group survival strategies. The following sub-themes will be explored and discussed in this section: Community rebuff affecting participant satisfaction; Acceptance, control, and satisfaction; Psychosocial recovery, social anxiety, emotional triggers, and trauma; and Balancing caregiving approaches through foresight and satisfaction.

8.3.3.1 The Impact of Community Rebuff on Participant Satisfaction

In this section, the participants' ideas about group survival increased caregiver outcomes by facilitating similar needs in their ongoing personality development. The participants defined the importance of gaining foresight about their situation and adopting supplementary coping processes by involving family members and other people in the wider community in their caregiving situation. ***Kim*** reflected on her sense of responsibility and her caregiving role based on her ongoing personality patterns.

> *... I think definitely (responsibility) ... is the key word. Yeah, I feel responsible for everybody and I think I always have done.*

Equally, the participants' ability to facilitate broader responsibility for the care of mental illness was greatly influenced by community ignorance and intolerance. The consequent rebuff of the community left ***Leah*** feeling vulnerable about her personal ability to cope.

> *... I tried to get help in any way I could to support myself to not become really frail, and I can always think that ... it was quite fashionable – glass half full or glass half empty ... it's easy at times to say 'yes, that glass is half full' and, in a way, it does become a habit or it's a way of ... looking at life. Then, when you fall off that half glass full little pedestal; then you're floundering around a bit in the proverbial.*

Sam described the repercussions of having full responsibility for caregiving; coping with the colossal issues of mental illness; her complex social obligations as a mother; and mortality issues concerning the person she cared for. ***Sam*** identified the particular 'supplementary' survival strategies that embellished her foresight and self-preservation.

> *... guilt comes with that too. I don't think you'd find a parent around with a child with mental illness that when you ... associate some blame on yourself ... then there's grief, then there's blame too that goes with that, and you might go through that process for the rest of your life ... but it's something you always revisit thinking what did I do wrong or I must take responsibility, that child didn't ask to be born so therefore I am responsible anyway, and you ... can quite persecute yourself very easily, but you have to be careful that you don't overdo that, and someone has to drag you back from that point or else you're wiping yourself off; the guilt becomes too great to deal with, and particularly if the child [suicides]and this hasn't happened, and it's a miracle it hasn't I don't think ...*

Coming to terms related to the participants' abilities to cope with their existential experiences of loss and grief. These experiences were associated with their perceptions of burden about coming to terms with the widespread cultural assumptions associated with their life-long responsibility for caregiving. ***Sarah*** described the hidden obligations of caregiving related to her independent ability to make key decisions and to take full responsibility.

> *... well, I suppose independence in the sense that it's all up to me, I think that that's probably ... that's about the only way that I can relate to it ...*

The participants also described coming to terms with their loss of personal identity and autonomy. ***Kate*** explained how her personal ideas about empowerment were rapidly absorbed by her immediate caregiving role in order to facilitate satisfaction and foresight about her responsibility to her own family and community.

> *... I guess a little bit of that; 'These are the things I can deal with and change and these are things that I've got no control over and it's somebody else's issue' or; 'That's your problem, it's not mine' and just letting go of a few things ... 'Look, it's never going to change, so that's the way it is, and just be grateful for the few of the jigsaw pieces that have fallen into place' ...*
>
> *... I think that would be true as my life has unfolded, that I just ... made a conscious decision; I'm going to move forward with my life. I'm not going to be bitter; I'm not going to blame, blame, blame; I just wanted to live in harmonious relationships with some peace, and that includes the person I care for and everyone around that. That's been a bit of a jumble, but I think it's the best it can be, without any other issues coming up to throw things off track.*

Likewise, the participants' overall mental health was necessary when balancing the overall needs of the family with their caregiving role. ***Ian's*** ability to seek and accept outside help highlighted his integration of similar needs and group survival strategies involving carer support organisations.

> *... you can only take so much ... dealing with that and caring for her ... we're both ... coming to terms with our son and have made decisions about getting further help ... It's working probably as good as it has ... but introduce another factor ... has potential to throw it off the rails ... so it's about recognising ... and doing something about that ... let's look and see whether that's the case ... [and that] we need to change our behaviour [and] ... don't be afraid to get that outside support and help.*

8.3.3.2 Acceptance, Control and Satisfaction

The participants described facilitating similar needs to enable foresight and create personal satisfaction about their caregiving situation in their immediate communities. Many participants also *came to terms* with mental illness by developing a clear cultural identity. ***Ian*** described coping with the collective threat of mental illness, secondary trauma, and depression by changing his social expectations about mental illness.

> *... she was hospitalised ... so it's been a fairly ... probably quite a quick turnaround in understanding; and my understanding ... in a meaningful way, really only started to ... this year. Before that, I was trying to ignore it, pushing it all aside, not really wanting to fully understand it; just hoping the problem would go away ... The stuff that happens around the mental illness still happens; that hasn't gone away ... as best I can ... I accept it much more readily and don't try and control it. I know for myself I'm in a much better frame of mind, so my trauma out of all this – I mean there's no doubt that I've suffered from ... secondary depression out of this, but I feel like my situation is much better now as well, which is helping my wife too. She doesn't feel as stressed by me and vice versa.*

Leah also described how her acceptance involved coming to terms with mental illness by realistically appraising the immediate threat of anxiety on her caregiving situation.

> *... once you accept it, life just becomes better. You're not struggling and fighting ... Well, the alternative isn't too appealing is it?*

Kelly described how her personal responsibility for caregiving enabled her to better cope by facilitating foresight about her ability to both change and control her ongoing situation.

> *... I think that's kind of natural really, you want to solve things, but when they become almost insolvable, you think 'Oh well, I'll try something else now, this is not working' ... you just have to go with the flow ... I know I was always on tenterhooks worrying about the next thing that was going to happen ... but now I just think 'oh well, if it's going to happen, it's going to happen', and then I'm just going to do this ... I just ... accept it.*

Mel also confirmed how her caregiving circumstances once triggered the feeling of 'threat' or *dread*. This secondary trauma experience was transformed by her acceptance of the situation and her esteem concerning her improved responses.

> *... my husband's got post-traumatic stress and my brother had schizophrenia ... when you've got them coming from more than one direction ... I used to dread them together ... you just ... think 'don't worry about it, just let it go ... let them sort it out'.*

Instead of focusing on achieving caregiving outcomes, *coming to terms* involved a process of building the participants' sense of interpersonal satisfaction. The participants explored how their new definitions of caregiving involved learning how to accept mental illness as part of the overall human condition. ***Ian*** used additional management strategies to enable him to cope with the complexity of mental illness and his own situation. This change in values, motivation, and esteem also provided ***Ian*** with greater foresight about his situation.

> *... You do come to terms with the fact that the mental illness is a thing that isn't going to go away like a broken bone. It's always going to be there, and it's how you manage it and accept it, so acceptance for me, has been a big thing, accepting that my wife isn't ever going to be 100 per cent perfect, and I think for both of us – and she also, I think, better appreciates that this time, and then therefore it makes it easier to ... cope. ... I've obviously at some point accepted that yes, I am going to go through it again, but trying to look at it in a different*

> *light, understand more about it and recognise that the outcome I might have thought about first up, [is] not a solution ... that the mental illness is fixed, like it goes away completely and that's all there is about it.*

Likewise, ***Sam*** reflected upon her ability to gain satisfaction from her caregiving role based on her new understanding of mental illness and by maintaining social and/or physical control of her situation. She described the personality changes that occurred because of this.

> *... It made me think about how much control I have tried to have, or think I have to have in everything that goes wrong around me and ... where does blame come into all of this? In some ways, I think I have come to terms with the situation and my life then ... because I like my life to be structured, like to know where I'm headed, what I'm doing, and even anticipating outcomes of anything that I might do before I even start to do them, I've got to know these things ... I judged myself really harshly early on in life, and certainly, when I became a carer; but I think I've mellowed over time ...*

Peter highlighted his persistence when dealing with misunderstandings and his own experiences of demoralisation while caregiving for dementia in his community. He described his deteriorating health, increased isolation and frustration, and personal disassociation.

> *... I didn't value my time as much as I valued the friendship, so that's why I put so much time into it, where other people were looking at their bottom line, their dollars and what they were earning and said 'well, we don't need this person to hold us down' ... they just weren't prepared to look ... or even come and ask ... and that's the sorriest part ... when they get into trouble, quite frankly, I don't think I'd bother going and helping them. That's a bad thing to say, but that's the way they're treating people, so you treat them back the same way ...*

Increased social and economic stigmatisation surrounded the participants' who continued to provide care in the community. The increasing stress and tensions were associated with the consequences of social drift in the community, in relation to the disability and financial issues affecting vulnerable people. ***Peter*** reflected on his ability to recover both physiologically and emotionally from the long-term impact of care.

> *... Well, has it really ended because I'm still talking about it? ... It's probably not only come round, it was actually actively white-anting and it's basically the tall poppy syndrome I think ... anyone who achieves tends to get cut down. ... to sit down and put a dollar for time and a dollar for what I spent over there, goodness knows what it would tally up to. I've never been game enough to try.*

8.3.3.3 Psycho-social Recovery

The participants *came to terms* with the long-term impact of treatment on their recovery by managing the overall treatment process. Participants also made extra efforts to integrate opportunities for interpersonal growth of the person in their care. ***Sam*** described the need to improve understanding in the community about the social aspects of recovery, highlighting the increased vulnerability and lifelong susceptibility of people with mental illness in her caregiving role as being dependent on community acceptance and understanding.

> *... For me, I live with a son who'll say when do I think I'm going to die or it will be 'Well, when you go, I'm going too'; that's what I live with. ... Yeah, it's like the use of the word 'recovery', that's also very contentious. ...*

Sam continued to articulate what recovery from mental illness may represent for caregivers. She explained how reliance on the political process in mental health treatment may perpetrate greater intolerance and ignorance about recovery from mental illness in the community.

> *... Recovery is not finite, it is a journey, and it doesn't have the same end - it doesn't have an end – and it'll be at different points of that whole continuum that any two, three persons might like to take. ... I get angry when I see it particularly in policy, as though it's a finite thing and something that everyone will get if they just concentrate and do the right things and take the right medication. Well, recovery is not like that with mental illness; it's only if you've got persons who do have poor insight.*

The participants' *appreciation and acceptance* of the needs of people with mental illness also needed to dovetail with their own lives and coping abilities. ***Kate*** described her ongoing struggle to *come to terms* with grief and psychiatric disability in relation to the expectations about recovery in the wider community.

> *... Yes, it is like there is no end-point where you get the sickness certificate and it's all over ... it just goes on and on, and I think that's when I realised that it's just going to have to dovetail with everything else in my life. ... But, in coming to terms with that, there's a sense of grief because I just knew her life was not going to result in how her friends' lives have turned out ... I mean, some people said to me 'oh when they get to late 20s, they'll grow out of this', but that was rubbish, that was just sort of comfort words for me.*

Ian described his increasing ability to identify with the needs of other caregivers, facilitating foresight about the future of his own caregiving and coping with mental health issues.

> *... I've got to live in hope ... for a long time, I tried to do that myself.... I'm the sort of person that loves to investigate things and research things and find out why things either work or don't work ... I think that's helped her a lot, but also helped me through doing a course ... to understand, and a lot more research this time, wanting to know about the illnesses that my wife has and also just how mental illness in a general sense, the most effective way for treatment of that, and I think it's helped us both come to ... grips [terms] ...*

8.3.3.4 Social Anxiety, Emotional Triggers and Trauma

The community treatment of mental illness highlighted social isolation. Participants' willingness to integrate their own experiences and hope was also linked to the ongoing psychological impact of trauma on their lives. ***Kelly*** described the tensions she experienced following the trauma of mental illness and her recurring distress and disassociation.

> *... you know ... it all flashes back ... the tension ... I get that feeling of absolute high anxiety and concern ... and a whole mix of different things ... frustration because usually it's – often the same old thing, and worry and being upset ...*

Robert explained how he pursued supplementary processes and knowledge of what would be the right behaviour pattern in his personality, to gain reassurance about his caregiving role. ***Robert's*** ongoing attempts to integrate increasing anxiety concerned his ability to adapt to his situation and challenge his ongoing circumstances.

> *... you're really in a pickle then ... fear steps in, it's unknown territory ... anxiety and anxiety's partners ... step into the breach ... they make ... those adaptations harder because they ... eat away and then you doubt yourself 'what am I to do next?' ... that next step isn't clear and it's not a tried and tested method ... [either] in those kinds of situations ... you're treading on eggshells, and then things blow up and then 'all right, goodness me', so then you've got to step back again and then try a different tack. … It's almost like you see what kind of response you get from these attempts to try and breach these problems until you find one that works ...*

Robert described the associated problems he experienced with his ongoing ability to cope with mental illness and the integration of his caregiving role. He described how the leftover tensions from his ongoing day-to-day role disrupted his sleeping patterns.

> *... That's when you start getting disturbed sleep and issues like that start to arise ... you can't sleep for worry ... it's almost like your tasking your subconscious to 'hey, fix this problem. When I wake up I want it fixed' ... sometimes, it just does not come to the party, then you're back at square one and the new day.*

The participants' struggle to find the right approach to caregiving also involved creating future opportunities for integration. ***Ian*** described the challenge of finding the *right* level of encouragement and his efforts at reciprocating healthier interpersonal patterns to facilitate foresight and hope in the relationship.

> *... I think there [are] some really good things that ... are happening now ... to achieve something worthwhile ... the hardest thing ... is being able to give a level of encouragement that's ... the right level. ... if you give too much encouragement ... they see you as being pushy and controlling or overpowering ... You do have*

> *to give a certain level of encouragement, otherwise it can quite easily fall away and I'm continuing to find that a hard balance ... without being too much or not enough, so that's a challenge.*

Mel described her powerlessness and subsequent helplessness to generate positive outcomes for the person in her care. She highlighted her need to re-establish control over the caregiving process by challenging the decisions of mental health staff. She also integrated her increasing frustration and disassociation by increasingly accessing 'private' community treatment.

> *... dread comes into it at times ... my particular dread at the moment is ... the last severe medication change ... he's constantly having medication altered – he was sent home from hospital manic ... that was pretty difficult to deal with until I could convince the hospital to take him back. Knowing that we're going to be going through it again, I also you know, anticipating anything could happen ... we're doing it privately with his psychiatrist this time so ... I'm counting on it being smoother ... because I know ... as they take him off his medication ... that he's not a very pleasant person to be around ...*

8.3.3.5 Balancing Caregiving Approaches via Foresight and Satisfaction

The participants' ability to cope with increasing tension also involved accessing independent sources of verification concerning their own caregiving behaviours. ***Peter*** described and analysed the long-term implications of trauma on the human mind and the need for early intervention in the community.

> *... if you're coming to terms, if you can't do it quick enough, or if it hangs around too long, that's when a deeper ... mental trauma comes through ... you can have physical trauma, which repairs and goes away. You can have mental trauma ... there's always a snippet hanging around ... whether it was 20 years ago, 40 years ago, you never totally forget. It's always in the back of the mind, and even though it can be suppressed, I believe certain circumstances can probably bring it out again ...*

The participant's interpersonal relief and satisfaction about their role primarily focused on their chance to communicate about their increasing tension and caregiving experiences with significant others. ***Ian*** described the personal satisfaction he derived from seeking counselling about his own experiences of secondary trauma.

> *... when ... my wife came out of hospital ... I started doing the full on checking business and then it all crashed down in a big way ... we went back to the family counsellor; it was put to me there ... 'can I stop checking her?' because if I couldn't, it was a big issue because clearly that wasn't going to help ... I didn't quite know how to answer that at the time ... so I've made a conscious effort to say 'well, if I choose to say no, I can't stop', then that in itself is a problem because that might have been a sign of deeper mental illness for myself. My wife can't stop doing things that she does. ... that was a big turning point in coming to terms ... recognising that I was doing something that wasn't constructive ... It's taken me a little while ...*

Coming to terms also involved finding ongoing, practical avenues of support. Accessing outside support provided additional interpersonal security and shielded the participants from increasing anxiety. Thus, being prepared for the eventualities of caregiving and the challenges of his situation prevented ***Ian*** from further frustration and interpersonal deadlock.

> *... Getting professional relationship help has certainly let me discover a few things that I hadn't known ... I'd probably say that you'll always be coming to terms with things because there's always new things presented ... I'm much better prepared ... to allow that to continue ... I don't know everything, and every day, I probably discover something new and you ... then put that into the mix ... what you do with that extra bit of information. So, it's about being resilient, but also ... about flexibility and being prepared to change ...*

In *coming to terms*, the participants confronted the new issues in their lives. The 'costs' associated with their ongoing caregiving roles emphasised the participants' personal vulnerability when achieving mental health outcomes. All the participants modestly acknowledged their increased ability to face struggles, the advantages of their improved awareness about mental illness, and of sharing their significant caregiving experiences.

Robert

> *... Looking back, I wonder how I made it. ... I suppose we don't sort of acknowledge that ... you just ... think 'well, they were the wars. I got a bit battle scarred and ... got the scars to prove it' ..., and you ... still carry on ... those wars do have medals that come attached' ... for having braved those elements.*

8.4 Acts and Ideals: Participants' Accounts of Their Caregiving Role

This section explores the participants' accounts as valid responses to their caregiving roles. According to Interpersonal Theory, the accuracy of peoples reports about their particular cultural situation are *inadvertently* discovered when their actions coincide with their ideas about how they should act. Sullivan (1954, p. 92) adds, "if his behaviour coincides with what he thinks he ought to have done, he can report that matter accurately". As outlined in the methods section (Chapter 5), this analysis of the interview transcripts first outlined '*what is and what was done'* in relation to the participants' lifetime observations of caregiving **acts** (Sullivan, 1954). The following analysis of '*what should have been and has been done*' describes the participants' caregiving **ideals** (Sullivan, 1954). This section describes how participants' caregiving actions coincided with their cultural ideals about caregiving to produce accurate reports. It makes an original contribution to knowledge by revealing how the participants' social organisation played a role in their coping outcomes. These following analyses are presented in two sections: 1) the participants' accounts of valid caregiving responses, and 2) the participants' caregiving *ideals*.

8.4.1 Participants Accounts of Valid Caregiving Responses

In this section, the participants' highly diverse and personal attitudes about caregiving are explored. The findings are presented under the following sub-themes: acceptance, empathy, and interpersonal development; community identity and caregiving acts; and the power of the survivor witness. Overall, the participants' statements about caregiving highlighted their ability to accept their situation *as it is* to achieve collective well-being. ***Chris*** exemplified most of the participants' responses when describing how her overall ability to cope with trauma was shaped by many different personality factors.

> *... Give one person a situation, and another person the same situation, and they'll look at it differently and react to it differently and act on it differently, so who knows which one's right, wrong, or indifferent?*

8.4.1.1 Acceptance, Empathy, and Interpersonal Development

The participants routinely corrected their caregiving attitudes to demonstrate their overall response to *what happened* in their families and to accept their caregiving situation. ***Lisa*** described how her acceptance of the caregiving role allowed her to feel *part of*, and belong to, a caregiving community.

> *... How diverse ... everybody is ... in the same situations, feeling or coping with something totally differently ... I don't think there is a right or wrong. I think if it works for that person, then that's all that matters ... one sees what needs to be done and accepts it and takes it, and generally, if we didn't feel good about it, I don't think either of us would be doing it. So, in ourselves, we accept it because we feel good about doing it.*

In these discussions, participants' shared observations and expectations about how their own roles coincided with their circumstances and immediately increased their empathy for each other. These shared experiences also highlighted participants' understandings of how it would feel to receive care. ***Chris*** talked about her support group and their solidarity with each other.

> *... When we're together as carers, we all have empathy for one another and we look to have the fun time ... where in individual caring roles, at times, laughter is not appropriate or it's the last thing from your mind ... if you don't do something, you can blow a fuse, and you go out and you laugh, you enjoy, you feel relaxed*

> *and then you come back and think 'I needed that', and you know that the release valve's worked because you come back feeling better and happier and you realise that you maybe should have done it before [laughs].*

The participants' empathy with each other and their good-natured approach to their roles improved their overall well-being and personal sense of fulfilment. Improved empathy also provided the participants with a sense of belonging and a clearer understanding of their situation. ***Leah*** described how she benefited from being around like-minded people and her solidarity with their contribution and caregiving values.

> *... I think also to give yourself ... you know, have a damn good laugh and really get on with it, that does you so much good ... a person could have two heads, and if they were talking the same talk as you are, about mental illness or disability or something, you'd get on. You know, it crosses all boundaries and I just love that.*

Robert described how his increased ability to empathise assisted his work as a mental health nurse, when supporting members of his community to overcome social isolation.

> *... when it comes ... to the listening to people, because they say that a problem shared is a problem halved ... people, especially those who are socially isolated ... benefit from that no end, and I see that with my clients at work, who are from the country. They're isolated and their friend groups may be isolated as well, so for them being able to have that outsource, it does them a wonder of good ... when you go to their door ... at the beginning, they're a bit down, but when you leave, they're in high spirits, so you feel like you've done some good just by being there and trying to help them the best way you can.*

8.4.1.2 Community Rebuff versus Caregiver Identity and Empathy

The participants also discussed how their caregiving acts (in themselves) comprised two opposing positions. They expressed their concern about the extent of stigma surrounding mental illness, and its ongoing and long-term impact upon their families. They also described how they attempted to communicate about their caregiving situations to address the constant misinformation and negative perceptions about mental illness in society. Their attempts to communicate their concerns to family and friends often involved the additional paradox of coping with their own exhaustion. ***Ian*** thus explained the supposed ambiguity of his existence as a caregiver, and the contradiction that occurred between his own caregiving acts and the mental health goals of society.

> *... I mean, it's mentally draining, and when you do catch up with people, they ask what you've been up to for however long, and often it's hard to actually say 'well, nothing' ... [when] you've managed to probably live some of the most demanding 12 months of your life, but you ... haven't anything to really talk about or show for it ... it's hard to explain to them just what you have been doing, the effort that's required to deal with these sorts of situations. ... People say 'you're doing a good job', you know, the closer friends that know our circumstances ... but again ... they don't really have a clue. I mean it's hard ... as with most things, unless you're living something; it gets hard for you to fully appreciate and understand what people are doing.*

The participants' ongoing ability to identify with their caregiving acts involved challenging dominant political attitudes and community approaches to mental illness. The following results emphasised the participants' attempts to avoid increased frustration and/or exhaustion about successive governments' inconsistent approaches to developing adequate social infrastructure and supporting community well-being. ***Robert*** expressed how he felt about his caregiving efforts being undermined in the community.

> *... I daresay it's not indigenous to this part of the country ... Once you go outside of the ... metropolitan area, care and those kinds of things, drop off. ... our government unfortunately is ... chopping ... services which are direly needed ... Since my wife's coming out of [hospital] there's been – there is no support for her ... She's been out almost a month, and she hasn't been able to get to see the mental health team, so those support structures are dismally lacking in the country ... it's quite a deplorable state of affairs.*

According to many of the participants, health services and organised political systems directly increased social disadvantage and the context of risk for caregivers in the community. ***Peter*** highlighted how programmed forms of communication about caregiving goals culminated in increased vulnerability and neglect in the community.

> *... it's going to be a very hard one to get sorted out because so many people do have that other agenda of where they want to go, without knowing or without thinking of personalities and people ... I suppose in all these systems of looking after people, there's a degree of politics ... and that's why it's so difficult to actually achieve in the long run, because of other people's agendas,* [and] *what money's available. Yeah, where do you finish?*

The participants' increased anxiety about achieving their own caregiving outcomes highlighted their supplementary efforts to increase community acceptance and understanding of mental illness. ***Kelly*** developed a number of pragmatic coping strategies to ensure ongoing economic accountability and advocacy. She described how she managed her new interpersonal issues of trust with the mental health services.

> *... it's not just a one-step thing. It's about reflecting about things and ... thinking about it, so to begin with ... I always go down the path of trust and then once that's broken and ... reflecting upon it, ... if I'm not happy, then I will take up responsibility and advocate ... I mean, even though I worked in a caring industry ... I just think caring's a word that we can attach dollars and services to ...*

Another issue raised was in relation to the cultural change from institutional treatment to community care which, it was felt, had defined and sharpened community stereotypes about mental illness. ***Mel*** emphasised how socio-economic factors had contradicted the validity of caregiving outcomes and their recognition in the community.

> *... That's a bone of contention of caring and the family carer ... because people ... as soon as they hear the word carer, they think you're getting paid for it and that's not the case.*

On a broader level, the participants' increased susceptibility to secondary trauma was associated with their exposure to institutional ambiguity and contradiction. ***Sam*** described how she developed a new social and cultural identity to provide a valid statement about her situation and increase her empowerment and autonomy as a caregiver in the community.

> *... I like to think maybe things happen in my life, but in accepting 'what if?', that doesn't mean that I'm happy with 'what if?'. ... I try just to reduce the stress factor in accepting in some ways, or trying to be a little bit more open and seeing that maybe there's more than one way for things to happen, or that there is a reason for something the way it is. Even though I may not agree, I can put reason to it, which I think is good to be able to do.*
>
> *... But for me in acceptance, I can still have a feeling like there's something hasn't been resolved or there's unfinished business ... and if I get really agitated ... and get fired up enough, well, I'll do things, as I've done before. ... I didn't bother about the hierarchy; I just made an appointment [with the minister] and went. ... I just went purely as a carer and said what I observed and what I felt and what I was looking at getting and this kind of thing. I mean, I don't know whether that shows courage or whether I'm just plain stupid, but I ... but I still don't feel at the acceptance level that I'm happy with 'what if?'*

The participants' expectations about overcoming organizational contradictions placed extra demands on their well-being and their ongoing ability to achieve valid caregiving outcomes in the community. They often facilitated, and increased, awareness about mental illness to establish the basic human right to belong to a caring community. They also described how the caregiving role provided them with accurate reports about their cultural situation. ***Leah*** both strengthened and maintained the relationship between her caregiving acts and her cultural ideal among caregivers to increase their overall empowerment in the community.

> *... It's a fine line that you're walking then, and to be relentless in moving and expressing what you need to do for the person you're caring for ... you've just got to keep up the pressure and that's where I found [for] a lot of carers ... it was an*

> *overwhelming, self-defeating exercise and I suppose I learnt something. ... Never would I hold myself up as an example of ... a survivor ... but I could see that if you didn't empower yourself and help to empower others, that the consequences of that are awful.*

Being able to provide accurate reports about caregiving also facilitated greater self-awareness for the participants. Increasing community stigmatisation and interpersonal deterioration improved the likelihood of participants' acting as *agents of change* in society. ***Sam*** described her new cultural ideal to improve both the welfare and lives of people with mental illness and the mental health service organisations. Her open acknowledgment of the cultural ideals that occurred in her caregiving situation clearly increased her validity, motivation, and social-esteem as a caregiver.

> *... You can't help but find that if you looked at yourself, your values do change because of the world you suddenly find yourself in. ... and it's made me want to have a role that says I have to inform others where I can, to better educate them ... So, therefore I have changed. I would hope I'm a better humanitarian as a result of it ... that's how I feel when I look around ... always it's the underdog I become interested in, where once upon a time, it would have been the achiever ... now it's the exact reverse ... I couldn't live any other way now ... If I wasn't doing what I'm doing, I would feel I was letting myself down as well as my son and other people, that I think I can still contribute for. The day will come when I can't do this, I know that, but I'm trying to do what I can in the available time that I have to do it ...*

8.4.1.3 The Mental Health Witness and Survivor

The participants also examined how their role as caregivers and survivors in the mental health system increased their moral awareness. As the principle advocates of people with mental illness, they outlined a number of ways of examining the mental health system's authority. ***Janet*** explained how social acknowledgement and empowerment for mental health workers depended on cultural change.

> *... I hope they soon realise that ... it's not the people, it's the system. ...we've got some beautiful people in these systems, but it's the system that we've got to change, not the people, or some of the people that work within these systems ...*

Seeking outside information and professional support was another way of developing valid responses to the participants' caregiving roles. ***Robert*** described an increasing need for moral awareness and better integration of ethical behaviour among the specialised professions.

> *... I was seeing a psychologist ... and it hasn't helped all that well. ...because they bring something to the table and they're expecting me to swallow it ... I'm trying to play out these things and 'for you to help me with some management tools' ... they're not on the same page. They've come with an agenda, and if you don't suit their agenda, it's sort of like 'I can't help you' ... it sort of straps you in 'hang on, we're going for a ride' ...*

The participants recalled how most of the disempowerment they experienced as caregivers concerned the negative presentation of mental illness. ***Leah*** described how her interpersonal recovery from social humiliation and emotional shame defined her as a survivor witness and provided her with ongoing validation about her caregiving role.

> *... shame is horrible, but I've dealt with that, and that's been mainly in mental illness and its presentation, how it presents itself and how humiliating and shameful and how uncomfortable I felt in the presence of other people when it's happening, and now that doesn't matter, that's all part of it.*

Many described their increasing frustration with the presentation of mental illness in the mental health system. They discussed how they often micromanaged the presentation of mental illness to reduce the impact of social stigma on their own situation. ***Kelly*** described how she deliberately focused on creating significant interpersonal interactions with mental health service staff to address the ongoing trauma of stigmatisation.

> *... a person having a mental illness ... is not the most difficult thing, it's working with service providers or systems that they work under, hospital systems or*

> *whatever, and stigma. ... if you see somebody treating you differently because of stigma ... you see your daughter treated in hospital in a way that you're not very happy with because it's not improving anything ... yes, it does affect you. ... to begin with, I was just dismayed, completely dismayed about how things went, but over time what do you do? ... You just go with the flow, or do you just decide 'well this is crap' and change, and you become strong and just fight them? ... if something's not going the way I think it should be going, I will go and talk to the psychiatrist or intervene in some way ... and make sure everybody knows what I think ...*

The participants' ongoing exposure to inequitable power relationships and institutional contexts of neglect also highlighted how Community Treatment Orders (CTOs) affected people with mental illness in the community. ***Kate*** described how the top-down approach of the mental health system often produced further trauma by criminalising mental illness.

> *... I've gone through all that, the Guardianship Board and the ... CTO six months, 12 months ... and ... I find it a bit stern ... I saw my daughter's medical file and my daughter was a bit shocked when she saw it ... and ... maybe they put the worst case scenario on there, so that they have got some backup and protection by the CTO ... I don't know legally if some of those comments will ever come off the file. I don't know where I am there ... it was so misinterpreted, but I haven't been able to address that. ... It's like attending a court ... Why do they have to be so mean and ... push the [security] button ... I wonder if any of them have got a family member ... [with mental illness].*

It was also felt that institutional discrimination both demonstrated the contradictions within the mental health system, and illustrated the importance of the participants' first-hand knowledge and lived experience. ***Mel*** described how the full responsibility for care involved facing the challenges of the mental health system and the nature of their interactions in the community. She explained how her valid caregiving acts as a principle caregiver increased her interpersonal susceptibility to secondary trauma.

> *... right back, early diagnosis my husband was frequently in and out of hospital. Constantly, there'd be things that I felt were antagonising him, and they'd sort of fob me off as if to say 'you wouldn't know' ... but gave me the feeling, that I didn't know what I was talking about and they were going to do what's best ... he'd get twice as upset, so I sort of felt 'quite discounted' with a lot of the service providers. ... it would last for ... five or six weeks ... and he'd be sort of not making any progression ... I knew there was something desperately wrong, and he had been having a heart attack ... I insisted on further action and then they came back and apologised ... I certainly do that now, I wouldn't have years ago ... the same thing with my brother with his schizophrenia ... 'you don't count' ...*

8.4.2 Participants' Ideals: What Should, and Have, Been Done

This section explores *what should be and have been done.* It describes and highlights where contradictions have occurred between the participants' caregiving roles and their cultural ideals (Sullivan, 1954). The participants' caregiving *ideals* are presented under the following two sub-headings; Experience and empathy; and Resolution and knowledge.

8.4.2.1 Experience and Empathy

The participants often described how their lived experience and knowledge about the distress that mental illness caused increased their empathy. ***Robert*** described how his sense of empathy increased his understanding about people experiencing mental illness in society and satisfaction about his caregiving role.

> *... when I look back at different aspects of my caring ... it's like evidence-based ... you see what has worked and hasn't worked, and it ... makes you a better carer from these different experiences that you've been through, that you are able to have a vast array of experience ... in order to understand and appreciate where other people have come from ...*

The ongoing adjustments to the needs of different people (especially in long-term care-giving situations) also revealed the participants' increased management skills. As a result, they were ready to embrace the personal accounts of the people they cared for. ***Ian*** highlighted his social and interpersonal responsibility in the broader context of his caregiving *practice*.

> *... For many years ... no-one knew about my wife's illness at all, what was going on. My parents didn't really understand, my brother didn't know, his partner didn't know; and yet they were the closest people we had. Once that kind of came on; and she was being able to more openly talk about that, it made it easier. Now some of her closer friends know a little bit, some more than others ... once you start to ... (a problem shared is a problem halved). ... so that's what should be done more of, because without doing that, that causes the isolation ... understanding that is one thing, putting it into practice is a whole other level.*

The participants also explained how their caregiving experience provided them with learning opportunities. For many, making the effort to truly understand the nature of people's needs involved forming shared experiences to achieve long-term and better outcomes for the people in their care. ***Sam*** shared her insights about involving her closest friends and family in crisis situations in order to make sense of her caregiving role, to generate interest in the person's well-being, and to express how things had turned out differently from her expectation.

> *... When that happens to your circle of friends and those closest to you, then you find you're far more relaxed in a social environment, or any environment where there's people, if they're going to start talking about the person I'm caring for, or 'what's happened? What's new? What's different or, you know, what crisis have you had to deal with?'...*

These findings emphasise that the participants need to reconnect with their immediate community. For ***Ian***, improving his overall interpersonal communication about mental illness meant finding the right time to communicate, determining the right social circumstances, and knowing exactly what information to share about his role.

> *... The first chapter was very hard, telling friends and what you tell them and how much do you tell them? The second time much easier, but haven't really had a chance to sit down and talk to them that much about it at all. Probably, if you get*

> *that chance, it'd make things a little bit easier and probably start to reconnect ... So, better communicating and being willing to communicate to others about circumstances. I mean some things you need to probably keep private still, but there needs to be a willingness to share more and that's not easy but it's – I think once you start to do that, it become easier.*

8.4.2.2 Resolution and Knowledge

The participants established common ground about their experiences of grief, to increase their collective knowledge about vicarious stress and secondary trauma. The emotional impact of trauma was exacerbated by enduring stigma about mental illness. They also described how community ignorance about mental illness increased their frustration. ***Leah*** shared her regret about entrenched attitudes in society toward mental illness that affected the value of her learning journey and experience.

> *... the regret is more in that you regret that people don't have the sensitivity or understanding. The regret is not inward maybe, as much as outward.*

For ***Kate,*** integrating the collective beliefs of society to resolve the issues of stigma and create hope about mental illness required research to explore how blame, victimisation, and scapegoating created social and behavioural pathways and contributed to the existential pain of mental illness. She explained how research about stigma and caregiving behaviour incorporated social justice issues.

> *... there's another layer of stigma that 'oh these people brought it upon themselves' or something, and that's terribly unfair ... I sort of understand my own journey more ... I let go of the guilt, or whatever, a long time ago, but it's just empowering to know there's other people on the journey ... that are looking at this seriously and not just lumped into other disability areas. It's quite specific, mental health ... there needs to be more research into ... the cause of some of the pathways ...*

The participants' growing insight about their own anxieties and experiences was often shared with other caregivers. *Talking out* mental illness reduced stigma and social isolation and ensured that the *future talk* and knowledge would be generated by caregivers, to safeguard the interests of the people receiving care. ***Ian*** described his need to communicate more openly about mental illness in his community.

> *... There's this stigma with mental illness that people are crazy and should be locked up, or what have you, but it's ... society becoming aware of a situation more in a general sense ... the closer people that you know, not being afraid to more openly discuss it, so that they understand why you're not going out with them, why they haven't seen your wife for three years. ... and they might have been more directly involved and so they start to understand, and all of a sudden, you build that 'oh, okay, so it's not quite as bad as what we think' and that's an important thing as well. Yeah, and you can still have your dark secrets ...*

Ian described how sharing his knowledge about mental illness increased discussion about the issue within the community; a sentiment shared by most of the other participants.

> *... once you start talking to people about this stuff, it's amazing how many other people either are dealing with it too, or know somebody, have had a connection with somebody who have dealt with it. I think one of the fears in this whole care-giving and mental health stuff ... is the fear that you will be looked upon in a negative way, or people will look down on you, whereas ... there's a very high level of it in society and growing, but it's quite amazing that the people you do start to talk to have been exposed to it in one way or another. ... When you've told somebody, you can see straightaway that the barrier actually comes down, and then they start talking about it, and it's like 'oh blah, blah, blah suffered from this and we recognise' – ...*

8.5 The Detailed Enquiry

This section presents the findings of the Detailed Enquiry based on questions from Sullivan's Interpersonal Theory which were chosen according to their relevance for this study (Sullivan, 1954). This section makes an original contribution to knowledge by assessing the participants' self-organisation, their *'I'* statements, and their personifications of care. The results of the detailed enquiry are presented under the following sub-headings: Values, esteem and vulnerability; Behavioural change; A justified life; Demonstration of purpose; Areas of shame and regret; Patterns of sleep; Level of achievement; and finally Future goals.

8.5.1 Values, Esteem and Vulnerability

The following findings highlight how the esteem of the participants compares to their experiences of disparagement as caregivers (Sullivan, 1954). Their discussions about self-esteem were mostly framed in the context of the changes that occurred in their personal values over time, emphasising how their caregiving values had both influenced their self-esteem and their *me–you* pattern(s) of interaction based on their long-term perceptions and learning experiences (Sullivan, 1956). ***Lisa*** described how her self-esteem had changed as her life had unfolded. She identified how the changes that occurred in her self-esteem coincided with natural stages of interpersonal growth.

> *... that goes without saying and I think that's with most people ... Some things we would be passionate about ... say, 16; when we get to 20, it's not even probably of value anymore. ... that's the momentum of life, the waves that go with life. My thoughts haven't changed ... the values might be, but that's a different thing.*

Leah highlighted how her shifting self-esteem transformed her material values to spiritual values. She described how this change in her worldview affected her overall approach to life.

> *... generally, my values changed. Things that were important to me mid-life have no value or significance now at all, and I think that's really interesting.*

The participants' revelations about their own 'self-worth' as caregivers also translated to their improved understanding of mental illness. ***Kate*** described her increased awareness about the impact of social disparagement upon people with mental illness.

> *... my personal values have changed a lot ... my attitude to homelessness because I know (50 per cent of them), it's because of mental illness or not being picked up with medications or there's some trauma in their life. ... When I see people, I don't judge them ...*

Peter described how his caregiving role involved opportunities to vicariously explore the changes that had occurred in his own values, due to the disparagement he experienced in the community. ***Peter*** continued to develop his understanding and empathy in order to provide assistance to people in need.

> *... Only towards certain people; my actual overall value probably hasn't changed; it's still probably just as deep in the caring side of things. At one stage ... I said 'well, bugger anyone else, I'm not going to worry about them', but I find I've put that behind me as well. In my work, I'm always talking to people and being caring about people ... even two days ago, someone pulled me up and wanted just to talk about their situation ... if I can help someone by doing that, well good on them.*

The participants outlined their overall identification with caregivers' whose shared similar needs facilitated satisfaction about their role (based on the changes that had occurred in their self-esteem), and created foresight about caregiving for people with mental illness in the future. ***Robert*** discussed his growing ability to communicate about his own experience and to generate well-being in the community by bringing people together.

> *... everybody deserves the right to be heard ... when you're younger, you feel a little bit more selfish, but as you get older, you understand that we're all at this table together and some take more than others, granted, but it's live and let live ... you get a bit more philosophical about things ... value preferences ... shift wildly ... you glean new information; you learn from experiences, and they in turn slowly evolve your values ... life is not ... black and white (it's everything), and we're on this big stage ... some people's roles are carer ... and some people's roles are caree ... it's learning those values; accepting them, and coming to terms with them; as well as finding ways ... to come together.*

The caregiving motivations, self-esteem, and values of participants changed with age, thus highlighting their desire for personal resolution. ***Kim*** discussed how her new mental health service perspective challenged her caregiving identity and her role as a mother.

> *... some of the things with the mental health course I'm doing ... I find ... a little bit confronting ... to change ... certain things ... with my son ... saying ... 'you can't use coercion' ... I use coercion with my son all the time ... 'but there has to be a two way ... that's not allowed, that's wrong' and you think, 'oh my God, I've coerced my kids all my life' ... it's all part of your values ... It's difficult and I think it's very in-depth ...*

The participants reflected on their self-esteem and personal values to further understand their place in, and relationship with, the world. ***Sarah*** described how the growing gap between her values and her caregiving situation reflected her increasing fatigue, distress, and frustration about coping with trauma.

> *... I find that identifying my values as they change is quite interesting, but it's exceedingly difficult for me to live by a lot of them. It's just - the way that I've ended up at the moment having to live, is really quite against my values in a lot of ways, which is really traumatising.*

Alternately, ***Kelly*** described how her increased awareness and esteem concerning mental illness improved her ability to empathise with others, and her continued resolve to fight society's prejudice towards mental illness.

> *... I've become a nicer person ... a more understanding person. Of course, I'm judgmental. Everyone's judgmental. But ... I'm aware that I try not to be judgmental and I try to understand where people are coming from. So, I try to put myself in their feet ... because of the crap that can happen in people's lives, and it's not about blaming them ... it's about trying to understand where they sit and so I don't know if that's values? … otherwise you go under basically. You have to draw on certain things.*

8.5.2 Behavioural Change

Participants reflected upon the changes that had occurred in their behaviour and personality because of their caregiving roles. They described their subsequent efforts to correct and/or *right* themselves (Sullivan 1954) by examining how and when these changes had occurred. ***Ian*** described how his behavioural changes contributed to the deterioration of his own personality over time and affected his ongoing ability to cope with mental illness. His subsequent inability to gain satisfaction and knowledge about his role highlighted the ongoing impact of disparagement and community *rebuff* on his personal esteem.

> *... I mean, that's been probably the most dramatic thing. Not wanting to sound unfair ... but since the mental illness ... my self has changed dramatically as a person and my behaviour around that ... short-tempered, get angry very quickly ... level of tolerance around things has deteriorated. ... I used to be quite a patient sort of person, whereas now I'm not, unfortunately with the kids ... I don't have a lot of patience with them ... I've seen myself change in ... just not having time for things; can't give things a lot of effort. Whereas once, I used to put in a lot of effort to things ... simple things like having a barbecue or going out on a picnic or the rare time that I might go with friends. And we'd be organising something, I'd always be in there, right in there amongst it all, doing everything, making it fun and exciting, and going that extra mile, where now, I just can't be bothered with that. I think I've lost a little bit of enthusiasm for life in some ways ... whilst we change over time probably anyway, there's no doubt obviously that the whole mental illness/caring thing has made that ... change so, yeah, I'm definitely a different person now than what I was seven years ago.*

The ability to readjust to normal life affected the self-esteem of many of the participants. ***Mel*** explained how caregiving for a person with PTSD usually involved coping with conditions outside of the *normal* range of human experience. She described how her attempts to readjust to the *normal world* depended on her ability to adapt to her ongoing lack of composure (from night terrors) and to realign her worldview.

> *... I guess with some things, I'm less patient, other things I just let totally wash over me ... whether I've been woken up a dozen times ... [involving] the behaviour of the person you care for, [and] in terms of adjusting ... you just can't be bothered so, 'don't start again today, it was enough last night', but he's got no idea of what even happened the night before. ... it's not until you get out with others ... that you think 'I'm adjusting so much to the other world that I haven't been in the real world for a long time' ... You mention that, and someone looks at you as if you're completely queer ...*

8.5.3 A Justified Life

The participants were asked about what they considered to be estimable and worthwhile about their lives and to indicate their feelings of justification and their reserves of security in their caregiving roles (Sullivan, 1954). ***Robert*** described how his increased acceptance and acknowledgement of other people's experiences increased his own sense of belonging and his ability to contribute meaningfully to the community.

> *... I think ... a worthwhile life is when you are able to contribute and be acknowledged for what you've done and how you've contributed ... it's not necessarily one part of your life, but over a wide variety of things - we all bring things to the table - and acknowledging other people's things and also having yours acknowledged ... their achievements, but then also acknowledging also your failures, because it's only through failures that sometimes it strives us on to achieve. Unfortunately ... we're human; we have the right to make mistakes along the road. I think that's the main thing for me, yeah, being acknowledged and accepted.*

Overall, the participants expressed their humour about being asked the research question; ... *That's a small thing to discuss (all laughing).* They described how their justification in life, and their caregiving role, highlighted the limits of their personal autonomy. ***Mel's*** long-term caregiving role demonstrated her unsurpassed knowledge and insight about mental illness and having a worthwhile purpose in life.

> *... I'm a carer for my son as well ... I feel like I'm being dictated to all the time. My husband's lifestyle and my son's lifestyle and all that, dictate my every move. ... Yeah, I don't know if I've had much of a choice; its 30-plus years, and the changes I've seen since ... I mean, my brother was 19 when he was diagnosed, so he'd be 65 now if he was still alive, so there's been a lot of things happen over the years and needed to happen and more needs happening so, yes, if I could have five cents worth in amongst it all I'd be ...*

The participants also recognised that they performed their caregiving roles to justify their collective social responsibility to care for mental illness in the community. ***Ian*** struggled to describe his personal sense of justification because of his ongoing responsibility to meet the day-to-day challenges of caregiving in his life.

> *... I mean, you could look at it and say well, no, it hasn't been worthwhile because I've missed out on so much, but then, you could get really negative about that. I think it's about going 'well it's happened, so I've dealt with it. It hasn't been the best, but let's try and move on and make tomorrow a bit better than what yesterday was'. That's where I'm at the moment, and ... have I always thought that way? No. ... Getting really caught up in the past and what's happened and getting angry about it and holding a grudge against your wife and yourself and everybody else in the world doesn't really do a lot ...*

8.5.4 Demonstration of Purpose or Higher Understanding

The participants were also asked about their security reserves based on their (religious or personal) belief systems, through actions that highlighted their higher purpose and direction (Sullivan, 1954). They discussed how their increased ability to resolve the complex issues associated with caregiving for mental illness involved pursuing alternative and innovative approaches to the challenges they faced. ***Robert*** highlighted how his former experiences and knowledge frameworks provided him with a higher purpose.

> *... I had to find something else in order to go on ... I remember a teacher saying that 'when you leave something fairly large, don't fill it up straightaway', and I*

> *always found that quite beneficial ... not to jump in where angels fear to tread,. ... one of my favourite mottos, 'stick to what you know and trust' ... Sometimes, I've wished I've turned right when I've turned left, but those things can't be undone ... you've just got to find a new way and how to deal with this new information and/or new problem or new situation.*

Kelly described how her self-belief contributed to her pragmatic approach to caregiving.

> *... I think ... faith in oneself ... luck of the draw ... be pragmatic about it all ... At the end of the day ... once you've got rid of all the crap, you think 'oh well, I'll just have to pick myself up and get on with it'.*

The participants also discussed how the practice of meditation contributed to their reserves of security. ***Ian*** described how carer support services had introduced him to coping methods based on mindfulness about his role, and how these practices enabled him to transcend and make sense of his own experience.

> *... I certainly haven't sought faith or any other divine intervention. Religion is not a part of my life, full stop, but ... [while] I don't fully understand mindfulness ... I understand [how] some basic principles behind it ... helped.*

Overall, participants recognised their need to balance the essential goodness of humanity with the bad in order to achieve overall well-being. ***Sarah*** described how spirituality highlighted the importance of existential existence for maintaining personal well-being and meaning.

> *... I've got a deep, underlying sense of the spiritual which has been massively shattered on frequent occasions. ... If I didn't think that there was more than this, I would probably just go and chuck myself off a cliff. .... even on an energy level, the whole oneness of everything ... it's a purification process ... allowing yourself to feel whatever it is that's actually going on for you. I think is really important ... because if you don't, then it creates things like illnesses and stuff ...*

While not specifically naming a religion, most of the participants described how their personal faith provided them with a clear purpose. ***Janet*** described how her faith restored her mental well-being by providing her with hope.

> *... Faith?, Well faith is a thing that's hoped for that we haven't yet seen, so faith gives me hope ... hope that things won't always be this way.*

Hope also restored the participants' belief in the future. ***Chris*** explained how her faith made her journey smoother by providing a higher purpose and meaning.

> *... Although religion didn't have a big part of it ... if something goes right, I tend to say thank you to myself, and to somebody else for helping make it go right ... I guess it's made it easier at times.*

The participants also discovered their own purpose and spiritual strength when facing the overwhelming challenges of their caregiving roles. ***Leah*** linked her personal faith to positive outcomes following many years of struggle and despair.

> *... I know it's going to sound really fanciful and perfect, but in the depth of my despair with mental illness, and I had nowhere else to go and I completely unravelled. I prayed to Jesus Christ and he never let me down. That's happened three times in my life, my caring life, when it was just unravelling at a rate of knots ... Ultimately, my seeking some safe place, for my son to continue his recovery and that's been answered now, so call it what you may.*

Kim described her increasing respect for both good and bad experiences to generate positive outcomes, hope, and a higher purpose.

> *... I do believe in God. I do say some prayers sometimes, and I very much believe in Karma ... I believe if I do good things, good things will happen and ... if I don't do good things, bad things will happen. ... I just believe in do unto others as you would expect them for yourself ... Is that a kind of faith? ... I try to instil in my children 'be nice to people and things ... My son's actually started going to church ... having the underlying faith within the household – although we don't*

> *... go to church, we do believe, and he's ... getting a lot more strength from it, which pleases me greatly.*

8.5.5 Areas of Shame or Regret

Participants were asked about a range of aspects of shame and regret that they had experienced in their caregiving roles. Most of the participants mentioned their regret about the associated shame of mental illness and its stigmatisation in society. They also mentioned regret about their feelings of disempowerment over past events, as ***Mel*** described.

> *... You always end up having 20/20 vision after the fact. When things are at their highest, you don't necessarily have that clarity so; ... I definitely have things I regret and I could have done better over the years.*

Peter also remarked that, while he hoped better outcomes could have come from past lessons, real life is lived from day-to-day.

> *... No shame ... you look at what you do. Regret? ... regret because I didn't achieve exactly where we wanted to be but ... you can't achieve everything, so you say 'well, I did as good as possible' and then move onto the next situation, whatever it might be ... you can't change history ... You can try and change the future and you live in the present, and once it's gone past what happened yesterday, well, that's yesterday, we've just got to live with it.*

The participants mostly described the regret of not spending enough time with other family members. They described how the extra time spent caregiving for the person with mental illness often left no time to enjoy the company of others. ***Kelly*** expressed her regret at not being available for her other children.

> *... I've got regrets ... always have regrets. ... I can live with them; but I suppose ... when my daughter became really unwell ... I regret not giving more direction for my son ... You know, all my time was taken up with my daughter and I had enough energy to do that, and my son sort of motored through teenage years with – well ... I was there for him, but I just wish I'd been a bit more there for him*

> *basically ... I mean, he's doing okay now ... I don't think I could have done anything much differently, but I do look back and think 'oh'.*

Similarly, ***Mel*** described how caregiving had a negative impact on her relationships with family members. She also highlighted the toll that caregiving had taken on her.

> *... my son didn't have any diagnosis of anything until 20-plus years ... and most of my time went into him ... even now the girls say 'yeah but mum you didn't have time, you were too busy with looking after him'. ... I mean, everyone's turned out all right, but ... I'm finding that this relationship with my husband, which has all taken place since we've married, that the kids are feeling the same again now ... because they don't feel [I'm] as approachable and that sort of thing ... because I live so far away I haven't got the time to devote to staying overnight or anything like that ... so, I guess that'd be the biggest regret, yes, the family regrets.*

8.5.6 Patterns of Sleep

In this section, the participants described how their caregiving role had a negative impact on their sleeping patterns. Sullivan (1954) stated that a person's sleeping patterns allowed them to process the unresolved left-over interactions of the day before. He also described how a person's sleeping habits offered clues about their self-organisation in relation to how much sleep they considered to be 'normal'. ***Janet*** described how her ongoing responsibilities had affected her sleep and daily routine.

> *... You never get enough rest as a carer - Come on, you're joking aren't you? ... It should be a damn lot more rest ... if I can get five solid hours sleep ... my body's time clock has adjusted to that ... because otherwise ... you might be thinking you're resting or you're trying to meditate, but the torment's happening, you know?*

Mel described how caregiving for a person with PTSD was accompanied by many broken nights and had made extra demands upon her normal levels of self-organisation due to the ongoing traumatic experiences.

> *... I just have so many broken nights ... I call our bed a concertina bed, it comes together – it can be strapped together or separated ... but I think it's separated permanently because I've been at the receiving end of too many punches or neck holds.*

The participants' also highlighted how their disturbed sleeping patterns had affected their mental and physical health. ***Robert*** described the ongoing impact of stress on his caregiving role, his sleep, and his day-to-day management of iatrogenic illness, due to his long-term anxiety issues.

> *... I suppose how I'm resting now ... I've been in a heightened level of anxiety that's associated with things that happen with my wife and what she wanted to do and things like that. Going to work is an anxiety, because you don't know what you're going to come home to, so I have got a bit of anxiety there. I take high blood pressure medication ... because I've been swapped [the medication] around a couple of times now, [and] ... they can't get it down ... that tells me ... these conscious and subconscious worries that ... persist ... [and] have their result, because they are the things that ebb away your energy and ... drain your power.*

Ian recalled his former tension and the importance of the activities that originally supported his personal levels of balance and self-organisation.

> *... I wouldn't say that I'm not rested and there's no sleepless nights – well, not now. There probably have been over time, and worrying and that kind of stuff ... but I think it's certainly taking time out for yourself and doing things for yourself that lacks.*

The participants described their increased susceptibility to secondary trauma when exposed to increased mental stress. ***Leah*** described how she used relaxation techniques to relax and to cope with her ongoing distress and the responsibilities of her role.

> *... just trying to discipline the mind when it runs off in all these directions. I've got a little strategy – now it doesn't always work – to focus on my actual mind*

> *and brain. ... I have to give that a shot, otherwise I too would be much more ... yeah, to relax, to really be relaxed, is just such a privilege.*

8.5.7 Levels of Achievement

This topic explored the participants' views about their life ambitions and personal vocation. Sullivan (1954) described how ambition functioned to measure the changes that occurred in a person's situation over their lifetime. Alternatively, Sullivan (1953) described vocation as a person's concept (of benefit or harm) regarding their ability to interact with and relate to others. Most of the participants described their life career and personal vocation as caregivers. ***Kim*** described how she had fulfilled her life vocation as a caregiver, significant family member, and a mother. She also reminisced on her opportunity to develop a professional career.

> *... not ... happy with how things have turned out. ... I think there's a part of me that ... career-wise ... would have liked to have done a lot more on a professional level; but on a personal level, I don't think I could have done any more as a carer for my family and everything, and that is a big part of my life. Yeah I think 'needs improvement' to go on the report card.*

Most of the participants expressed enthusiasm about their life achievements, which was both contagious and inspiring. They described the value of caring for people with mental illness and the pleasure they derived from their caregiving role. ***Janet*** described how she had developed her relationships and interactions through her personal identity as a caregiver and through a like-minded community.

> *... Where I am now, I certainly wasn't 15 years ago ... I've achieved some things ... if I hadn't been caring for a person with a mental illness, I would never have done those things, but the fact that I did, they were real achievements ... because they're things otherwise I would not have even thought about doing: and meeting with like-minded people ...*

Mel continued to follow her life vocation by personally advocating, increasing, and advancing knowledge and awareness about PTSD and contributing meaningfully to the lives of others.

> *... I'm quite happy with mine [achievement] at the moment. I'm just still ongoing with advocacy and different training ... I just feel as if I'm at a level I'm quite happy with, but still significantly doing help for others as well. ... if anything that I say or do helps with the next step ... you know, from my lot, if you know what I mean, so if just one little thing can help the next person understand, or whatever else, I'm all for it ... I suppose I haven't sort of stopped to put words to things for such a long time ... if anything that I say or do helps with the next step ... The more we can get out there the better. ... I thought in particular being a mental health carer ... it's just help where you can, basically.*

Leah defined her new goal and purpose in life to continue to help, and to interact with, others. She described how her vocational pathway had resulted in personal reinvention.

> *... Reinvented myself and come around for another go ...That's empowering too ... when you think you've reached a certain age where you know it's not the norm to want to do things, but then ... you can't stifle urges. ... I'm talking about things that I want to achieve and having goals ... when some people look at you and think ... 'why would you be wanting too many goals now?'*

Similarly, ***Robert's*** vocational journey as a caregiver resulted in an increase in social experiences and aesthetic development, which were only surpassed by fulfilling his ambition to become a mental health nurse.

> *... 20 years ago, I dreamed to be a nurse, but I didn't think I was going to be one, but now that I have, I've said like 'well, what was I worried about?' There's that step, you know, you look at something and it's so far in the future and you sort of think 'well, it's only by going those little steps that you get there'.*

8.5.8 Future Goals

The final question asked participants about their thoughts for the future. The researcher centred the discussions on the participants' own initiatives and findings. ***Ian*** defined his future goal of accepting life as it comes and appreciating each day for what it is.

> *... just to continue on the journey that I'm on, and ... be open to learning and accepting ... to become more tolerant ... don't set the bar too high for tomorrow ... if it goes along as good as today is, and today's been okay, then that's fine. Just accept what happens, that's my plan for the future.*

Ian defined his future purpose as creating avenues for early intervention and access to information and community support. His understanding of this need followed secondary depression and learning about how caregiving affected his own behaviour.

> *... As a general thing around care-giving ... my wife and I talk about ... and recognise it, and this is one of her aims with being a peer worker ... to try and get more people suffering from mental illness to be aware of the help that's out there ... when you're in hospital, it's all about ... the medication and your time in hospital, it's not 'so what happens when you get home?' ... the mental health system doesn't deal with that. Once you're out, you're out, and the next person's in and they're caring for them. ... acute care at a hospital level kind of works, but not when the people are out of that environment because they're on their own, or they think they're on their own, but they're not; they don't need to be.*

Participants faced increasingly complex issues associated with accommodating treatment goals in the community, the increasing costs of care, and understanding their future impact upon society. Their ongoing ability to cope with their role had implications reaching beyond the immediate personal, emotional, and mental health issues of caregivers. ***Peter*** defined his future goal as increasing knowledge about the total *cost of caring* for the wider community.

> *... if we can help somebody else to know what they're getting into when they're caring, to know that sometimes they have to perhaps look a lot further afield than what their immediate caring job is, because what their action is today, may have*

> *a repercussion next year, and they have to be aware of what's happening in that direction. ... if we can sort of lay bare some of the hassles of caring that caring can create - and maybe this is why some people don't end up caring, because they just don't want to be involved in that sort of situation. My involvement now is to perhaps throw some light on some of the worst things that can happen ...*

Most of the participants described the need to identify what works for individuals and the community as being important in the future. ***Peter*** identified the need to increase foresight about the future outcomes of caregiving in peoples own interpersonal situations, by acknowledging the mutual *give and take* that occurs in caregiving relationships.

> *... How ... many other people are likely to get involved ... immediate family – husband, wife, child, daughter, parent – ... probably not too many ... where a community became involved ... somebody said to me, there should be a committee formed to work out what he needs to do ... Well, bugger that ... a lot of caring is really on a one-to-one basis as opposed to how many people onto one situation.*

Most of all, the findings described in this chapter highlight the participants' ability to overcome their prior traumatic experiences and former neglect by taking time out for themselves. ***Robert*** highlighted how his increased susceptibility to secondary trauma could be addressed in the future.

> *... I think my quest for the future is to try ... to do things for myself on occasion, instead of for others all the time. You forget to take time out for yourself ... we tend to neglect it ... I think it's because we become so carer-focused ... we wonder ... when we're hung out to dry why we feel the way we do.*

The participants' overall recognition of their caregiving achievements involved their ability to celebrate their life journeys. ***Robert*** described how his personal day-to-day awareness usually concealed the overall significance of his life journey.

> *... like seeing ... the journey that you've made ... you can look back and see where you've come from, and ... those rough patches ... prop yourself up ... and*

> *say 'right, I've come this far and that's a good thing and what I'm doing is beneficial and there is a lot of good that comes from it, but I also have to balance things a little bit too' ... whereas ... you're just thinking of the day-to-day duties. You don't normally take that time to look back over what you've achieved.*

Similarly, the following participants described the benefits of being involved in the research, and how it enabled them to recognise and celebrate their own fascinating lives.

Janet

> *... you've given me some things to think about ... I've got a lot out of it because I've got a transcript here that I can go over ... in black and white, so you can keep a handle ... [when] you look at it, you think it's something you should be reading in a novel.*

Leah

> *... I've been surprised at the depth of emotion when I've been talking with you and sharing ... it's sort of a reflective thing ... Well it's just been a revelation. ... 'Is this our lives? Is this really us?' Yeah, 'I'd like to meet this person'.*

8.6 Summary

Chapter 8 has revealed the participants' astonishing caregiving journeys. The methodological framework and findings outlined in this chapter allowed the participants to both explore and define their own experiences of vicarious stress. Interpersonal theory provided a set of practical and clear methodological guidelines for the exploration by gradually increasing the participants' awareness of secondary trauma. Thus, the communication processes engaged with in this research remained sensitive to the particular issues and problems posed by secondary trauma. The intellectual generosity of the participants towards the researcher and the research methodology also increased the validity of the findings.

Chapter 8, the Detailed Enquiry, has presented a set of rigorous findings by incorporating rigorous methodological principles to generate research findings about vicarious stress. Both participants and the researcher produced the findings of this stage. This chapter also explored the relationship between the participants' development, their 'self', and the rest of their personality, by investigating their personifications of care, social organisation, and subsequent coping processes in caregiving situations. Chapter 8 has made an original contribution to knowledge by exploring the relationship between the three main interpersonal tensions and the integration of vicarious stress based on the participants' own caregiving experiences, interactions, and unique perceptions of secondary trauma.

Chapter 9 presents an overall summary of participants' caregiving role based on the analysis of their cognitive modes from the Detailed Enquiry (Chapter 8) transcripts. The chapter will present the findings from the fourth and final stage of data collection, the 'Caregiving and Stress Forum'. Participants and host organisations were invited to the forum in order to contribute to the findings of the research. The forum was adapted from the *'Termination'* stage in Sullivan's Interpersonal Theory (Sullivan, 1954), and provides a summary of the overall research findings, final feedback on the research project, and the participants' statements of the overall benefit of the research.

CHAPTER NINE

The Termination of Research and Final Summary

9.1 Introduction

Chapter 9 presents the analysis of the participants' cognitive modes from the Detailed Enquiry stage, and the results of an open forum about the Caregiving and Stress research. As demonstrated in Chapters 6, 7 and 8, the methodology of Interpersonal Theory has guided and directed the data collection procedures in this research on secondary trauma. Chapter 9 will firstly present 13 vignettes signifying each participant's cognitive modes as *prototaxic (being), parataxic (doing),* or *syntaxic (knowing)* (Sullivan, 1953) as a final summary for the participants involved in the research. These findings were analysed according to the processes outlined in Chapter 5. Chapter 9 also presents the results of the final 'Termination Stage' of the data collection for the project, and was adapted as an open forum morning tea presentation and Q and A discussion on the research. The *Caregiving and Stress* Research Forum was conducted in December 2012 at a central metropolitan location (Flinders Victoria Square Campus, Adelaide CBD), and was attended by approximately thirty (30) people from host organisations, carers' associations, friends, and other interested parties and stakeholders.

9.2 Summary of Participants' Cognitive Modes: Being, Doing, and Knowing

The particular qualities of each participant's cognitive modes provide an overall summary about their caregiving role and statement of benefit about the research. Table 9.1 first outlines the three distinctive cognitive modes of Interpersonal Theory, as defined in this research.

According to Sullivan (1956, p. 29), these three cognitive modes describe the "inner elaboration of events" in people's lives. Sullivan (1953, p. 29) stated that "the difference in these modes lies in the extent and the character of the elaboration that one's contact with events

Table 9.1 The Three Cognitive Modes of Interpersonal Theory

Being Primary information/ sentience	Sullivan (1953) defines the *prototaxic* as theoretical perfection, because the precise data is literally impossible to document. *Being* occurs in early infancy before reciprocal communication and symbolic language is established. *Being* thus refers to participants' *sentience* as "the primary data out of which we come to have information" (Sullivan, 1953, p. 27). This early prototype suggests how the participants' observations of early caregiving and early responses to their environments influenced their subsequent cognitive development. As the earliest caregiving experiences, these non-verbal interpersonal messages have intrinsic meaning over the entire life-cycle (Trevarthen, 2001).
Doing *Me* and *you* patterns of interaction	The *doing* mode illustrates the verbal communication of information that reflects and contains recollections that provide emotional connection (Sullivan, 1953). *Doing* also highlights how the development of '*me and you'* patterns form interactions between the self and the rest of the personality (Sullivan, 1954, p. 130). *Parataxic distortions* also indicate where communication with others is being influenced by earlier interactions and other relationships.
Knowing Shared meaning based on an understanding of symbolic language	The *knowing* or syntaxtic mode indicates agreement about conveyed communication based on mutual understanding of a shared symbolic language (Sullivan, 1953). The *knowing* mode also represents a more complex conceptualisation of meaning, involving accurate recall of past actions, and the anticipation of future action involving foresight (Sullivan, 1953).

has undergone". For this study, each participant's cognitive modes are presented according to the following sub-headings; Being and Doing (first recollections and interactions), Being and Knowing (recollections that provided meaning), and Doing and Knowing (interactions that provided meaning). The following 13 vignettes provide an overall summary of the particular qualities of each cognitive mode that occurred for the participants.

9.2.1 Being and Doing: Participants' First Recollections and Interactions

Sullivan (1953, p. 84) described how *living beings* initially develop signs about their experiences to "roughly approximate the esteemed expressions of their culture carriers".

From there, goal-directed behaviour recognises differences between experiences (or signs), as *doing* in the parataxic mode.

Janet defined her childhood *responsibility* to integrate trauma and early esteem. These covert behaviour patterns established responsible caregiving processes in her personality. ***Janet's*** subsequent leadership/ advocacy roles facilitated an understanding of mental illness.

> **Being** ... *I feel good if I'm helping somebody else. It's like a lift ... I've lived like this for so long ... I don't know how to change it ...* **Doing** ... *I can get five solid hours sleep ... otherwise you're lying there ... but the torment's happening, you know? ...* **Knowing** ... *Where I am now, I certainly wasn't 15 years ago ... faith gives me hope ... hope that things won't always be this way.*

Ian supplemented the esteem he first received from his grandparents by improving his *self-awareness*. He achieved *self-control* by interacting with other caregivers and support groups to increase his understanding of mental illness. **Ian's** subsequent caregiving role involved sharing his experiences.

> **Being** ... *Just accept what happens, that's my plan for the future ...* **Doing** ... *I'm not less worried, because I'm not afraid that it [split with my wife] can still happen, because it could, but I'm less worried about the consequences now ...* **Knowing** ... *There's no doubt I've suffered from ... secondary depression ... but I feel like my situation is much better now as well (which is helping my wife too).*

Sam's self-esteem was initially shaped by the support of her family. She explained how her subsequent behaviour affected her personal control and responsibility. ***Sam*** used her lived experience to facilitate better political outcomes for people with mental illness.

> **Being** ... *[it] governs how I conduct my whole life still and having to do things around other people's ... [and] family's expectations ...* **Doing** ... *It made me think about how much control I have tried to have, or think I have to have, in everything that goes wrong around me ...* **Knowing** ... *I cringe at some of the*

> *things that have been said ... but I sort of think, well, with the information they've got, they don't know any better ...*

Kim's self-esteem was maintained by her *expectations* about caregiving and family. She focused on maintaining the *balance* between her goals and her caregiving activities, and described her responsibility to facilitate the best outcomes for her entire family.

> **Being** ... *I don't think I could have done any more as a carer for my family ... and that is a big part of my life ...* **Doing** ... *I have to take a step back and say 'okay, how do I have to look at this to make myself well enough to look after everyone?' ...* **Knowing** ... *you just need to do what needs to be done to make it work, which is what I did.*

9.2.2 Being and Knowing: Recollections that Provided Meaning

According to Sullivan (1953), foreseen relief (from near and distant past and future anticipations and expectations), determines the success of actions. The participants' caregiving gestures and speech symbolised how their working circumstances with others were validated.

Peter *sought* relief from the rebuff of his caregiving role by rebuilding his self-esteem. These caregiving actions and interpersonal forms of communication validated his caregiving identity and *common sense* approach to his prior circumstances and secondary trauma.

> **Being** ... *In hindsight, I can picture myself [in need] ... I'd certainly appreciate someone else helping ...* **Doing** ... *where I'm working ... probably 80 per cent of those people ... have got broken marriages ... I seem to somehow ... drift into a counselling role ...* **Knowing** ... *I've been over and over things well before you contacted us, and so it's pretty well gelled in my mind just where things were ...*

Chris's own actions highlighted her *teamwork* with caregiving organisations and information networks. She described her interpersonal circumstances in meeting the needs of other people over time, and highlighted the type of *interactions* that validated her ongoing caregiving role.

> **Being** ... *I can self-rely ... and still give care and support ... but [am] aware that you yourself need help* ... **Doing** ... *[I] regret that I didn't speak up more for myself* ... **Knowing** ... *Everybody has a right to lead a healthy life and do whatever ...*

Kelly's foreseen relief about her current situation highlighted her former self-reliance and independence. She clearly validated her purpose of seeking to increase the social capital of people with mental illness. ***Kelly*** practically accepted and acknowledged her goal to facilitate foresight about the care of people with mental illness in the community.

> **Being** ... *Be pragmatic about it all ... once you've got rid of all the crap, you think 'oh well, I'll just have to pick myself up and get on with it'* ... **Doing** ... *if I can help somebody ... somehow, I've made a bit of difference … trying to assist somebody that's doing something* ... **Knowing** ... *It's also given me direction ... I found something that I'm really passionate about ... it's really important ...*

Kate described her early *impressions* of family in relation to her self-esteem. Her foreseen relief about her caregiving responsibilities was determined by actions that emotionally safeguarded the whole family. These caregiving experiences validated her working circumstances with other people.

> **Being** ... *I guess people think 'oh that's Kate's ... thing and she'll cope with it, like she's coped with other things in her early life'* ... **Doing** ... *I've just learnt to play my cards a bit closer to my chest because I ... don't want to take on [other/ family] ... reactions as well* ... **Knowing** ... *I'm probably a better person for ... this sort of lived experience ...*

9.2.3 Doing and Knowing: Interactions that Provided Meaning

Sullivan (1953) described how cognitive *doing* symbols, signs, and dreams shaped a person's referential processes. The participants identified and observed their (overt and covert) activity patterns as symbolic events that increased their full experience of life (Sullivan, 1953).

Mel identified how her early observations of her mother shaped her self-esteem and the success of her current work and interpersonal circumstances. Subsequently, her life experience increased her validity as a mental health advocate.

> **Being** *… I never quite know what's in mind for me, so I just try and keep on ... my mother was a support ... I reflect back on her, but none of the others ...* **Doing** *... If ever I'm in a group of veterans ... 'all of these fellows have got the same problem; they're not necessarily thinking as clearly as what another rational person would be' ...* **Knowing** *… I've taken on several roles of advocating ... I'm constantly trying to ... fight the stigma ... my husband [s][PTSD] ... was war caused, but [with] my brother [mental illness], it's a different stigma.*

Leah referred to the importance of previous role models for her current activities. She identified how her social interactions with other caregivers provided her with opportunities for personal reinvention and emotional connection. ***Leah*** identified how her lived experience corresponded with the needs of her community.

> **Being** *... You know how you give, give, give, mothers and carers and supreme givers that just leave a little bit, a little bit of humour maybe, a little bit of laughter ...* **Doing** *... seeing my life with other people's caring roles ... to give yourself ... a damn good laugh and really get on with it ...* **Knowing** *... I feel it could never be any more powerful than it is right now ...*

Lisa described the importance of her early life skills for her current caregiving role. She focused on interactions and activities that created the greatest good for the most people. ***Lisa's*** increased life experience highlighted her understandings of her ongoing caregiving role and life circumstances.

> **Being** *... I can see ... what needs to be done ... I just made sure ... that it did come about ...* **Doing** *… I think if it works for that person, then that's all that matters ... we do it the best we can ... for me it was probably that ... sort of difficultness ...* **Knowing** *... in a world ... one gets dealt with what one gets dealt*

> *with ... it's not as good as it could get, or even might get, but it's certainly maybe better than others may have ...*

Sarah described how her family's expectations about caregiving shaped her self-esteem. Her ongoing caregiving activities were characterized by the symbolic events of her past. ***Sarah*** described how her subsequent life experience highlighted her social isolation as a single mother and caregiver.

> ***Being*** *... I can only be incredibly grateful that my kids aren't ten years younger ... it would have been absolutely horrendous trying to cope with a situation like that now ...* ***Doing*** *... I don't feel like I'm specifically fulfilling any particular purpose ... that I'm actually just making things worse for everybody ...* ***Knowing*** *... One of the biggest causes of my stress ... I didn't even identify with until last year ... being a parent, but actually needing to be more ... what would happen under normal circumstances?*

Robert successfully resolved his earlier experiences of neglect through his trusting nature. These highly adaptive activity patterns supported his ongoing caregiving interactions. ***Robert's*** increased communication skills reflected his overall life experience.

> ***Being*** *... when I look back at different aspects of my caring ... just by being there and trying to help ... it's ... a give and take sort of relationship ... sometimes it feels like it's more give than anything else ...* ***Doing*** *... as you grow up, you find patterns that ... help yourself to cope with things ...* ***Knowing*** *... Communication is one of the greatest things that has changed my behaviour ...*

9.3 Final Data Collection and Termination of the Research

According to Sullivan's Interpersonal Theory, the Termination Stage provides a final summary and statement of benefit for the participants involved in the research; a prescription of future action based on the research findings; a final assessment of the research process; and formal leave-taking (Sullivan, 1954). In response to this process, the researcher presented a PowerPoint Presentation (Appendix 10) containing 13 slides that summarised the early findings of the research project. The PowerPoint presentation was followed by a question and answer discussion (see Forum Discussion Guide, Appendix 9). During the forum, the participants sought verification and clarification about the early research findings.

The forum was audio-recorded and transcribed by a professional transcription service according to the processes outlined in Chapter 5 (Methods). Following transcription, the researcher emailed and attached the PowerPoint slides and the Q and A transcript to the participants, requesting feedback and expressing gratitude for their participation. Several participants' responses expressed their appreciation for the research.

9.3.1 The PowerPoint Presentation

The PowerPoint slides presented current literature about secondary trauma and traumatic stress. Forum participants asked if the current research findings reflected the literature. They also asked for verification about the definition of caregiving (to be held responsible for the care of another and to provide ongoing practical, emotional, and psychological support). The significant gaps in knowledge and the literature were explained to participants.

The typologies of vicarious stress, vicarious trauma, compassion fatigue (iatrogenic illness), and secondary trauma were explained to the forum participants. Overlapping symptoms between the typologies were described and compared to PTSD symptoms, to highlight how trauma may be transferred from the individual to the caregiver. The role of resilience was also discussed. An explanation of the interpersonal method highlighted the importance of participant observation for observing the relationship between stress and participants' coping patterns throughout development. The subsequent development of a working hypothesis about secondary trauma allowed the researcher to explore the relationship between the typologies of traumatic stress and the transfer of trauma.

The researcher raised questions that had occurred in the literature in relation to caregivers' interactions with, or exposure to, traumatic events. The researcher also described Figley's (1999, p. 22) account of caregivers' susceptibility to secondary trauma, involving four main interpersonal domains: (1) caregiver empathy as a major resource; (2) caregiver motivations to help; (3) caregivers' prior experience; and (4) caregiving for vulnerable populations. Overall, the researcher represented the growing field of research about vicarious stress and secondary trauma, its increasing impact upon caregivers, and its significance for future mental health policy and practice. The researcher concluded by stating that Sullivan's Interpersonal Theory had an important role to play in future research on secondary trauma.

9.3.2 The Q and A Forum Discussion

Three main slides supported the Q and A forum discussion. These covered research interactions: *personal, developmental, collaborative, and collective*; possible social and cultural strategies to address secondary trauma: *first-hand local relevance, improvements to the learning environment, agreeing on suitable goals, and the relationship to recovery*; and finally, the incorporation of: *past ideas, new communication, and awareness*. The findings from the Q and A discussion are presented under the following four sub-headings; The survey sample and results; Guilt, grief, and stigma; The mental health system; and Cultural attitudes.

9.3.2.1 The Survey Sample and Results

This research sample consisted mainly of mature participants from community support groups and non-government organisations (NGOs). This particular representation of the caregiving demographic highlights a need to find ways of recruiting younger caregivers (as was also suggested by a sibling support group coordinator in an email to the researcher). One forum participant also questioned the appropriateness and efficacy of the recruitment process.

> *... did you also just do a general call out to consumers? ... Like the broader community ... younger, newly married couples, they wouldn't recognise that they're a care giver ... potentially being a part of an organisation is maybe something that happens later in life ... that age data ... is probably skewed ...*

A program coordinator from an NGO carer support service confirmed that mature caregivers often accessed her program. She also emphasised how de-institutionalisation had impacted upon caregivers' interactions with the wider community.

> *... [we] are as often their first base of getting any understanding of what the hell has happened to them and where they find themselves ... [the carers] are a little bit older ... we have a few that are coming in, in their 20s now ... in the last 24 months ...*

The program coordinator confirmed that her program funding was based on providing community support for caregivers.

> *... When they ask the question of 'I'm not a carer', you actually support someone, whether they live with you or not, that has a mental illness ... that's the term that we use and that's how our funding comes ...*

9.3.2.2 Guilt, Grief and Stigma

The NGO program coordinator highlighted how caregivers' personal backgrounds often affected their ability to look after themselves. She explained that caregivers' recovery from stressful and traumatic experiences was often affected by their feelings of guilt and grief.

> *... The ability to actually care for one-self ... [to] know what your levels are ... to actually understand ... and know when you actually can't give anymore; that's really, really hard ... but some people ... don't realise there's a guilt there. Understanding that first and early in your journey is important ... the guilt and grief ... the loss that we feel of our lives as carers ... our loved one from what their outcomes in life would have been and that's really relevant ... their interaction of their background ... to understand their behaviours ... learnt*

> *responses ... family circumstances ... [and to] acknowledge that everyone has a different personality ...*

The forum participants also associated their increased feelings of powerlessness and personal vulnerability with the overall trauma they experienced as family members. The following forum participant described how family caregivers' need more community support. She also highlighted the need for more objective and constructive assessments of family caregivers by mental health professionals.

> *... the ongoing grief for carers, I think is a really important one ... I'm really interested in ... the conclusion of your PhD ... because historically carers, especially parents, are often blamed for contributing to the problem ... what should be to me, the outcome ... an absolute need for a carer assessment for someone who's providing especially comprehensive support for someone with a severe and ongoing mental illness.*

Most of the participants confirmed that they were not adequately prepared for their caregiving role in the community. The following participant revealed how mental health service professionals continue to censure family caregivers.

> *... I'm a family and carer consultant ... my first husband was long-term with schizophrenia, and I have a son and daughter both with a mental illness, so I've had a lifetime of caring and, as you say, now working ... to make things different ... I know at the time when I was dealing with young social workers coming in and pointing their fingers saying 'you're not doing this right' or 'you're not doing that right', you really feel trodden down. You want support and help. You want to know how to deal with things, but not to be judged, and that's what I felt at the time; that I was judged ...*

Consequently, the forum participants often fulfilled advocacy roles in the community to address the ongoing inequities within mental health service provision. They largely associated their increased vulnerability to secondary trauma with the deleterious impact of social stigmatisation upon their lives. The following participant described the subsequent effects of dis-association on their family, identity, and future outcomes.

> *... the fear sometimes ... 'who else in my family?' ... so adapting to the new awareness can sometimes have a detriment as well, of 'what else can go wrong?'*

The participants described how their well-being significantly improved by knowing how and when to access outside support. Most of the participants described the imperative of accessing the right information and receiving relevant and practical advice, as was exemplified by the following participant.

> *... Support groups are really relevant to a lot of people where you can share and who had that same journey ... I think a lot of people are carers and they don't know it, it's only when you get that diagnosis of 'your son, your daughter has' ... that's what the psychiatrists say, and you have to digest all that, and then it tips your own life into 'now, how do I provide support outside of the medical field?' ... you get into a very crisis situation of putting things in place in the community ... [Carer Support] organisations are vital for the community system of helping carers ...*

9.3.2.3 The Mental Health System

The forum revealed how deinstitutionalisation negatively affected caregivers in the community. The participants explained how communication about the goals of treatment needed to be clear to safeguard the rights of people with mental illness. The following participant highlighted a significant gap in relation to the treatment of mental illness.

> *... in the early '90s, we got rid of mental health institutions. We put people in the community because 'hey, people can live better in the community', but what we forgot to do is provide any funds to people to work in the community to help these people, so we just dumped them in some hospital or whatever and left them to fend for themselves ... the traditional way we've treated people with disability, people with mental health problems, is ... it's not a person who comes in to see the psychiatrist, it's a bag of symptoms ...*

Participants constantly raised the issue of the rights and needs of people with mental illness. They also described the failure of the mental health system to address their own support needs, and their perceptions of burden as community caregivers, as one participant described:

> *... the fact that when things are running reasonably smoothly ... you try very hard to get on with your life ... but when things go badly, you're confronted over and over and over again with the frustration of knowing that you're going to be the person who supplies the support for this person, that the system isn't going to react the way it should ...*

The nature of the participants' traumatic experiences, as caregivers who cope with ongoing unforeseen crises, were also discussed in the forum. The following participant spoke about the overall impact of poor mental health literacy on her life.

> *... we've started up a support group, so hopefully that'll communicate ... part of my reaction when our daughter isn't well, is the fear ... the threat of suicide was there ten years ago 'I'm going to kill myself'. When you get that phone call ... that is constantly with us and ... is such a stress.*

The forum participants explained how early intervention was crucial for addressing secondary trauma in the community. The following participant emphasised that accessing information about support is most beneficial when provided early in a mental health crisis.

> *... It's the not knowing, not being supported, not being helped in those early days when you don't know anything ... although we've got good services now, there's a lot of gaps where people aren't getting the right support at the right time.*

There was also discussion about how the creation of a political voice was crucial for increasing the participants' visibility in the community in relation to the issues they faced. The participants identified how family caregivers were increasingly held responsible for managing mental health treatment by themselves. The following forum participant described the shared and often precarious experiences of family caregivers in the community.

> *... like I said before, how people have to try and do things themselves, but it's very, very difficult ... [a caregiver] on TV last week whose son committed suicide ... couldn't get any mental help for her son in that area, so she's now trying to organise it herself unofficially ... so that they can deal with the situation and force the authorities to do something about it. Now, this shouldn't need to have happened. The mental health situation should be improved ...*

The participants highlighted how institutional responses to mental illness too often involved recurring cycles of diagnosis, poor prognosis, and re-hospitalisation. They also described how they were continually isolated from the treatment process. The following forum participant described his communication with mental health services and his increasing distress.

> *... I'm talking about the communication and how these things happen ... my son was diagnosed ten years ago as a paranoid schizophrenic, right? ... He got put into the [place] mental health ward ... we went every day ... but I [also] went on discharge and I said 'what's the situation?' 'Oh we can't tell you'. Eventually, I forced an interview ... with the management ... (they don't correspond with ... anybody else), all these seem to work individually ... because he was discharged ... with what they call an adjustment disorder, after being a paranoid schizophrenic for nine years. Now this is ridiculous ... as carers, we're supposed to put up with this, but who do we turn to?*

The researcher then explained how Interpersonal Theory was beneficial for reducing anxiety and exploring normal human responses to anxiety, such as anger. The same forum participant continued to describe the social and cultural complexity of managing mental healthcare.

> *… You've not mentioned anger. Sometimes, it can be a reaction to the system ... I'm not saying you're going to get angry with the person that's got the problem; you're getting angry with the situation.*

One participant explained how caregivers currently have legitimate rights within the mental health system, adding that increased awareness of this information was needed to maintain these rights and ensure that caregivers continue to access people in institutional care settings.

> *… when they have problems and the system isn't working well enough to actually know you have some rights … to allow people to know that you have those, and from the time of discharge planning, that you have a right to be there … to make sure that when we go into locked wards and discharge of our son or daughter and that the staff actually know that you are a regular visitor, even if you're not there very long … allow them to know, so they can't use that as 'you're not needed', discharging and they've gone home and you don't know about it … that's really traumatic; you go and they're not there, and you're not told.*

One participant also described how new work health and safety standards involving smoking bans in mental health systems denied the autonomy and rights of people with mental illness.

> *… as an ex-smoker … they've banned smoking in mental health institutions. Now there's nothing more needed to put more stress on a person than to say 'you're a smoker are you? But you can't smoke in here' and you're locked up for two weeks perhaps in a secure ward without a cigarette …*

9.3.2.4 Cultural Attitudes

The participants explained how their experiences of social stigmatisation connected with prevailing cultural attitudes about mental illness. Most of the forum participants expressed their frustration towards the institutional discrimination they experienced. The following participant described the negative consequences of the attitudes of professionals for people with mental illness and their caregivers.

> *… Over the ten year period … I find that communication and information is very poor within the mental health system … you can be a carer; but not an official, court-appointed carer of a person. You can ask for information about your son or daughter (that's in a mental institution) and they will not give it to you … unless they sign a form to say that you can have that information, you can't get it. Then you get frustrated … Recently … I found out that when a person was admitted to a mental institution, there was a form that they could fill in with their carer as they left the institution … [That] form has been in circulation for at least five years … until I asked the question … 'oh yes, the form's still out there, but for the*

> *last 12 months they got five replies' - five - and I said 'well, is there nobody to help the people fill in these forms?' So, one of the nurses from [place] got up and said 'well, I'm not helping them, I haven't got time'. ... Now, this attitude needs to change. As far as I'm concerned a person with a mental illness ... are not there to be punished, and they're still punished by the way ... getting your point of view over, to somebody that really cares ...*

The forum participants discussed how Centrelink payments (e.g., Disability Support Pension), negatively affected public attitudes toward mental illness. They highlighted how the overall disadvantage of people with mental illness diminished their long-term opportunities to maintain positive mental health outcomes in the community. The following forum participant described the ongoing impact of disability on the person in her care.

> *... when that person you care for is on the full disability support pension ... it hits home ... that normality is just taken away from them.*

She described how her own diagnosis allowed her to advocate on her brother's behalf and uphold his direction for recovery with mental health professionals.

> *... accidental caring ... having my own personal journey and lived experience ... the lines blur at times ... I've been involved ... as a carer ... until I tell them I have my own lived experience and then they're not sure how to deal with me ... when my brother ... asked me to be his carer ... I was talking to the medical professions and they kept telling me that he could live only in supported accommodation ... because we've got the same diagnosis - he said 'you can live by yourself, why can't I be allowed to? ... I said 'well, yes, of course you can be allowed to' and he said ... no-one's let me try', so I went to the medical profession, I sat there ... I said 'no, he can try and live by himself'. He now lives out at [place] and he's living the life he wants to live.*

One forum participant briefly raised a concern about the National Disability Insurance Scheme (NDIS) *as the solution to a whole lot of problems*, but received no comments. A participant then introduced the overall context of family needs that affect caregivers.

> *... effective communication, not only with our immediate family because ... siblings will come in ... they are supportive of their brother or sister but they ... get so frustrated at how much mum and dad give to that person and ... carers ... to acknowledge the rest of your family, [and] realise that you have more than one person that you're looking for ...*

Although Sullivan was involved in the early development of family therapy (see Chapter 1), one forum participant challenged the researcher's emphasis on Interpersonal Theory.

> *... Just about the interpersonal theory, I kind of disagree that it's not being used in the medical field because, isn't family interviews getting to that? ... But to look at someone in the full picture, that's a part of getting the family together and saying 'what's your views? Tell me what you think is contributing to this'.*

A number of forum participants then interjected with the following comments.

> *... Who does that? Yeah? Well, I personally have not been in that situation where that has happened.*

Another participant then shared their own experience of family therapy, to provide an example of what happened to them.

> *... My son was interviewed – this has only happened once in 20 years, but the family were interviewed individually and together, and we all wrote an assessment of what we believed his needs to be, and every single response from other members of the family were ... [separately] identical ... my son said everything was fine with his life because he doesn't understand he's got a mental illness, but he said he would like a girlfriend; so, that's what the services decided to follow up ... they appointed a support worker to try and help him to find a girlfriend which was really, probably, the bottom of what his needs really were.*

One of the other forum participants then questioned whether the research explored the ongoing effects of caregiving on the overall health of the participants.

> *... as well as looking at trauma, did you look at the other health effects associated long-term with being a carer?*

The researcher explained that the findings presented a variety of health issues that linked directly to the participants' long-term responsibility for caregiving and ongoing stress. One forum participant highlighted the need for research to investigate the impact of mental illness on family caregivers' own mental health.

> *... I know from my experience, when my daughter is well, I'm well; when she falls in a hole, I fall in a deep hole as well and feel equally as unwell as she is ... Have you looked at that? ...*

The following forum participant added that mental health staff also needed to be educated about mental illness. She described the ongoing disparagement that caregivers and people with mental illness often experienced in the community, and emphasised the need to raise mental health professionals' awareness about the impact of their negative attitudes upon care.

> *... my daughter tried to commit suicide three times - she says the third one was a mistake (it was an error) – but the medical profession have just written her off and said 'drugs are the only thing that are going to help' ... also the medical profession needs to be trained as well.*

The researcher shared her goal of developing interpersonal training at tertiary level so that professionals may safely observe how they respond to mental illness and to caregivers. The researcher added that Interpersonal Theory can play a significant role in professional development, as well as providing a sound methodological approach for trauma research.

9.4 Summary

This chapter has demonstrated how an action research methodology can result in participant comfort, interpersonal security, and developmental growth. The analysis of the participants' cognitive modes highlighted how their own lived experiences influenced their subsequent caregiving roles. The forum presented the early research findings of the project, exploring the underlying issues of community care by ascertaining and sharing in the forum participants' day-to-day experiences. This chapter has also touched on the underlying economic and political tensions that surround secondary trauma. Consequently, the chapter has made an original contribution to knowledge about secondary trauma by confirming and/or challenging previous findings, as well as providing a final summary of the research project.

Chapter 9 has revealed the ongoing impact of social stigma upon caregivers and people with mental illness in the community for these forum attendees. It especially valued the collaborative approach of the participants that aimed to address cultural deficiencies in the community treatment of mental illness. Accordingly, the forum emphasised the need for future research in the areas of youth care, grief and support, responsibility, co-dependence, caregiver illness, family access, and therapy. The next chapter will discuss the overall contribution of this thesis to the body of knowledge and its implications for future research. Chapter 10 will also present the researcher’s overall discussion of the findings of this thesis.

CHAPTER TEN

Discussion

10.1 Introduction

This thesis began with a review that set the context for caregiving and trauma by exploring how the care of mental illness has developed over time. Based on this background understanding, Interpersonal Theory was introduced as a mechanism by which secondary trauma could be explored. The original contribution to knowledge of this thesis about secondary trauma includes the following. This research asked the participants to think beyond their caregiving roles and experiences to observe their patterns of interpersonal interaction. This approach is in contrast to much of the current literature which appears to focus predominantly on caregiver burden. Participants also heard themselves talk about their circumstances differently from their ‘expected story’ and began to interpret the experiences of secondary trauma differently, through concepts that are particular to Interpersonal Theory.

Chapter 10 presents the main arguments arising from this research program concerning how secondary trauma, as it affected a small South Australian sample of mental health caregivers, was identified using Interpersonal Theory. The main issues covered in this chapter are: caregiving and development; how secondary trauma relates to community mental health care; implications for future research. Chapter 10 also identifies strategies that may be used to address secondary trauma, and compares the findings of the current research with existing literature. The potential limitations of the research are then outlined, before making a number of recommendations for future studies in the field and offering some concluding comments.

10.2 Caregiving and Development

The findings of this research derived from the four stages of Sullivan's Interpersonal Theory: survey, individual interviews, detailed enquiry interviews, and forum. These stages provided differing information about participants' social organisation and interpersonal security, and the purpose they assigned to caregiving. The three key concepts of Interpersonal Theory ('resolved needs', 'ongoing patterns' and 'coming to terms') were related to caregivers' sense of self-concept and personality. This sense of self-organisation and the caregiving role was then related to the types of vicarious stress ('vicarious trauma', 'compassion fatigue' and 'secondary trauma'), revealing their potential impact and thus relevance to the current research. Subsequently, secondary trauma was defined more broadly and deeply as "multiple constellations of symptoms" (Kisiel et al., 2014, p. 2) involving significant caregiving events over the participants' lifetimes (Finkelhor, Ormrod, & Turner, 2007).

The significant highs and lows participants associated with caregiving and/or traumatic events over time (Sullivan, 1953) also revealed how the cognitive modes of 'being', 'doing', and 'knowing' related to the different ways caregivers functioned, as well as the associated interpersonal outcomes of these modes. These long-term positive outcomes and intellectual growth also highlighted the relationship between participants' integrations in their caregiving situation with particular forms of social behaviour (Porges, 2001; Sullivan, 1954).

In this research, participants' subjective descriptions of their own caregiving role increasingly emphasized the outcomes of their interpersonal situations as prevalent social and societal factors. For example, Robert, Janet, Kelly's early family development emphasized their later entry into the nursing profession, while Louise and Nadia's adult caregiving roles directly linked to survival outcomes from their immediate family environment.

The following section discusses how these caregiving role involvements, interpersonal situations, and behaviours were typically externalised as ongoing activities that incorporated the signs and symbols that increased participants' full experience of life (Sullivan, 1953).

10.2.1 Setting up the Vicarious Learning

The resolution of complementary needs linked to the participants' personality development, by outlining their first internal working models of their self-concept (other and self) and their intra-psychic internal working models (internalised representations) (Humphrey & Benjamin, 1986). Participants' early care experiences were strongly related to the cognitive mode of 'being' and involved their earliest perceptions about their self-concept, relating to their significant interactions with primary caregivers. One of the most significant interpersonal outcomes of infancy involved the events of early attachment. Several participants described in detail how their attachment relationships formed, and the disruption of these attachments at key points in their lives. The participants' interactions with early attachment figures and even 'cold, unhelpful figures' provided specific homeostatic functions that demonstrated how early "stresses and response mechanisms" had preserved specific developmental pathways (Finkel & Holbrook, 2000, p. 241). Roth and Sullivan (2005) confirmed that the evolution of classically conditioned responses to care are quickly learned and expressed through cognitive sentience and in proclivity to the primary caregiver regardless of the quality of care.

10.2.1.1 The Role of Language

The participants' first personifications of care also highlighted the most valued cultural expressions among the family group (Sullivan 1953). Thus, the participants' self-concept was intricately interwoven into the rapid development of spontaneous social behaviour and communication (Porges, 2001). This research also revealed how the participants' caregiving expectations were symbolised through gestures, speech, and actions that produced an anticipated relief from stress, and validated their caregiving function and interpersonal circumstances (Sullivan, 1953). Sullivan (1954) signified the instrumental purpose of transitions in communication (smooth, interrupted, and/or abrupt) to address the anxiety caused by interpersonal development. Kymalainen and Weisman de Mamani confirmed the earlier comments of Wynne, Singer, and Toohey (1976) that parental failure to effectively communicate with their offspring both contributes to early stressful experiences and their subsequent “confusion, distress and dysfunctional communication patterns” (2008, p. 86).

The participants’ early communication patterns also demonstrated how their self-concept was interrelated with the interpersonal outcomes in their lives. They highlighted what Humphrey and Benjamin (1986, p. 984) described as “repeated interpersonal experiences in intense relationships” involving *double-bind* situations. Thus some of the participants explained how their inability to bond with their primary caregivers was exacerbated by their feelings of invalidation, punishment, and their inability to escape or “meta-communicate” about their situation (Humphrey & Benjamin, 1986, p. 984). Other participants described how they experienced long term problems in “perceiving and maintaining a shared focus of attention” with their primary caregivers. These situations were indicative of *communication deviance* involving “pseudo-mutual” relations and unstructured, indefinite, vague and loose, and/or fragmented, poorly integrated communications (lacking in closure) (Humphrey & Benjamin, 1986, p. 986) that participants also described over the course of their later lives.

10.2.1.2 The Early Caregiving Role

The participants explained that, during childhood, they were able to differentiate between the isophilic love (of one's own kind) involving immediate family and friends, and the dyadic relationships with secondary groups and communities (Hartup, 2009; Sullivan, 1954). While ongoing social isolation was evident in the families who had immigrated to Australia, the participants highlighted the positive influence of family for their cultural identity and the sense of belonging provided by their immediate communities. The participants also described how their childhood experiences and family interactions conferred important expectations, or social markers, that provided primary role formations about caregiving (Hogan, 1982; Sullivan, 1953). Most of the participants described their childhood need to preserve family identity and to uphold and conform to expectations about caregiving roles, interpersonal security, and belonging throughout their early upbringing.

In particular, participants echoed Kate, Grover, Kulhara, and Nehra's (2013, p. 135) description of the primary caregiver's "personality, quality family relationships and degree of social support", that enriched their early understandings about themselves. The important role of the family for mediating stress also raised the participants' estimations of their own "capacity to encounter and survive deprivations" (Sieber, 1974, p. 573). Sieber (1974) argued that the support of the primary group also helps individuals to survive harm and death by increasing their buffers of self-esteem and conceptions of potency in future family relationships, adolescent groups, and sexual relationships.

The long term implications of these relationships were also evident in the results of this study. For example, Shoda, Mischel, and Peake (1990) described the importance of delayed gratification for predicting later competence and coping skills. The participants' development of delayed gratification during childhood also reflected their individual values and expectations about the less desirable immediate outcomes, and the more desirable but delayed long-term outcomes, based on the "specific contingencies" of choice in their interpersonal situations (Shoda et al., 1990, p. 985). These outcomes were made increasingly apparent as participants' interactions with their primary caregivers related their cognitive mode of 'being' to their self-concept, to provide a personal resource that later equipped participants to cope with their caregiving role. These outcomes also exemplified how participants' later behaviour was influenced by their choice of cognitive mode. As the participants increasingly developed emotional reciprocity through their interactions with their primary caregivers, they began to understand how they could possibly resolve their interpersonal difficulties. This process was highlighted by Roth and Sullivan (2005) as offering important indicators for understanding how developmental learning relates to the processing of emotional memory. Markus and Nurius (1986) confirmed that early child-parent interactions enable the self to regulate behaviour by setting clear goals and expectations around care. Savage and Bailey (2004) outlined how these quality relationships with immediate family may contribute to overall interpersonal satisfaction and lower levels of psychiatric symptoms and burden.

10.2.1.3 Implications for Vicarious Trauma

Porges (2001) confirmed that stress imposes clear psychological limits on the early range of social behaviour. These emotional states involving the stressful events in participants' lives were frequently related to their earliest personifications of care (Sullivan, 1956). For example, the participants' unresolved needs were often associated with expressions of anger and frustration, from not being allowed to adequately express their early care needs. Epel, Daubenmier, Moskowitz, Folkman and Blackburn (2009) found that subsequent negative emotional states (e.g., anger, guilt, and anxiety) incur ongoing reappraisal and coping. Savage and Bailey (2004) also indicated that maintaining caregiving roles in very close or enmeshed families can result in feelings of resentment, depressive symptoms and anger, as described by the participants in this study. These feelings of resentment and anger also exemplified how participants' unresolved needs were linked to the captive caregiver role described in the literature (Figley 1999; Porges, 2001).

Accordingly, Pearlin et al. (1990) argued that the problems of caregiver stress result from the diminishing of the self-concept or from barriers to its development. Van der Hart, Nijenhuis, Steele, and Brown (2004) explained that the cognitive action systems that promote ‘doing’ may involve the emergence of more than one caregiver role, due to the interrupted development of normal problem-solving pathways. They added that defensive forms of adaptation allow *ongoing patterns* to emerge in the personality, because they avoid traumatic recollections until they are reactivated in “a wide range of social and personal contexts” (Van der Hart et al., 2004, p. 911). The findings clearly confirmed that the participants had integrated their childhood traumas by more broadly ‘generalising’ their avoidance behaviours and/or intrusive and traumatic recollections over time (Van der Hart et al., 2004). The participants also linked their ongoing and recurrent traumas to their prior experiences of emotional and/or physical neglect and stress. Tyrka et al. (2010) confirmed how traumatic experiences may increase the risk of secondary trauma due to the potential long-term harm they cause to mental and physical health.

10.2.2 Ongoing Patterns of Caregiving

Sullivan’s (1954, p. 123) framework clearly confirmed how the interpersonal outcomes associated with participants’ resolved needs and reciprocal patterns of activity tended “towards future integration or reoccurrence” based on the improvement of self-esteem in the caregiving relationship. Carver, Reynolds, and Scheier (1994) described how near and distant perceptions of self are connected to the future self and provide the basis for ongoing regulation, motivation, and coping styles. For example, the participants’ ability to transform their unique self into ‘doing’ actions was often motivated by their notions about ‘the future self’ (Dörnyei, 2009). Thus, the ‘doing’ mode often demonstrated how the participants were able to integrate the unique aspects of their self with the more variable cognitive structures of role performance guided by self-image and reference groups (Hogan, 1982).

Wachtel (1972) confirmed the cultural approach of Sullivan by describing how old situations are recreated perceptually (in terms of past experiences), and by the perceptions that produce or provoke a particular expected behaviour. Similarly, participants' cultural adaptation to caregiving was exemplified by the values and support from their families. The participants' early development of caregiving roles also safeguarded them from anxiety and formed the psychobiological basis for their later coping patterns, by focusing their self-system away from the other issues in their lives that produced stress (Porges, 2001). For example, during their juvenile development many participants played an important role in their families by caregiving for their siblings. This was especially evident as the participants' early caregiving roles demonstrated how they began to think about what they could do "to effect a satisfactory resolution" in their family situation by providing ongoing interpersonal security for their siblings (Sullivan, 1954, p. 125). Many of the participants also learned how to cooperate with their primary caregivers to achieve their approval. The current findings also suggested that a lack of correction and competition in peer relationships during the juvenile stage may have impacted on the participants' later personality development due to their failure to compete, and subsequent subjugation to the caregiving role (Sullivan, 1956).

The participants' pre-adolescent development demonstrated their ability to experience intimacy and love in their peer relationships (outside of the family group) and, as such, represented their first step to complete social integration (Sullivan, 1956). As so few intimate peer companions were acknowledged in the results, participants could have been more susceptible to loneliness over the course of their later lives (Sullivan, 1956). Yet, interpersonal satisfaction resulting from the participants' involvement in two (and four) member peer groups was associated with their positive outlook, shaping group norms and offering vital opinion leadership for the future (Sullivan, 1956). The participants' responses and adaptation to their social situation was reinforced by being able to turn to their friends for advice. The participants' also sought significant role models during their adolescence to enable them to develop and evaluate their knowledge about their life experiences (Pardess, 2005). Participants' increasing empathy and tolerance towards the events and situations that surrounded them, included their objective evaluations about their family situation.

Pardess (2005) also described how role models allow the evaluation of overall needs and the assessment of available resources during times of crisis. This was made evident as participants' caregiving roles shifted from observer to crisis intervener (Pardess, 2005) and as the participants actively identified with other peers they perceived to be in need of their care. Participants' accounts of their late-adolescent development highlighted the problem-solving processes they used that actively mediated between stress and adaptation (Folkman, 1984). The participants' increasing problem-solving skills highlighted their ability to regulate their coping efforts, through two main types of control: generalized individual beliefs about outcomes (the threat to well-being); and the appraisal of control over specific situations (particularly in challenging environments) (Folkman, 1984).

10.2.3 Implications for Compassion Fatigue

The results of this study highlighted how the participants were able to adjust their psychological state to maintain positive social behaviours into their adult caregiving roles (Porges, 2001). These behaviours were dependent on the ongoing demands for coping (based on their adaptive capacity and success) and the cognitive strategies that mediated the challenges associated with caregiving and knowing how to provide ongoing support (Epel et al., 2009; Hunt, 2003). Parkes (1994, pp. 121-122) confirmed that consistent signs of coping and personality to moderate stress and life's challenges come into play when, "all of the developmental (stress-related) capabilities … are reckoned according to their adaptive capacity (mediation of challenge) and success".

The participants’ self-judgements about the success of their caregiving interactions also highlighted their own preparation and available resources to fulfil their adult caregiving roles. Consequently, ongoing patterns in the formation of their roles highlighted the relationship between compassion, altruistic behaviour, and motivation (Radey & Figley, 2007). These ongoing caregiving activities also contrasted the changes in mode, from the cognitive aspects of vicarious trauma to the emotional and social symptoms of compassion fatigue. Wachtel (1972, p. 779) described the relationship between cognitive strategies and coping with life demands as two realms in the “flux which we designate as personality”. Piedmont (1999) confirmed that while personality may be set after age 30, humans’ unique ability to rise above their experiences allows them to see the larger patterns in life. The degree to which participants exercised their knowledge of this ability illustrated how stress may transform caregiving from an “ordinary and essential exchange between two people in close relationships to unequally distributed concerns about burden” (Pearlin et al., 1990, p. 583).

10.2.4 Knowing and Secondary Trauma

Call, Finch, Huck, and Kane (1999, p. 689) described how family groups involve a “long history of reciprocal exchanges” that represent how ‘power and resource’ benefits shift over time. Pearlin et al. (1990, p. 589) argued that the primary stress of caregiving upon the self-concept and the secondary strain of roles and activities affects the way that caregivers organize their lives and judge themselves. Likewise, the results revealed that as participants took on the larger caregiving responsibilities from their former family relationships, they learned a sense of reciprocity and resource benefits related to their caregiving roles and to their construction of social meaning (Clarke, 2008). Consequently, Call et al. (1999, p. 689) suggested that perceptions about caregiver, “burden may also be conceptualized as an evaluative component of the exchange relationship”. Besides evaluating the caregiving needs of their new situation, the participants also highlighted how they needed to ‘know’ about how they could achieve a satisfactory outcome.

Concerning secondary trauma, many participants echoed what Pearlin et al. (1990) described as the social order and status of caregivers, who feel cut off from the larger society yet still remain very influenced by its organization. Accordingly, the participants described how they maintained their adult caregiving role by remaining flexible themselves, thereby ensuring that they had timely responses to varying daily stresses (Parkes, 1994). Participants also echoed the “daily dependencies” of caregiving that symbolised the “changes that have overtaken the life and the self of the caregiver” described by Pearlin et al. (1990, p. 587). These changes emphasised what Pearlin et al. (1990, p. 589) described as an isophilic loss of self, based on “the extent that the identity and life of the caregiver has been closely bound to the caree” and the ongoing dependency of their dyadic relationships, based on ensuring the satisfaction of another’s basic needs. In terms of the participants’ overall resistance to care, these changes also indicated a “profound restructuring” of their caregiving roles and the development of a separate role identity outside of the (once familiar) caring relationship (Pearlin et al., 1990). As interpretations of the patterns tended to dictate the changes, the participants’ also described paying particular attention to the personalities of the people they cared for, synonymous with Corrigan’s (2004) description of caregivers’ extra monitoring behaviours.

Above all, the participants described the significant challenges they associated with communicating openly about their caregiving experiences. This was especially apparent where increased stigmatisation also represented society’s collective social values about mental illness. The participants described the effect of stigmatisation upon their personal lives when they were in the presence of the people they cared for as humiliating, shameful and uncomfortable. Van der Hart et al. (2004) explained how caregivers’ evaluations of stigma encompass previously neutral objects (such as the person in care), and the emotional learning associated with shameful or traumatic events. The participants also indicated that communicating about their caregiving role assisted them to integrate their painful experiences, as ‘a problem shared is a problem halved’. Alternatively, denying or prohibiting conversations about mental illness and the most demanding role in their lives overwhelmingly contributed to the participants’ anxiety and affected their overall health (Adams, 2008; Van der Hart et al., 2004).

The participants also described their deliberate efforts to include the person they cared for in their ongoing communications with others, as demonstrated by including the person they cared for in social situations. Accordingly, Van der Hart et al. (2004) described how disassociating from the shameful feelings of stigma includes risking the disintegration of the self-system as the motivational system. Thus, most of the participants coped with the social and emotional symptoms of secondary trauma along a continuum of anxiety, first developed from the sympathy of others and then, more objectively, the empathy associated with an improved understanding about mental illness. The continuum of emotion and stress was described by Porges (2001, p.131) as incorporating ‘with feelings’ historically associated with the sympathetic nervous system, in contrast with the parasympathetic nervous system "that guards against feelings” (such as for the caree when they are re-traumatised). Van der Hart et al. (2004) highlighted the likelihood that all or most parts of the personality would also engage in relational defences by focusing on a very limited range of cues, such as fixing attention on threat, rest, and caretaker needs, and performing specific actions, such as defence, recuperation, and attachment behaviours. The results thus reflected Van der Hart et al.’s (2004) findings about protecting the self-system by inhibiting empathy as the participants selectively focused on, and attended to, a limited range of actions such as caregiving and advocacy work.

10.3 How Secondary Trauma Relates to Community Mental Health Care

This section explores the mental health strategies identified in the literature and by the participants of this study to address experiences of secondary trauma. This exploration takes into account the limited opportunities for role enhancement that exist in the current MHS culture. Wiles (2003) stated that caregiving during the early stages of mental illness highlights the benefit of knowing which preventative, early intervention, and treatment actions to pursue. Reynolds and Seeger (2005, p. 49) confirmed that “traditional notions of health promotion and risk communication” during the pre-crisis stage of trauma “educate the public about potential threats” that help caregivers prepare for future risk. Wiles (2003) suggested that problems with access to information about mental illness and treatment present a major obstacle for mental health care and for family caregivers and highlights the ongoing interdependencies that occur between the MHS and family caregivers.

10.3.1 The Gaps in Mental Health Literacy

Mead and Hilton (2003) highlighted society’s need to overcome a lack of mental health literacy, both from the nature of the experience of the immediate crisis as well as from the interpersonal perspective. The participants often echoed Mead and Hilton’s description of a mental health service culture that did not actually help, but rather confused caregivers about their own interpersonal perspective and the meanings they derive from their own experiences. Consequently, Pardess (2005) emphasized the importance of increasing awareness about the grief and loss associated with the care of mental illness as caregivers first enter their roles, to avoid over-involvement (as a stage in the process). The participants repeatedly described falling through the cracks of MHS support and the subsequent strategies they employed to stay at arm’s length from the ongoing demands of their caregiving situation. Gaps in mental health literacy were highlighted by Pardess (2005) who explained how caregivers often experience a sense of ambivalence towards accessing and receiving help due to their immediate concerns about its long-term meaning for their own situations. Pardess (2005) emphasized the role of patience to uncover the real needs of the caregiving situation and to obtain necessary information. Pardess (2005, p. 615) also added that patience also increases prioritisation and realistic judgments about care, rather than acting through automatic responses simply by *doing* ‘something’. This helped caregivers by preventing “unrealistic expectations and rescue fantasies that result in the sense of failure, guilt, frustration, or helplessness”. These processes were also described by the participants in this study.

Watts and Hodgson (2015) described how caregivers’ unmet needs exemplified the inadequacy of MHS to provide adequate support for caregivers. They added that the ongoing lack of caregiver involvement in treatment and collaborative approaches to assessment were often detrimental for caregivers’ physical and mental well-being. Lawn et al. (2013) highlighted how for more than twenty years, national mental health policies and principles have failed to close the gap between MHS and mental health caregivers’ needs. This yawning divide identified the worldwide need for greater collaboration to stem the impact of marginalisation upon caregivers, as Lawn et al. (2013, p. 201) stated, continue to be “ignored, rejected or seriously undervalued by services, sometimes with detrimental consequences for the person’s care, and carer and staff safety”. The findings from a majority of the participants thus confirmed Biegel, Song, and Milligan’s (1995) comparative analysis of family caregivers and mental health professionals that cited the need for partnerships to address caregivers’ unmet needs. The two areas most commonly identified involved the need for improved communication and to actively involve caregivers in the treatment process (Biegal et al., 1995). The participants frequently reported feeling actively persecuted and blamed by MHS as the source of the mental illness. Falloon (2003, p. 20) described the ongoing legacy of “communication defects” involving family caregivers.

> *... for many years, the family system was thought to be the root of all evil and families were accused of inadvertently abusing their offspring through a variety of subtle communication strategies ... (Falloon, 2003, p. 20).*

However, the participants continued to generate tangible mental health outcomes by playing a very important role in the lives of the people they cared for with mental illness, even though they confirmed what Dixon et al. (2004, p. 207) previously described as "feeling overwhelmed, frustrated, alone, thirsty for practical knowledge, and abandoned by people from whom they usually seek support". This situation increased participants' susceptibility to secondary trauma in the areas that Figley (1999) had previously described, including the extra demands upon caregivers' empathy, their increasing concerns about their prior experiences and recurring traumas, and the vulnerability of the people they care for.

Wiles (2003, p. 203) described the extra efforts caregivers made to capture the "gaze" of MHS and support services, also reflected in the results of this study. Too often, the participants' experiences of burden appeared to relate to their ongoing tensions and the belated resolution they associated with MHS care systems. The participants described significant differences in their expectations about the role that the MHS should play, and this was made especially apparent by their extra efforts to establish and negotiate a different legitimacy for themselves as informal caregivers, as previously described by Dixon et al. (2004). The participants also exemplified Wiles' (2003) description of positive perceptions about the system that were held only by mental health staff and not caregivers, leaving caregivers in limbo about MHS outcomes. This study also confirmed the writings of Savage and Bailey (2004, p. 203) who argued that caregivers' understandings of, "their own context and the needs of the person for whom they care" are often at odds with the "fragmented, arbitrary and confusing" nature of mental health legislation and public service provision. As such, the participants in this study also echoed Mead and Hilton's (2003) depiction of psychiatric interventions and treatment that conflict with the prevailing views of recovery and wellness in crisis care systems. Wiles (2003, p. 203) described how caregivers felt “disheartened” by their experiences and their ongoing contact with MHS and treatment. This feeling was reflected in the results of this study as the participants described how they needed to become strong and determined to fight the system.

Wiles (2003) also described caregivers’ overall dissatisfaction with their access to relevant information, mental illness treatment, MHS interactions, and other resources. This finding was confirmed by the participants who had obtained help for themselves and their families in a range of alternative ways. In addition to the extra practical and financial burdens of the caregiving role, the participants also expressed their regret about the time they spent caregiving (instead of bringing up other siblings or offspring) as well as their growing concern for the adult offspring with mental illness who they will leave behind. This study affirmed Piedmont’s (1999) description of the search for constructive meaning and closure, especially towards the end of the caregiving life. Savage and Bailey (2004) outlined that MHS need to take into account the length of time and the stage of the caregiving life journey when offering support. In addition, Moen, Robison, and Dempster-McClain (1995) confirmed the need for the MHS to focus on the trajectory of well-being over the life course, in light of shifting roles and situations and the unique social/cultural contexts that confront mental health and family caregivers.

10.3.2 The Implications of Role Strain

The relationship between ‘coming to terms’ and cumulative role strain described by the participants also highlighted the interplay between role structure, social agency, and coping strategies, as also outlined by Pavalko and Woodbury (2000). Pearlin et al. (1990) described secondary intrapsychic strains, such as a lack of caregiving (history), family, and available networks, as an antecedent process that diminished positive elements of self and increased susceptibility to stress. This process was described by participants as a gaping hole in care, involving aspects of their ‘missing self’. Pearlin et al. (1990, p. 589) also described the intrapsychic strains as “a fragmented and blurred persona that excluded other activities and roles which once provided validation”. The participants also mentioned that their ever-increasing exposure to the effects of cumulative anxiety, stress, and depression diminished their former involvement in familiar activities, their social lives, and their ongoing contact with friends and relatives. Call et al. (1999) and Adams (2008) suggested that these processes of deterioration often resist and contest caregivers’ prior ‘biology, psychology, and culture’. The increased strain placed upon the participants’ support networks also highlighted the extra intrapsychic efforts required to manage interpersonal loss.

The caregiving role highlighted other issues that required participants’ daily management and exemplified by their new roles as care managers (Savage & Bailey, 2004). The findings also confirmed those of Moen et al. (1995, p.270) who argued that making assumptions about caregiving, that other roles and well-being create, is only “a very limited snapshot picture of a far more complicated relationship”. The role options for the participants were similar to those reflected in Pavalko and Woodbury’s (2000) study of social roles and processes which indicated differences in levels of anxiety between spouse and worker roles. They suggested that secondary interactions, such as working as a volunteer (church or club member or friend), offer more opportunities for role management, while primary relations, such as spouse, parent, worker, or family caregiver are more constrained. They thus questioned how caregiving dynamics, such as role strain and role enhancement, may occur when entering a caregiving role (compared to other roles), differences in levels of involvement, and the health impacts (at earlier or later stages over a person’s life.

The participants also developed strategies to increase their own involvement in mental health treatment. The harm of confining the problems of mental health care to family caregivers was described by most of the participants, as were their increased efforts to improve public perceptions about mental illness in the community. The participants also confirmed how they expected that they would "act differently if the situation were different", but that they did not allow it to be different (Wachtel, 1972, p.784). The ability to recreate (or control) the same situation repeatedly without change (Wachtel, 1972) highlighted how participants were deprived of the knowledge that would allow them to transcend their situation and change it.

Subsequently, most of the participants involved in this study mentioned the changes that had occurred in their own behaviour since becoming a mental health caregiver, and the vigilance that had resulted from their long-term caregiving role. Savage and Bailey (2004) described the feelings of uncertainty for caregivers who experience a lack of control and who may feel manipulated by the persons in their care. Pearlin et al. (1990, p.587) stated that caregivers' vigilance serves to maintain "damage control" to ensure that no future harm results. However, harm was a phenomenon described by many participants, as a sign of deeper mental illness for themselves. The participants also described situations in which there was a possibility of control, to just stand their ground, and other situations which provided no possibility for control at all, in which they cognitively accepted their situation much more readily (or regulated their emotional responses to it) as another integration of burden (Pavalko & Woodbury, 2000; Wachtel, 1972). Alternatively, navigating the unpredictability of mental illness and the behaviours it presents, involved the participants' ability to prepare by knowing how to come to terms with the changed situation, as exemplified by the unanticipated changes in their caregiving situation, involving medication and diagnosis.

10.3.3 The Different Contexts of Threat and Challenge

Due to the differing implications associated with threats and challenges in mental health caregivers' lives and their engagement with the MHS, crisis intervention strategies that address how emotional memories are stored are of great importance in determining future coping behaviours for caregivers. This finding is important for addressing secondary trauma, as participants' emotional memories, self-concept, and personality are closely linked to their caregiving role-identity and therefore their subsequent ability to integrate societal expectations about care, mental illness, and trauma.

Parkes (1994) pointed out that coping and cognitive appraisal may determine different cognitive states, as well as offering outcomes for stressful experiences. Parkes (1994) added that the interplay between appraisal, coping efforts, and emotional states also contributes to physiological regulation by forming the basis of coping and perceptions of safety in the self-system. Hunt (2003) confirmed that the assessment of the stress environment (as positive, negative, or neutral) involves both affective (emotional) and subjective (cognitive) appraisals of the best coping resources to reflect the ongoing role changes occurring in caregivers' lives. The participants often highlighted that the challenge of coming to terms with mental health care often mediated their emotional reactions to crisis and, most likely, their physiological reactivity (Epel et al., 2009). These reactions illustrated a coping continuum that placed "survival on one end and positive social-emotional experiences on the other" (Porges, 2001, p. 124). This view is confirmed by Sullivan (1954) who described appraisal as a manifestation of the self-system that protects individuals from anxiety.

The cognitive modes of being (dispositional) and doing (situational) (Parkes, 1994) that have been explored in this research have demonstrated that the participants' successive appraisal and reappraisal processes were associated with their emotional states and were increasingly influenced by personal and environmental factors (Lazarus & Folkman, 1984). The findings also highlight how threat appraisals "drive negative emotions" (such as fear and anxiety) and the subsequent evaluations and negative emotional responses that enhance stress cognition pathways (Epel et al., 2009, p. 2; Porges, 2001) which are also suggestive of the symptoms of vicarious trauma. Epel et al. (2009) added that the (perceived or imagined) ongoing threat of daily exposure to threatening or challenging events activates both negative (anxiety-related) and positive emotions (energy and elation). Alternatively, Maddi et al. (2006) associated challenges with personality hardiness. This hardiness was most apparent among those participants who expressed feelings of not being entitled to comfort and security (perhaps through neglect), and who pursued their opportunities to grow and learn from both their positive and negative experiences.

The social and emotional factors of compassion fatigue and secondary trauma involved the two different contexts of threat and challenge, as the participants' immediate mental health crises and their ongoing interactions with the MHS involved participants' "constantly changing (moment to moment) cognitive and behavioural efforts to manage the demands of a stressful situation" (Epel et al., 2009, p. 3). Wachtel (1972) highlighted the relationship between problem-solving concepts, adaptation, and cognitive control, exemplified in this research by the situations in which the participants knew when their functioning was uncharacteristic**,** and which demonstrated their readiness to shift cognitive mode (alongside understanding what the consequences of either staying in the same, or changing, mode may be). Subsequently, the participants' choice of coping strategy and their ability to control their stressful and traumatic experiences occurred in response to the perceived demands of adaptation and through the development of "a perceptual-cognitive strategy" that could provide them with a new view of their world (Wachtel, 1972, p. 782).

These survival strategies (Valent, 2002) distinguished the participants' maladaptive coping techniques (emotional responses) from their active behavioural coping (problem-solving) strategies (Carver et al., 1994). Hooker, Monahan, Shifren, and Hutchinson (1992) distinguished between psychological stress (individual perceptions about coping ability) and perceived stress (the appraisal of stressful situations). These distinctions also connected the self-concept and motivation to regulation strategies such as optimism and/or neuroticism, as outlined by Carver et al. (1994). Hooker et al. (1992) confirmed that neuroticism and/or optimism indirectly affect perceived stress levels, by moderating the relationship between appraisal, coping, and emotion, with links to (secondary) depression, locus of control, and psychological well-being. Subsequently, Hooker et al. (1992, p. 368) described personality "as a construct worthy of further study" because of its ability to predict perceived stress.

10.4 Implications for Future Research

The implications of the findings of this thesis for further research and practice with mental health family carers centres on the potential for a new understanding and improved communication about secondary trauma to arise by using approaches informed by Interpersonal Theory. The findings show that this approach appeared to empower caregivers about their own choices and reasons for fulfilling their roles. The findings of this study also highlight how secondary trauma and PTSD experiences are treated (and perceived) in relation to mental health caregivers, with a range of implications for changing societal expectations about caregiving, for changing mental health practice by those who work with mental health family caregivers, and for research with these populations.

The participants pointed out that media representations of mental illness often increased their feelings of guilt and fear and consequently contributed to their ongoing disempowerment, helplessness, and social isolation. Therefore, the findings of this study demonstrate that society itself plays a role in influencing how mental health caregivers are rewarded, or not, for the important caregiving roles that they perform. Therefore, more research is needed that looks at the caregiving role as part of the overall process of socialisation with the broader community and society (Turner, 1988). The participants also suggested that the media can play a greater role in challenging the internal rules of secondary groups and powerful institutions that commonly shape public perceptions about people with mental illness (Clarke, 2008). This is therefore another area for further research that might look particularly at the media as an ‘institution’ with a range of influences on society and that defines the culture of perceptions about trauma and care through the lens of burden.

10.4.1 Mutual Accommodation, Exploitation and Structural Disassociation

Turner (1988) outlined the problems of secondary trauma by explaining that the function of social institutions (to meet the collective needs of a society) occurs in addition to interpersonal experience and structure. He added that these approaches “assume patterns of integration between society and personality and specify relationships between the two” based on the dominant values held by a society, basic personality structure, and the generalisation of individual interpersonal experiences (Turner, 1988, p. 1). For example, Lawn et al. (2013) described how the improved mental and physical heath of caregivers may simply be achieved by paying attention to caregivers’ needs, having access to routine contact, trusting relationships, realistic education and targeted support. However, most of the participants argued that a knowledge mismatch has occurred between their identified needs and the interpersonal skills and processes required to fulfil those needs. The increased potential for the exploitation of community mental health caregivers highlights a basic source of disturbance in the ‘role-set’ of caregivers as individuals in which MHS, as role partners, treat the status of informal caregivers differently because of their particular location in the overall social structure (Merton 1957; Sieber, 1974). These structural differences further highlight the differing values and moral expectations of these two groups, along the lines of Sieber's (1974, p. 569) point that "the greater the number of roles (not inherently offensive), the greater the number of privileges enjoyed by an individual". Therefore, because mental health caregivers are grouped in the one role (caregiving), they are excluded from a range of privileges enjoyed by others in the social structure.

These fundamental differences also demonstrate the power and resource benefits of MHS during a crisis to determine the available resources of caregivers and to shape perceptions and obligations about caregiving that frequently exceed MHS "allotment of rights". Therefore, the exploitative nature of inequitable relationships may take for granted the "tendency for rights to be adjusted to" (Sieber, 1974, p. 569). Thus, the participants often described how their responses to MHS were motivated by their increased frustration and anxiety about their situation. Turner (1988, p. 1) explained that mutual accommodation incorporates and generalises "interpersonal experiences (as associated emotional states) rather than facilitate their functional integration into society". This was especially reflected by the participants' comments about the fact that there has to be 'give' somewhere and as a rule, it is caregivers who give. The implication of this research for MHS, caregivers and researchers, highlights the potential of Interpersonal Theory to explain how emotional reciprocity and interpersonal integration occurs in caregiving situations. The application of Interpersonal Theory may also help to transform the burden mindset that dominates mental health caregiving by moving attention away from the source of their anxiety.

A significant area for further research is the exploration of PTSD and mental health caregivers. Porges (2001) argued that structural disassociation as a cultural phenomenon becomes evident when limitations in physiological regulation become difficulties in living. As a demonstration of this idea, the vital role played by the participants in facilitating deinstitutionalisation necessitated additional structural changes in their personalities (or functions) that significantly affected their ability to maintain emotional regulation and social behaviours (Porges, 2001). Van der Hart et al. (2004) described how caregivers' immediate association with interpersonal stressors (such as mental illness and its treatment) paralleled the PTSD symptomology of secondary trauma. The participants in the current study often described how they felt separate from the real world and how they experienced repeated traumatic events in their caring role, suggesting that they experienced levels of dissociation that are akin to PTSD symptomology and secondary trauma. Van der Hart et al. (2004, p. 910) confirmed how ongoing exposure to interpersonal stressors involving more than one traumatic event may represent "more complex levels of structural dissociation". Clearly, this is an area that requires further research.

10.4.2 The Role of Gender in Systems of Inequality

Thoits (2003, p. 180) stated that "generally, the more role-identities individuals hold, the more purpose, meaning, behavioural guidance, and approving social feedback they have available, and thus, the better should be their mental health or general well-being". Consequently, Hothschild (1995, p. 332) suggested that vulnerable and at-risk populations (such as people who are poor, disabled, mentally ill, elderly, and women) seek new "cultural grounds" to describe their growing crisis and cultural frameworks through which "care" is perceived. The issues of gender inequality highlight the increased need for social change in relation to MHS' and society's ongoing expectations about the community treatment of mental illness. This research has emphasised how the work of caregiving is still being perceived through the historical lens of the Enlightenment and female circumscription.

In particular, the female participants involved in this study highlighted the role of gender in the reduced privileges of women as caregivers (Hothschild, 1995). Nelson and Wright (1996,

p. 461) argued that “gender role expectations … [are] transmitted across generational lines”. This was exemplified by the participants’ observations of their own mothers, their ongoing self-sufficiency and independence, and their overall sense of responsibility for others. Nelson and Wright (1996, p. 461) also confirmed how many female caregivers did “not expect their needs to be met by others”. The "care deficit" (Hothschild, 1995, p. 332) created by deinstitutionalisation was also evident in the participants’ private lives, their status as working mothers (married or single), and in the overall lack of personal support they had experienced. Waerness (1987, p. 208) explained how "women ... are faced both with the task of caring and … achieving … the greater measure of economic independence". This was confirmed by the female participants who described how men put in place the need for women to accept the caregiving role.

Ribeiro, Paúl, and Nogueira (2007) also highlighted the instrumental and rational approach to caregiving by males. The male participants in this study described their emotions as husbands or partners, and their work as caregivers, while avoiding expressions about the emotional aspects of their caregiving roles, by keeping things to themselves. Gollins (2001) and Ribeiro et al. (2007, p. 303) framed males’ gendered understandings of themselves and their personal notions of identity as “a worker, a husband, a loving husband; Mr. Anyone, but never primarily as carers”. Beutler, Nussbaum, and Meredith (1988) also highlighted the impact of stress upon the personality and the higher risk of substance abuse and stress-related physical complaints for males exposed to high-stress situations. Regarding male role integration and behaviours, Beutler et al. (1988) observed personality changes in male police officers’ roles which were detrimental to their performance and well-being in general, and which are commonly referred to in the literature as the *John Wayne Syndrome.* These nuanced gender differences in the mental health caregiver experience warrant further research.

10.4.3 Conquering the Secondary Trauma Divide as Mental Health Activists

The findings of this thesis also suggest that further investigation of the notion of mental health activism by family caregivers should be explored from a developmental perspective and from a trauma perspective. Thoits (2003, p. 179) explained how "personality and well-being resources" involve the capacity of society to shape the self. She added that caregivers' personal resources not only "facilitate self-selection into roles but influence the decision-making of gatekeepers, [as] a social selection effect" (Thoits, 2003, p. 182). The participants confirmed that their former identities contained the "pre-existing physical and psychological characteristics" that informed their subsequent acquisition of a new social identity (Thoits, 2003, p. 181), often described by the participants as a form of life pre-destination. The participants confirmed their self-conception and the selection of their new roles as mental health activists to bring meanings that were relevant to themselves "back in line with identity standards" (Thoits, 2003, p. 191). The participants often mentioned that their new social life allowed them to take control of their situation, achieve their goals, and to take risks, such as going to the minister or to the press with their caregiving concerns.

Thoits (2003, p. 181) stated that "when the social environment feeds back a discrepancy between how the self ought to act (the identity standard) and how the self actually behaves in the situation, the person will alter the current situation, or seek and create a new situation" to deal with the new information or new problem. The participants who achieved a new understanding of their situation through their activist roles exemplified Hunt's (2003, p. 29) findings in relation to Australian caregivers whose 'prior traumatic experiences' also "related to positive effects" and (differentially) to burden, as burdensome or stressful activities were increasingly associated with interpersonal satisfaction or growth. This increased satisfaction deriving from their improved understanding of mental illness confirmed the participants' capacity for autonomous action (Hogan, 1982), exemplified by the variability that occurred in their caregiving situations over their life journey.

The participants' belief in their new abilities as mental health advocates highlighted their commitment to the struggle and their desire to influence community health outcomes positively (Maddi et al., 2006) through their newly discovered freedom to tell it like it is. The participants' development of a new identity also transformed their feelings of powerlessness and helplessness into opportunities. Mead and Hilton (2003) and Jordan (1992) confirmed the increased potential for positive outcomes to arise from crisis, to advocate for a just cause, and to address the socio-political consequences of inequality, as antidotes to trauma. Participants' described how their new roles as mental health activists also involved forming new social rituals that symbolised their shared caregiving experiences and created meaningful patterns of interaction in the community. The participants' obvious enjoyment of the company of other caregivers and their involvement in support groups increased their integration into society through their mutual feelings of empathy and fulfilment, as well as providing the vital social connections that moderated the signs of deterioration (Adams, 2008).

The participants' abilities to identify with other caregivers' needs also reduced their social isolation and facilitated foresight about the common knowledge that occurred *outside* of their own caregiving relationships. Subsequently, the participants were helped by observing themselves as "being in crisis" and by thinking about how others would describe their crisis (Mead & Hilton, 2003, p. 88), by seeing how other caregivers coped. Pardess (2005) argued that role models of the lived experience are especially important for providing guidance in the early stages of a mental health crisis, because they enable the processing of information about ongoing access to mental health resources and care.

The participants also described spirituality as a new direction for their recovery. Piedmont (1999) highlighted the important role spirituality played in the self-system and its potential to enhance coping resources or psychological outcomes by restructuring, reorganising, and integrating the personality. Allport (1950, p. 142) added that the new self-awareness and well-being based on the long-term direction of one's psychological disposition confers "marked integration upon personality" and engenders "meaning and peace in the face of the tragedy and confusion". Spirituality also has a "hard-wired evolutionary significance" to subordinate individual needs to the larger group by providing a broader and more holistic reality of heart and mind that creates "joy, security and coherence despite the many (internal and external) conflicting and competing forces" (Piedmont, 1999, p. 1009).

Recognising spirituality as a separate domain of personality also offers passion and depth (Piedmont, 1999) to secondary trauma experiences, in the faith and hope that the situation can change. The ability to integrate 'the infinite' also redefines the environment, goals, rituals, and meanings of trauma for the community (Piedmont, 1999). Likewise, Epel et al. (2009) and Piedmont (1999) identified the benefits of transcendence to repair the damage caused by stress by independently altering stress pathways, understanding the impacts of change, avoiding automatic responses, reducing reactivity, increasing empathy, regulating and adapting to threat appraisals, and maintaining meaning and connection, as supported in the results of this study by the mindfulness education provided by carer support programs.

10.4.4 The Cost of Caring

This research also provided an important indication of the knowledge mismatches that occurred between the participants' subjective evaluations (of their ability to cope) and their objective evaluations (assessment of their resources) (Carlile, 2004). Knowing how to come to terms with the demands of caregiving highlighted the importance of participants' cognitive appraisals of caregiving outcomes, rather than objective indicators, such as ongoing access to formal care (Hunt, 2003, p.30), particularly evident as the participants readjusted their caregiving role to meet the needs of the whole family. The participants' ongoing appraisal of their ability to cope with their caregiving role also indicated the existing demands for care and, in addition, offered benchmarks in relation to the improvements that had occurred (or were expected to occur) based on their objective assessments of the health, behaviour, and functional capabilities of the person in their care (Pearlin et al., 1990). Subsequently, Adshead (1998) and Epel et al. (2009, p. 3) highlighted that "objective stress (years of caregiving) and perceptions about life stress" also occur in people with major depression, from a lower socioeconomic status, females, and in older caregivers.

Likewise, this research reflects Savage and Bailey's (2004) finding about the Australian demographic that has unequally distributed care to older unpaid caregivers in the community. Lefley (1996) suggested that the process of deinstitutionalization has also catapulted (untrained and unprepared) family members into primary caregiving roles. This situation highlighted the common knowledge "that actors use to share and assess each other's domain-specific knowledge" (Carlile, 2004, p. 555). Carlile (2004) referred to three main factors in the transfer of common knowledge over time, involving difference, dependence, and novelty. Firstly, differences appeared between the participants' long-term commitment to mental health caregiving and limited access to MHS resources, and the knowledge invested in mental health policies and services. Secondly, the need to develop interdependent working systems based on the "pooled, sequential, and reciprocal" common knowledge (Carlile, 2004, p. 555) highlighted the mutual dependence of MHS and family caregivers to achieve their own goals. Finally, the "prototyping" methodologies of mental health care covertly undermined "the participatory and relational nature of sharing all that is not known" about mental health caregiving (Carlile, 2004, p. 555).

The issue of caregiver burden therefore represents the known differences and dependencies of providing support to people with mental illness. However, because of the complexity of the modern caregiving situation, MHS also assess, manage and share in the caregiving role. The novel situation posed by deinstitutionalisation has also placed MHS in the more powerful position that underscores the long-term costs associated with caregiving (Carlile, 2004). Pavalko and Woodbury (2000) associated a wide range of additional economic and human costs with government policies that increase family responsibility for care. The participants often described how their adverse reactions to stressful life experiences related to their secondary trauma and depression. Linden, Earle, Gerin, and Christenfeld (1996, p. 117) identified that stressful life experiences influence iatrogenic illness in the body's initial response to challenge and "physiological activation of a defence system". Linden et al. (1996, p. 118) referred to caregivers' "exhaustion with enduring activation or reactivity" when failing to resolve the stress of crisis. The participants also described symptoms similar to PTSD. Likewise, Nelson and Wright (1996, p. 460) described the notion of "*folie a deux*", in relation to the sharing of psychiatric illnesses.

Tyrka et al. (2010) found 'in-common' biological risk factors for psychiatric disorders (such as major depression and post-traumatic stress disorder) that are comorbid with metabolic disorders, and immune and cardiovascular diseases. The increased potential for iatrogenic impacts from caregiving were also evident in the current study and warrant a deeper investigation to understand this process more clearly. The participants also confirmed what Pearlin et al. (1990, p. 587) described as "formidable stressors" concerning the "constant and painful reminder of the changed person" receiving care. This situation highlighted the dominant focus of bio-chemical, pharmacological, and psychotherapeutic treatment to isolate the symptoms of mental illness and change the person rather than their situation, as was previously outlined by Porges (2001).

10.5 Limitations of the Current Research

There are a number of limitations in relation to the interpretation of the current research and the validity of the findings. Firstly, the survey method was a major limitation due to its bias towards respondent populations who are familiar with the Internet and had access to the technology. As Internet access was the main method of recruitment, it may have excluded many potential respondents in the mental health caregiving demographic. A limitation of access to respondents also occurred due to the specific affiliation of the research to caregiving support groups, mental health organisations, and data services. This process also attracted a number of ‘informal’ caregivers who were also caregivers in their employment. However, this method of recruitment was followed because it increased the probability of gaining ethics approval. In some instances, potential respondents contacted the researcher in person and by post to obtain information about the research. The support organisations themselves also distributed the information provided by the researcher. This limitation may have also biased the survey results as the sample was confined to the South Australian population and the cultural limitations of a white middle-class demographic. The organisations themselves identified another limitation of ‘survey exhaustion’ affecting caregivers in the South Australian demographic that may have significantly contributed to the reduced response rate. Another limitation of reduced participation meant that stage 3 (detailed enquiry) was conducted as small group interviews, consistent with the methods outlined in section 5.6.

In addition, the information about the research was provided only in English, limiting the possibility of community mental health caregivers from diverse cultural backgrounds taking part in the study. Another limitation of the sample and the recruitment process was identified after a number of surveys had been returned by respondents unable to participate due to their experiences of secondary trauma.

The findings of this study may also be skewed to some extent as most of the participants demonstrated strength of character through their determination to contribute to research about secondary trauma. The forum participants also identified the word '*caregiving'* as a limitation as some potential respondents may not self-identify as caregivers. To overcome these concerns in future research, the researcher would conduct information sessions at carer support and mental health organisations and would meet caregivers in person to further clarify and define the research terms.

The participants also outlined how they may have misunderstood entire sections of the researcher's analysis due to the narrow turnaround time given. This limitation could have been minimised by initially meeting the potential respondents in person to clarify their participation goals, the interpretation of the research stages, and to agree on the time they needed to review the transcripts. The Stage 2 participants may also have felt obliged to continue onto Stage 3. However, this issue was discussed with the participants beforehand and their voluntary participation was confirmed. The final limitation involves the area of interpersonal supervision and transference issues concerning the researcher's capacity for intimacy and the various types of adaptation she undertook to encourage participant responses (Sullivan, 1962). This typically involved openly declaring her personal bias as a former mental health caregiver and as a PhD researcher.

10.6 Recommendations

This research has demonstrated a new contribution to knowledge that indicates a point of departure from past understandings about secondary trauma (Sullivan, 1954). It highlights how communicating with caregivers (through Sullivan's Interpersonal Theory) may offer a useful framework for MHS in their interactions with family caregivers, and in their future engagement in trauma-informed care. This research explored the cultural and social aspects of development and the caregiving role in relation to secondary trauma.

The use of Interpersonal Theory took participants on a different and arguably richer path through the process of recounting their experiences, moving them beyond the concept of burden that has been prevalent in the literature for more than two decades. The adoption of this approach is important for MHS organisations and their staff to enable them to process and appropriately share sensitive information about caregivers' potential secondary trauma experiences. Caregiving was explored as a construct that commenced with early development and then traced over the participants' lifetime. The participants' experiences of secondary trauma contained distinct stages in their interpersonal development associated with changes in their self-schemas and personalities (Sullivan, 1954). Figley (1999, p. 10) stated: "yet little is written about the cost of caring … it is important to know how helpers become upset or traumatised as a result of their exposure". Therefore, by indirectly exploring the basis of traumatic difficulties, the researcher and the participants identified how their experiences of secondary trauma were acknowledged as interpersonal tensions, and the relationships that may contribute to a greater theoretical understanding of secondary trauma (Sullivan, 1954).

The conceptual development of knowledge about secondary trauma contained in this thesis also enabled the participants to cope with and develop their understanding of secondary trauma, based on their alertness, intelligence, and responsiveness to the research questions. The use of Interpersonal Theory enabled the participants to draw upon and safely describe their own lived experiences and caregiving role involvements. This process increased their understanding about the relationship between communication and their caregiving motivations, as aspects of their personalities were revealed to them, often for the first time. As evidenced by their feedback, the participants' increased awareness and enhanced knowledge of secondary trauma occurred in a safe research environment, specifically aimed at addressing the needs of mental health caregivers. In addition, this thesis strongly suggests that longitudinal studies may further confirm the relationships between the different types of vicarious stress, and might contribute significantly to ongoing understandings of the continuum of secondary trauma.

Interpersonal Theory offers a set of valuable processes for mental health caregivers and trauma research that can also be applied more generally; that is, beyond caregiving roles. The use of Interpersonal Theory in this study began with a process perspective of crisis that first explored the pre-event stages of risk in relation to secondary trauma by exploring the participants' developmental experiences. Then, "by moving through the eruption of some triggering event during crisis stages", such as their current caregiving role (Reynolds & Seeger, 2005, p. 49), the accepted views about the caregiver burden were challenged by providing indirect and objective pathways for their experiences of anxiety and allow participants to safely observe their experiences of secondary trauma. The adaptation and application of this technique is especially valuable for future research, because secondary trauma is generally perceived to be a problematic area for data collection due to the specific methodological issues of PTSD transmission. Another possible direction for future research is the consideration of how caregivers' experiences of secondary trauma may affect people with mental illness.

The extraordinary results provided by the individuals involved in this research took less than three hours of their time. Each participant contributed to a holistic exploration of secondary trauma that supported their lived caregiving experience and outlined the potential for early intervention strategies for secondary trauma. This research also attended to the research aims, by using blended forms of communication about trauma and allowing the participants the opportunity to improve their communication about their experiences. The stage-specific analyses of caregiving stress thus emphasized "the developmental features of crisis and the various communication needs and exigencies of audiences at various points in the ongoing development of an event" (Reynolds & Seeger, 2005, p. 49). By addressing the anxiety caused by interpersonal development, this research has highlighted the instrumental purposes of communication and proposed that these broader approaches to data collection may address the future needs of mental health caregivers by acknowledging the scope and nature of trauma rather than relying on traditional models of risk and crisis intervention (Reynolds & Seeger, 2005). This process therefore emphasises how the participants' creativity challenged the common assumption that cultural conflict "results in immobilisation and pathological responses" by recognising the increased potential for post-traumatic growth (Sieber, 1974, p. 576), such as can be argued by a focus on burden for which there appears to be little resolution; 'it is what it is'. This distracts caregivers from resolving the anxiety they experienced during their interpersonal development. This research also affirmed a "mutual focus on daily life and not the traumatic past" (Van der Hart et al., 2004, p. 912).

This research also indicated where significant gaps exist in the education of mental health professionals. These gaps in knowledge highlight the potential of interpersonal supervision and the importance of future research to explore issues of transference by sharing intimacy and adaptation to increase mental health (Sullivan, 1962). This research is also significant because it moves the analysis of secondary trauma towards an exploration of personality and interpersonal development and their potential to indicate and predict stress behaviours in the community (Porges, 2001). Pursuing the theoretical value of collaboration thus occurred in the context of identifying the "practical and political mismatches" in knowledge transmission and in addressing the negative consequences of the "path-dependent" nature of traumatic stress responses and mechanisms (Carlile, 2004, p. 555).

10.7 Final Comments

In the process of interviewing these participants, it was apparent from their descriptions of their roles as mental health caregivers that many had experienced secondary trauma. The use of the Interpersonal Theory methodology was perceived by the majority of participants to be useful as a way of helping them to articulate their lived experiences and to integrate their recurring conflicts and avoidance behaviours by safely exploring their traumatic memories. These findings increase our knowledge and understanding of caregiving and secondary trauma by more broadly reflecting the general pattern of all interpersonal processes (Sullivan, 1954). This research is important because it may help to address the increasing prevalence of secondary trauma in Western society, and may also direct research in how to improve the incorporation of survivor witnesses' and caregivers' lived experiences.

This thesis has demonstrated how trauma, as an historical product, has the power to shape cultural perceptions as well as to form positive social behaviours, by providing humanity with the symbolic meanings essential for ongoing communication and social integration. Sullivan emphasized the specific use of interview skills at key points to improve situations and reflect esteem so that "all situations fall under the theorem of reciprocal emotion and that the processes in interview situations follow this general pattern of all interpersonal processes" (1954, p. 126). The complex interpersonal processes outlined in this thesis underpin the human capacity to transfer information, translate meaning, and transform identity and knowledge (Carlile, 2004). The circumstances of rapid social change present humanity with a challenge to treat psychological and physiological stress appropriately. The benefits of action research and Sullivan's Interpersonal Theory have been instrumental in clearly investigating traumatic stress by allowing the participants both to familiarise themselves with, and to understand, the field of secondary trauma. This application of Interpersonal Theory has contributed to improved perspectives about future mental health interventions, education, and practice, which are also important to inform the future trauma discourse.

This new contribution to knowledge demonstrates an urgent need for reform in the areas of community education, peer support, counselling and respite services, and organisational and caregiving relationships. By continuing to construct empowering relationships based on emotional reciprocity and social integration, this thesis has provided clear guidelines and structures for the development of humane mental health strategies. This thesis significantly contributes to new knowledge about vicarious trauma, compassion fatigue, and secondary trauma by defining how mental health caregivers' tensions become integrated as intrapersonal and interpersonal experiences. The participants' improved understandings of secondary trauma thus emerged through their reciprocal exchanges with the researcher and in the context of their shared economic, political, social, and cultural environment. By not focusing directly on the participants' secondary trauma experiences, or their anxiety, this research has explored both the lived experience and the emotional and cognitive nature of communication. It has therefore highlighted the importance of emotional intelligence and the role of cognitive development as they relate to personality and the developmental processes that occur within wider society and how these processes help improve the understanding of the trauma experiences of mental health caregivers. Together, these processes might well improve our understanding of and responses to trauma experiences more generally.

APPENDICES

APPENDIX 1

ETHICS APPROVAL

FINAL APPROVAL NOTICE

Project No.: **5689**

Project Title: Knowing Care: An Exploration Of Secondary Trauma Involving Caregivers Of People Who Experience Mental Illness

Principal Researcher: Ms Cindy Eggington

Email: eggi0004@flinders.edu.au

Address: Department of Disability Studies

Approval Date: 3 August 2012

Ethics Approval Expiry Date: **30 June 2014**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided with the addition of the following comment:

Additional information required:

1. Please ensure that copies of correspondence requesting and granting permission to conduct the research from the , , and the are submitted to the Committee *on receipt* (Conditional approval response – number 1).

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress report must be submitted each year on the **3 August** (approval anniversary date) for the duration of the ethics approval using the annual progress / final report pro forma. *Please retain this notice for reference when completing annual progress or final reports.*
If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request and an annual report.

Your first report is due on **3 August 2013** or on completion of the project, whichever is the earliest.

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such matters include:

- proposed changes to the research protocol;
- proposed changes to participant recruitment methods;
- amendments to participant documentation and/or research tools;
- extension of ethics approval expiry date; and
- changes to the research team (addition, removals, supervisor changes).

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form to the Executive Officer. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.
Change of Contact Details
Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforseen event occurs that may affect the ethical acceptability of the project.

Andrea Fiegert (nee Mather)
Executive Officer
Social and Behavioural Research Ethics Committee

c.c Dr Brian Matthews
Ms Louise Reynolds
Dr Sharon Lawn

Andrea Fiegert (nee Mather)
Executive Officer, Social and Behavioural Research Ethics Committee
Research Services Office |Union Building Basement
Flinders University
Sturt Road, Bedford Park | South Australia | 5042
GPO Box 2100 | Adelaide SA 5001
P: +61 8 8201-3116 | F: +61 8 8201-2035 |Web: Social and Behavioural Research Ethics Committee

APPENDIX 2

LETTER OF INTRODUCTION

INTRODUCTION LETTER

This letter is to introduce Cindy Eggington who is a PhD Candidate in the Disability and Community Inclusion Unit at Flinders University. Cindy is undertaking research leading to the production of a PhD thesis on the subject of secondary trauma involving caregivers of people with mental illness.

It is hoped the information will promote a better understanding of a type of vicarious stress associated with care, called secondary trauma. This research project will explore secondary trauma in relationship to care and to recovery, early intervention and prevention.

Cindy would be most grateful if you would assist in this project, by volunteering to complete an anonymous survey. No more than ten minutes would be required. Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the data, the resulting thesis, report or other publications. Participants will be free to discontinue at any time and/or to decline to take part in the research.

Cindy intends use the information provided in the survey as a basis for ongoing research. This information will contribute to information about stress associated with the caring role, on the condition that the participant's name or identity is not revealed in subsequent research stages and/ or findings. To maintain respect and confidentiality for the information and respondents indicating their wishes to volunteer for ongoing research, a space for contact details is provided at the end of the survey.

Any enquiries you may have concerning this project should be directed to brian.matthews@flinders.edu.au or by telephone to Brian Matthews at 82013448

Thank you for your time.

Yours sincerely

Brian Matthews Senior Lecturer
Disability and Community Inclusion Unit

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number: 5689). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

APPENDIX 3

INFORMATION SHEET

INFORMATION SHEET
STRESS ASSOCIATED WITH CARE

This project will explore a type of stress associated with caring called secondary trauma. The information will be analysed to promote a better understanding about caregiving, based on participant evaluation of the data.

My name is Cindy Eggington and I am completing this research as requirement for candidature for a PhD in Disability and Community Inclusion at Flinders University. My thesis will discuss ‘Knowing care. An exploration of secondary trauma involving caregivers of people with mental illness’.

The first part of this research will involve voluntary and anonymous participation in a survey. This participation is completely voluntary and not compulsory. The survey will form the basis of voluntary participation in an interview for one hour. The interviews will discuss how caregivers relate to the caring role and benefit from participation in the research. Following qualitative interviews’, a third stage of research will consist of volunteers to participate in group interviews. Volunteers will be asked to give their feedback on the transcripts of the individual and group interviews. Finally an open forum will include all of the participants of all/ any stages of data collection and interested stakeholders.

Participation in the interviews or focus groups is not compulsory. The interview and focus groups will be recorded using a digital voice recorder, with the consent of participants. Focus groups and forum will have optional visual recording. This data will then be transcribed by a professional known to the Disability and Community Inclusion Unit, for efficiency and expediency. All personal information will be removed, and the transcripts will be stored as a computer file. The files will be destroyed once the results have been finalised. This will enable the researcher to accurately collect all that has been said. The research will be monitored by 2 supervisors and an external assessor.

We envisage no distress to be caused by this research. However, participants who may become uncomfortable as a result of the research are advised to contact the following services for support:

Carers SA: 1800 242 636
Carer Support: 1800 052 222
Lifeline: 131114

Participants who choose maintain confidentiality may seek support outside of their affiliated organisation. In this case more than one number is provided. Participants who may have any concerns are asked to discuss these with their organisational representative in the first instance.

All participants have the right to withdraw from further participation at any stage. They may also identify particular aspects of their contributions that they would prefer to remain confidential by indicating this to the researcher at the time of data collection. Whether individuals participate or not, or withdraw after participating, it will have no effect on any treatment or service that is being provided to them.

Privacy and confidentiality will be maintained by the removal of all personal identification or other identifying information from the collected data. Participants involved in the group interviews and forum are asked to respect the confidentiality of others who contribute to research. Group norms regarding this will be clearly stated at the beginning of each group interview and at the forum.

As a PhD project, this research is not funded by external interests. I am interested in the exploring the relationship between traumatic stress and care, with a view to minimise disability and adverse impacts.

I would be grateful for your participation and contribution to this thesis.
The summary of the results will be available for distribution among participants.
Participants involved in stage 2 and stage 3 will be asked to evaluate their transcripts and findings.

Thank you for your attention and interest.

Regards

Cindy Eggington
Disability and Community
Inclusion Unit Flinders University
Please Ph: 8291 6539 or email, cindy.eggington@flinders.edu.au regarding any enquiries or seeking further information.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number: 5689). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

APPENDIX 4

COVER LETTER FOR THE CAREGIVING AND STRESS SURVEY

Exploring Care-giving Stress

This research is being conducted by Cindy Eggington, a PhD Candidate at the Disability and Community Inclusion Unit at Flinders University.

This survey is the first stage of a PhD research project that explores how stress is being experienced by care-givers. Cindy asks individuals who identify themselves as care-givers for people with mental illness to volunteer to complete this short survey.

The results from this survey will help to better understand and improve our knowledge about caring relationships.

The survey should only take five to ten minutes of your time. Participants may return the survey by clicking on the submit button at the end. Please submit the completed survey on or before September 30, 2012. Unfortunately, surveys returned after this date may not be included as part of the data collection.

The information provided in this survey will remain anonymous and confidential. Your participation is voluntary and does not seek any information which can identify you or those that you care for.

After completing this survey, you may choose to volunteer for a one hour face to face interview to discuss your care-giving role and reasons for being a care-giver. The interview will also explore what we can achieve from our discussion, and what you know about care-giving based on your former experiences.

Your participation in the interview stage is not compulsory. Volunteers are invited to contact Cindy and/or provide your contact details at the end of this survey. Your contact details are confidential.

A third stage of research will ask those who have been interviewed to participate in a group interview. Individual and group interview participants will be asked to give feedback about this research project. All participants will be invited to a forum which will share the findings of research.

For further information about this project please email Cindy at:
cindy.eggington@flinders.edu.au

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number: 5689).

Thank you very much for your contribution.

APPENDIX 5

CAREGIVING AND STRESS SURVEY

CAREGIVING AND STRESS SURVEY

Section 1

Please indicate your answer by clicking on the appropriate boxes.

1. Are you?

○ Female

○ Male

2. How old are you?

○ 18-25

○ 26-40

○ 41-55

○ 56-70

○ 70+

3. What study have you completed since leaving school?

○ None

○ TAFE/ Technical School

○ University Degree

○ University Post Graduate

4. What is your current relationship status?

○ Married

○ Partner/ De-facto

○ Single

○ Divorced

○ Other ☐

5. What is the nature of your relationship with the person (s) you provide care for?

○ Family member/ Spouse

○ Friend/ Companion

○ Peer Worker

○ Mental Health/ Community Support Worker

○ Other ☐

6. Are you receiving a Centre-link payment or any other payment for your care-giving role?

○ Yes

○ No

7. Do you consider yourself as the person's main care-giver?

○ Yes

○ No

8. On average, how many hours are you care-giving a week?

☐

9. For how many years have you been a care-giver?

☐

Section 2
How would you personally describe care-giving?

	Never	**Rarely**	**Occasionally**	**Frequently**	**Always**
Care-giving is personally satisfying	○	○	○	○	○
Care-giving contributes to my personal growth	○	○	○	○	○
My care-giving role is an obligation	○	○	○	○	○
Care-giving increases my feeling of self-worth	○	○	○	○	○
My care-giving role is well meaning and purposeful	○	○	○	○	○

Section 3
How do you perceive your care-giving?

	Strongly disagree	**Disagree**	**Neutral**	**Agree**	**Strongly agree**
My life decisions are influenced by my care- giving role	○	○	○	○	○
Care-giving increases my sense of control	○	○	○	○	○
Care-giving affects how I make my daily choices	○	○	○	○	○
Care-giving involves time management skills	○	○	○	○	○
My care-giving role is rewarding for me	○	○	○	○	○

Section 4
What do you do in your care-giving role?

	Never	**Rarely**	**Occasionally**	**Frequently**	**Always**
I make my care- giving interactions easy to understand	○	○	○	○	○
I adapt my care- giving to the situation	○	○	○	○	○
My care-giving is guided by the person's needs	○	○	○	○	○
I discuss goals for care-giving with the person	○	○	○	○	○
I follow a familiar routine	○	○	○	○	○

Section 5
What is your attitude towards your care-giving role?

	Never	**Rarely**	**Occasionally**	**Frequently**	**Always**
I want to learn more about care-giving	○	○	○	○	○
I do what I need to do in my care-giving role	○	○	○	○	○
I know what my care-giving role is about	○	○	○	○	○
I am motivated by my care-giving experiences	○	○	○	○	○
I am improving my knowledge about care-giving	○	○	○	○	○

Section 6
How are you managing your care-giving role?

(Please tick one answer.)

○ I often stay completely involved in the care-giving process

○ I switch off from my care-giving role whenever possible

○ I can switch off completely from the caring role and take time out for myself

Section 7
How are you practicing your care-giving role?

	Never	**Rarely**	**Occasionally**	**Frequently**	**Always**
I trust in my own experiences as a care-giver	○	○	○	○	○
I perform specific care-giving tasks	○	○	○	○	○
I fulfil an essential care-giving role	○	○	○	○	○
I learn from other care-givers' experiences	○	○	○	○	○
I carry out my care-giving role independently	○	○	○	○	○

Section 8
What do you consider is most important in your care-giving role?

(Please tick all applicable answers.)

○ Honesty

○ Trust

○ A caring environment

○ Good sense

○ Responsibility

○ Support and guidance

○ Recognition from others

○ Other ☐

Section 9
How do you feel about learning and care-giving?

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
More research is needed	○	○	○	○	○
There are certain things I want to know more about	○	○	○	○	○
Care-givers should be involved in research	○	○	○	○	○
I benefit from learning opportunities	○	○	○	○	○
I want to learn more about answers to common issues	○	○	○	○	○

Thank you for participating in this survey.

We envisage no distress to be caused by this research. However, participants who may become uncomfortable as a result of the research are advised to contact the following services for support:

Carers SA	1800 242 636
Carer Support	1800 052 222
Lifeline	131114

Would you like to participate in a one hour interview?

Your participation is voluntary and not compulsory, but would be greatly appreciated.

The interview will provide an opportunity for you to talk about your care-giving role, and to participate in a group interview if you choose.

You are also welcome to contact Cindy if you have any questions about the survey or research project.

Please provide your email address and/or phone number in the following space if you would like to volunteer for an interview, or would like more information.

Submit

APPENDIX 6

CONSENT FORM

Flinders
UNIVERSITY

CONSENT FORM FOR PARTICIPATION IN RESEARCH
(By interview)

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

Being over the age of 18 years hereby consent to participate as requested in the………………………………….……. for the research project on
……………………………………………………………………………..……………
…………………………………….

1. I have read the information provided
2. Details of procedures and any risks have been explained to my satisfaction
3. I agree to audio recording of my information and participation
4. I am aware that I should retain a copy of the information sheet and consent form for future reference
5. I understand that
    - I will be asked to give feedback on the transcripts of individual and group interviews
    - I am free to withdraw from the project at any time and am free to decline to answer particular questions
    - I will not be identified and individual information will remain confidential
    - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
6. I agree that the unidentified transcript will be made available to supervisors and myself
7. I have had the opportunity to discuss taking part in the research with a family member of a friend

Participants Signature…………………………………………………… Date ………………………….

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

Researchers Name…………………………………………………………………………… ……………………………

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number: 5897). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

APPENDIX 7

INTERVIEW GUIDE

Stage 2 Interview question guide

First I would like to ask some questions about care and the way care was first perceived in your life.

Do you mind if we go over a rough outline of how you perceived care from your family and personal history?

Rough outline

How would you describe growing up in your family?

Let's begin with first recollections of care.

Did you have a big family?

Relatives, makeup of the family was it big, was it extended, did you have many sisters and brothers?

And what relationship with siblings, brothers, sisters?

Were both parents working, qualified, their perceptions of care?

Are they still alive?

Were your parents together?

Your recollections of their presence in your life?

How did the home care environment feel or work for you?

How did it work when both parents, stayed at home, when there was a full house, or when relatives or friends stayed?

What kind of people were they?

Do you think you moved around a lot, or did you stay about in one place during your childhood?

And how did this feel, to be in one place and around people and situations you were familiar with?

Where did you spend most time growing up?

What did this mean for you?

So the next question looks at your recollection of your family's social, cultural or economic position in society.

So we looked at your family makeup, how do you think this influenced the way you feel or think about care?

On this level, did you associate much of the care with close relatives?

And so can you recall your first experience of caring?

Educational History

The next stage talks about when you moved into school for the first time.

We will talk about how this relates to caring now later on.

What was your primary or pre-school like?

Can you recall if any of those caring relationships still played a role?

Did this stage represent anything new to you in the way of caring?

Now I would like to talk about interpersonal relationships for the first time, really outside of the family.

Do you remember your first best friend?

What or how was caring now?

What was having childhood friends like in school?

How do those relationships pan out?

What do you remember about care then?

So it can be anything, competition?

Was there any change during this time, that affected the way your see care, say family pets, or events?

So now we are going to talk about becoming a teenager, and just before.

Is there anything you would like to add from the last stage to infancy, childhood and juvenile stage of growing up?

<u>30 mins</u>

So now, before you became a teenager, was there a special relationship in your life, say a special friend?

Did this work out?

What was being a teenager like in terms of care?

Was there a special close friend?

Do you remember anything about caring from this time?

Of course during the teenage years, we become interested in intimacy.

We don’t need to enter into this data, but if there is anything about the intimacy say from before with your close friend to adjusting to more partner roles and attraction, to the peer group?
We can enter each stage slowly.
First, intimacy in terms of care?
Second, peer group?
Third, adjustment as a young adult?
Occupational history
Thank you for all of this information.
Now we will see how it relates to caring now.
What have you become aware of or know about caring now, given our conversation about these stages?
Marriage, Children Family?
Do you mind if we talk about this new awareness now, until it’s time to finish the interview?

End interview.

APPENDIX 8

DETAILED ENQUIRY QUESTION GUIDE

DETAILED ENQUIRY QUESTION GUIDE

This detailed enquiry is a very general type of discussion which centres on themes only.

- Everyone was asked the same questions
- Background details are broadly referred to in the group interview.

1. The first half of the question guide remains basically the same (as in the ethics application):

How did participants find the individual interview?

Was there any new awareness resulting from the interview?

Broad discussion about themes.

How do your themes (categories) relate to care?

How have they informed you about your caregiving?

What did you discover in your 1st category (2nd, 3rd, etc.)?

Has this changed your thoughts about your care-giving role?

2. General discussion (for modification)

Is there a relationship between the themes?

How does this relationship relate to your care-giving role?

In what way does it explain your care-giving role?

What are your basic thoughts about:

- a justified life?
- faith or any other exalted purpose?
- shame or regret?
- your “self”?
- the rest of your personality?

Is there anything you want to add about these and your care-giving role?

Final summing up about durable characteristics associated with themes
(e.g. values, behaviour, rest, achievements, ideas)

Conclusion (involving participants)

What has impressed me?

Amending misunderstanding or missing information

Outline of new awareness resulting from group interview

Thank you. (close)

APPENDIX 9

FORUM DISCUSSION GUIDE

Stage 4 Forum Discussion Guide

Open Forum

This open forum provides an opportunity to present and discuss the research project's findings.

This forum will contain the participant assessment and interpretation of the results and outline of benefit concerning participants who have contributed to the research project.

The summary of findings will be presented as follows;

1. Evaluation of life experience.
2. Evaluation of themes.
3. Learning related to care.
4. Evaluation of issues identified in care.
5. Evaluation of representations involving traumatic stress (30 minutes).

Short Break: Refreshments provided

6. Confidence and growth resulting from findings.
7. Issues that need to be addressed.
8. Characteristic or representative models to be used in future planning (30 minutes).

APPENDIX 10

POWERPOINT PRESENTATION

Forum
Caregiving and Stress

Cindy Eggington
PhD Candidate
Disability and Community Inclusion Unit
Flinders University

Welcome

I acknowledge the traditional owners and custodians of this land the Kaurna people

PhD Research

Knowing Care

An exploration of secondary trauma involving caregivers of people with mental illness

Presentation

First half
- Background to research
- Early findings

Second half
- Discussion
- Q and A

Defining Secondary Trauma Vicarious Stress

- Vicarious trauma (situations, recollections impact on carer outlook) (Jenkins & Baird, 2002)
- Compassion fatigue (structural limitations and resources, perceptions) (Evans, 1996)
- **Secondary trauma** (symptoms of Post Traumatic Stress, individual to carer) (Kishur, 1984)
- Susceptibility factors (Figley 1999)

Questions from the gaps in knowledge

- How do people become traumatised? (American Psychiatric Association, 2000)
- What role does resilience play? (Raphael, 2006)
- What can we do to prevent and lessen the impact of traumatic stress? (Figley, 2006)
- How do we address it in the future?
- What are the indicators of traumatic stress? (Figley, 1999)

–Looking for the patterns

Care-giving and Stress Project

Why use Interpersonal Theory as a method?

- Electronic survey (reception)
- Interviews (developmental framework construct of care-giving)
- Detailed enquiry interviews (relationship to traumatic stress)
- Forum (summary and conclusion)

(Sullivan, 1954)

Early findings 1: Survey

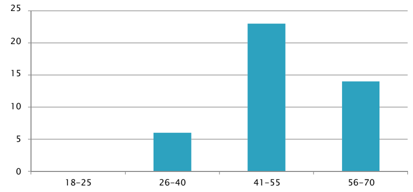
9 Organisations and 1 Data base

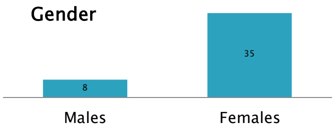
- 43 respondents
- inform other research data

18 questions ;
- 9 demographic (6)
- 8 motivation and strategies

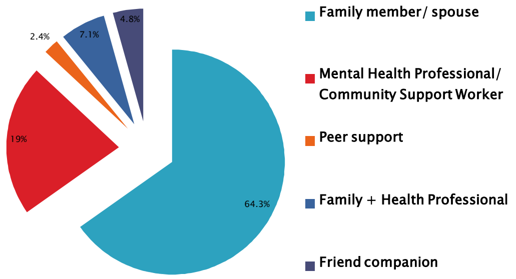
23 primary care-givers

Age

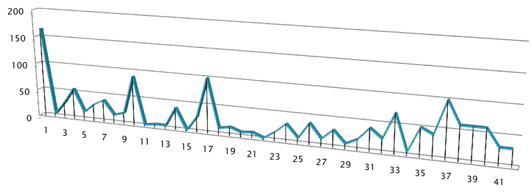




Type of care provided

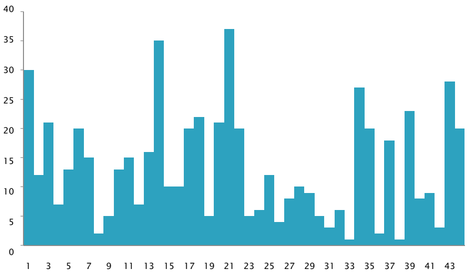


Hours of care per week



Average: 38.3

Years involved in caregiving



Average:12.5

Interviews

18 participants
- 13 female, 5 male

Type of care being provided
- 14 family/spouse
- 3 family/spouse/workers
- 1 friend
- **Range of care**
  - Mental illness: 14
  - Disability /mental health : 4

Interview stage, early findings

Understanding of care
- Developmental stages (Sullivan, 1956)
- Question guide: 1-2 hours (1.20)

Feedback

Care-giving and integration
- Resolved needs
- Ongoing patterns
- Coming to terms

Situation in relationship to care
- What is done
- What should be done

Table of themes, examples of patterns

Resolved needs	**Continual patterns**	**Coming to terms**	**Situation**	**Outlook**
Awareness of our-selves as resource	Development of personality and interactions	Anticipation of life /experiences	In relationship to what we do	What we think should be done
Security	Adaptability	Responsibility	Identity	Management
Resilience	Responsibility	Flexibility	Tolerant	Leadership
Achievement	Flexibility	Resilience	Separation	Responsibility

Early findings **Detailed Enquiry**

10 female interviews
3 male interviews

Patterns in care

Summary of categories
- Participant feedback
- Discussion about caregiving
  - Characteristics of care
  - Concept of self and rest of personality

(Sullivan, 1954)

Early findings **Detailed Enquiry**

- Relationship between life experience and care
- Participants described the benefit of learning

3 categories (analysis: being, doing and knowing)
(Sullivan, 1953)

Data linking development to indicators of traumatic stress giving new perspective about secondary trauma

---

Detailed Enquiry themes, direction

Being	**Doing**	**Knowing**
Learning from observation	Interacting with others	Understanding of the situation
Example	Reinvention	Recognition
Awareness	Self-reliant	Security
Trust	Structure	Adapting

Summary of early findings

- Clear relationship between integrations and types of vicarious stress
- Correlations between ‘self’ and rest of the personality
  - Positive response
  - Participants saw benefit and value in study

Morning Tea

15 minutes

Help yourself and have a talk

Followed by

- Future issues for consideration
- Implications for mental health carers

Q and A

Forum Q and A

Future issues for consideration

What is the impact of secondary trauma on care and caregivers?

Caring interactions

- Personal
- Developmental
- Collaborative
- Collective meaning (social and cultural)

Future issues for consideration

What is the impact of secondary trauma on recovery?

- First hand experience
- Local relevance
- Past ideas and current care
- Adapting to new awareness
- Care and communication

Implications for mental health caregivers

How might we identify strategies to address Secondary Trauma?

Improvements

- Learning environment
- Suitable goals
- Relationship to recovery

Thank you

Harry Stack Sullivan
Participants
Participating organisations
Supervisors and colleagues

References

- American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders. Text Revision. DSM-IV-TR.* (4th ed.). Washington:
- Evans, F, B. (1996) Harry Stack Sullivan. Interpersonal theory and psychotherapy. Routledge: London.
- Figley, C, R, (2006) From Veterans of War to Veterans of Terrorism: My Maps of Trauma ,in Mapping Trauma and Its Wake. Autobiographic Essays by Pioneer Trauma Scholars (Ed)s. Charles R Figley. Psychosocial Stress Series. Routledge: New York.
- Figley , C, R. (1999) Secondary Exposure to Trauma and Self Reported Stress Among Therapists. Chapter 2, in Secondary Traumatic Stress. Self- Care Issues for Clinicians, Researchers, and Educators. Second Edition. Eds. B. Hudnall Stamm, Ph.D. Sidran Press: Maryland.
- Figley, C, R. (1999) Chapter 1, *Compassion Fatigue: Towards a New Understanding of the Costs of Caring* in Secondary Traumatic Stress. Self- Care Issues for Clinicians, Researchers, and Educators. Second Edition. Eds. B. Hudnall Stamm, Ph.D. Sidran Press: Maryland.
- Jenkins , S, R., & Baird, S. (2002) Secondary Traumatic Stress and Vicarious Trauma: A Validational Study. *Journal of Traumatic Stress, Vol. 15, No. 5, October 2002, pp. 423-432*

References

- Kishur, G. R. (1984). Chiasmal effects of traumatic Stressors: The emotional costs of support. Unpublished master's thesis, Purdue University, West Lafayette, IN.
- Raphael, B, (2006) Prevention framework for adverse mental health outcomes, potentially achieved through intervention with affected populations at heightened risk, recognizing resilience; In Mapping Trauma and Its Wake, Autobiographic Essays by Pioneer Trauma Scholars .Ed. Charles ,R ,Figley .Psychosocial Stress Series: Routledge, New York
- Sullivan, H., S. (1953). *The interpersonal theory of psychiatry.* In H. S. Perry, M. G. Gawell (Eds.). Tavistock Publications: London.
- Sullivan, H., S (1954). The Psychiatric Interview. In H. S. Perry, M. G. Gawell (Eds.). Norton and Company: New York.
- Sullivan, H., S. (1956).Clinical Studies in Psychiatry. Ed(s); Perry, Helen Swick; Gawel, Mary Ladd; Gibbon, Martha. The Norton Library: New York.
- Treatment Protocol Project (2004). *Managing of Mental Disorders.* (4th ed.). Sydney: World Health Organisation.
- World Health Report (2001). *Mental Health New Understanding, New Hope,* Geneva: World Health Organisation.
- Zimmering, R., Munroe J., and GulliverS, B. (2003) Secondary Traumatisation in Mental Health Care Providers. Retrieved from http://www.psychiatrictimes.com/ptsd/content/article/10168/47641

REFERENCES

Abramowitz, S. A. (2005). The poor have become rich, and the rich have become poor: Collective trauma in the Guinean Languette. *Social Science & Medicine*, *61*, 2106-2118.

Adams, P. J. (2008). *Fragmented intimacy. Addiction in a social world*. New York: Springer.

Adams, R., Figley, C., & Boscariono, J. (2008). The Compassion Fatigue Scale: Its use with social workers following urban disasters. *Research in Social Work Practice*, *18*, 238-250.

Adams, K., & Galanes, G. (2006). *Communicating in groups: Applications and skills.* (6th ed.). Sydney: McGraw Hill.

Adler, R., Rosenfeld, L., & Proctor, R. (2007). *Dynamics of interpersonal relationships in interplay. The process of interpersonal communication.* (10th ed.). New York: Oxford University Press, Inc.

Adorno, T. W., & Horkheimer, M. (1997). *Dialectic of enlightenment* (Vol. 15). London: Verso.

Adshead, G. (1998). Psychiatric staff as attachment figures. Understanding management problems in psychiatric services in the light of attachment theory. *The British Journal of Psychiatry, 172*, 64-69.

Ajdukovic, D. (2004). Social contexts of trauma and healing. *Medicine, Conflict and Survival, 20,* 120-135.

Alberts, J.K., Martin, J.N., & Kakayama, T.K. (2011). *Communication in society*. Boston: Pearson Education Inc.

Aldenderfer, M. (1993). Ritual hierarchy and change in forging societies. *Journal of Anthropological Archaeology, 12*, 1-40.

Allport, G. W. (1950). *The individual and his religion: a psychological interpretation.* New York: Macmillan.

American Psychiatric Association. (1952). *Diagnostic and statistical manual of mental disorders*. Washington, DC: Author.

American Psychiatric Association (APA). (1980). *Diagnostic and statistical manual of mental disorders (3rd ed.).* Washington, DC: Author.

American Psychiatric Association (1994). *Diagnostic and statistical manual of mental disorders (DSM)*. Washington, DC: Author.

American Psychological Association, & American Psychological Association. (1994). *Diagnostic and statistical manual of mental disorders (DSM-IV)*. Washington, DC: Author.

American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders. Text Revision. DSM-IV-TR*. (4th ed.). Washington DC: Author.

American Psychiatric Association. (2010). *Summary of practice-relevant changes to the DSM-IV-TR*. Retrieved from http://www. psych. org/practice/dsm/summary-of-practice-relevant-changes-to-the-dsm-iv-tr.

American Psychiatric Association (2013). *Posttraumatic Stress Disorder*. Retrieved from http://www.dsm5.org/Documents/PTSD%20Fact%20Sheet.pdf

Andreasen, N. C. (2007). DSM and the death of phenomenology in America: An example of unintended consequences. *Schizophrenia Bulletin*, *33*, 108-112.

Anechiarico, B. (2009). *Vicarious trauma. What are the protective measures?* Retrieved from https://ccoso.org/sites/default/files/vicarious%20trauma.doc

Anglo-Saxon Chronicle. (1003). *Peterborough manuscript*. Retrieved from: https://classesv2.yale.edu/access/content/user/haw6/Vikings/ AS%20Chronicle%20Peterborough%20MS.html).

Australian Institute of Health and Welfare (2012). *Disability, Ageing and Carers, Australia: Summary of Findings*. Retrieved from: http://www.abs.gov.au/ausstats/abs@.nsf/ Lookup/3A3DE262338473D9CA257D5700200283?opendocument

Australian Institute of Health and Welfare (2016). *Mental health services in brief. Mental health series*. Cat. no. HSE 180. Canberra: AIHW. Retrieved from, www.aihw.gov.au/publication-detail/?id=60129557182

Australian Bureau of Statistics. (2008). A Profile of Carers in Australia. Commonwealth of Australia. Retrieved from: http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/ 0/4D0A63D991E01ED3CA2574E1000DF871/$File/final%20pdf%204448.0.pdf

Australian Bureau of Statistics. (2010). *Mental Health Year Book Australia, 2009-10.* Retrieved from: http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/ 1301.0Chapter11082009%E2%80%9310

Australian Oxford Dictionary (2006). (Ed). Bruce Moore. South Melbourne. Oxford University Press.

Bandura, A. (1977) *Social learning theory*. New Jersey: Prentice Hall.

Bandura, A. (2001). Social cognitive theory: An agentic perspective. *Annual Review of Psychology*, *52*, 1-26.

Barberis, D. S. (2003). In search of an object: Organicist sociology and the reality of society in fin-de-siècle France. *History of the Human Sciences*, *16*(3), 51-72.

Barkway, P. (2009). *What is mental health? Theories on mental health and illness*. Australia: Elsevier.

Barnard, C. I. (1938). *The functions of the executive*. Cambridge: Harvard University Press.

Batson, C., Fultz, J., & Schoenrade, P. A., (1987). Distress and empathy: Two qualitatively distinct vicarious emotions with different motivational consequences*: Journal of Personality, 55*, 19-39.

Bell, H., Kulkarni, S., & Dalton, L. (2003). Organizational prevention of vicarious trauma. *Families in Society: The Journal of Contemporary Social Services*, *84*, 463-470.

Bentley, S. (2005). A short history of PTSD: From Thermopylae to Hue. *The Veteran, 3:*13.

Bergesen, A. J. (2004). Durkheim's theory of mental categories: A review of the evidence. *Annual Review of Sociology*, 30, 395-408.

Beutler, L. E., Nussbaum, P. D., & Meredith, K. E. (1988). Changing personality patterns of police officers. *Professional Psychology: Research and practice*, *19*, 503-507.

Bhui, K., Warfa, N., Edonya, P., McKenzie, K., & Bhugra, D. (2007). Cultural competence in mental health care: a review of model evaluations. *BMC Health Services Research*, *7*:15.

Biegel, D. E., Song, L. Y., & Milligan, S. E. (1995). A comparative analysis of family caregivers' perceived relationships with mental health professionals. *Psychiatric Services*, *46*, 477-481.

Biggs, J., Kember, D., & Leung, D. Y. (2001). The revised two-factor study process questionnaire: R-SPQ-2F. *British Journal of Educational Psychology*, *71*, 133-149.

Birmes, P, Hatton, L., Brunet, A and Schmitt, L (2003) Early historical literature for post-traumatic symptomatology. *Stress and Health,* 19, 17-26.

Birnbaum, A. (2008): Collective trauma and post-traumatic symptoms in the biblical narrative of ancient Israel. *Mental Health, Religion & Culture*, 11, 533-546.

Blakely, S. (2000). Madness in the body politic: Kouretes, Korybantes, and the politics of shamanism. In J. Hubert (Ed.). *Madness, disability and social exclusion: The archaeology and anthropology of difference* (pp. 119-127). New York: Routledge.

Bleiberg, K. L., & Markowitz, J. C. (2005). A pilot study of interpersonal psychotherapy for posttraumatic stress disorder. *American Journal of Psychiatry*, *162*, 181-183.

Blum, F. H. (1955). Action research. A scientific approach? *The University of Chicago Press, 22,* 1-7.

Bogousslavsky, J., & Moulin, T. (2009). From alienism to the birth of modern psychiatry: A neurological story? *European Neurology*, *62*, 257-263.

Borg Jr, M. B. (2004). Venturing beyond the consulting room: Psychoanalysis in community crisis intervention. *Contemporary Psychoanalysis*, *40*, 147-174.

Boswell, T., & Chase-Dunn, C. (1996). The future of the world-system. *The International Journal of Sociology and Social Policy*, *16(*7/8), 148-179.

Bowers, L. (1998). *The social nature of mental illness*. Cornwall: Routledge.

Bowlby, J. (1951). *Maternal care and mental health*. Geneva: World Health Organization.

Braddock, D., & Parish, S. (2001). An institutional history of disability. In. G. Albrecht, K. Seelman, M. Bury (Eds.). *Handbook of disability studies*. Sage Publications. California.

Bretherton, I. (1992). The origins of attachment theory: John Bowlby and Mary Ainsworth. *Developmental Psychology 28*, 759-775.

Brissaud, S. (1907). Tanon, Danger des injections d'alcool dans le nerf sciatique au cours des névralgies sciatiques. [Tanon, Danger of alcohol injections in the sciatic nerve during sciatic neuralgias]. *Revue Neurologique*, *15*, 633-634.

Briquet, P. (1859). *Traité clinique et thérapeutique de l'hystérie*. [Clinical and therapeutic treatment of hysteria]. Paris: Bailliere and Son.

Brophy, L., & McDermott, F. (2013). Using social work theory and values to investigate the implementation of community treatment orders. *Australian Social Work*, *66*, 72-85.

Brown, W. L. (1920). *The sympathetic nervous system in disease*. London: Henry Frowde & Hodder & Stoughton.

Boulton, R. (1987). *People skills*. Sydney, Australia: Simon & Schuster.

Burns, T. R., & Carson, M. (2002). Actors, paradigms, and institutional dynamics: The theory of social rule systems applied to radical reforms. In R. Hollingsworth., K.H. Muller, E.J. Hollingsworth (Eds.). *Advancing socio-economics: An institutionalist perspective* (pp. 109-147). Oxford: Rowman and Littlefield.

Call, K. T., Finch, M. A., Huck, S. M., & Kane, R. A. (1999). Caregiver burden from a social exchange perspective: Caring for older people after hospital discharge. *Journal of Marriage and the Family*, *61*, 688-699.

Callaghan, S., & Ryan, C. J. (2012). Rising to the human rights challenge in compulsory treatment–new approaches to mental health law in Australia. *Australian and New Zealand Journal of Psychiatry*, *46*, 611-620.

Campbell, J. (1972). *The hero with a thousand Faces*. New Jersey: Princeton University Press.

Campbell, J. (1972). *Myths to live by*. New York: Penguin.

Canfield, J. (2005). Secondary traumatization, burnout, and vicarious traumatization: A review of the literature as it relates to therapists who treat trauma. *Studies in Social Work, 75*, 81-101.

Caplan, G. (Ed.). (1961). *Prevention of mental disorders in children: Initial explorations*. New York: Basic Books.

Caplan, G. (1964). *Principles of preventive psychiatry*. Oxford: Basic Books.

Capra, F. (1982). *The turning point. Science, society and the rising culture*. London: Fontana Paperbacks.

Carer Recognition Act. (2010). *An Act to provide for the recognition of carers and for related purposes*. Retrieved from https://www.comlaw.gov.au/Details/C2010A00123

Carlile, P. R. (2004). Transferring, translating, and transforming: An integrative framework for managing knowledge across boundaries. *Organization Science*, *15,* 555-568.

Caruth, C. (Ed.). (1995) *Trauma: Explorations in memory*. Baltimore, MD: Johns Hopkins University Press.

Carver, C. S., Reynolds, S. L., & Scheier, M. F. (1994). The possible selves of optimists and pessimists. *Journal of Research in Personality*, *28*, 133-141.

Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*, *56*, 267-283

Casamajor, L. (1943). Notes for an intimate history of neurology and psychiatry in America. *The Journal of Nervous and Mental Disease*, *98*, 600-608.

Casey, K. L. (2010). What part of 'no' don't you understand? Talking the tough stuff of the bible: A creative reading of the rape of Tamar, 2 Samuel. *Feminist Theology, 18*, 160-174.

Centers, C., Fundraiser, H., Gifts, P., Gifts, C., Giving, C., & List, W. (1994). Diagnostic and statistical manual of mental disorders. Retrieved from: http://www.gracepointwellness.org/5-depression/article/8212-diagnostic-and-statistical-manual-of-mental-disorders

Chamberlin J, (1990). The ex-patients' movement: Where we've been and where we're going. Ruby Rogers advocacy and drop-in centre. *The Journal of Mind and Behaviour,11*, 323-336.

Charcot, J. M. (1867). *Maladies des vieillards. Goutte et rhumatisme* [Diseases of the elderly. Gout and rheumatism]. Paris: Delahaye & Lecrosnier.

Christ, C. P., & Plaskow, J. (1989). Weaving the visions. New patterns in feminist spirituality. *Signs, 19*, 480-498.

Clarke, R. A. (2008). *Against all enemies: Inside America's war on terror*. New York: Free Press.

Clarke, L. (2009). Misplaced epistemological certainty and pharmaco-centrism in mental health nursing. *Journal of Psychiatric and Mental Health Nursing, 16,* 199-205.

Cohen, S. (1983). The mental hygiene movement, the development of personality and the school: The medicalization of American education. *History of Education Quarterly*, *23*, 123-149.

Cohen, M. N. (1985). Prehistoric hunter gatherers: The meaning of social complexity. In T. D. Price, & J. A. Brown (Eds.). *Prehistoric hunter gatherers* (pp. 99-119). Orlando: Academic Press.

Collins, T. (1971). The psychology of tears in the old testament: Part I. *The Catholic Biblical Quarterly*, *33*, 18-38.

Combs, G., & Freedman, J. (2012). Narrative, post structuralism, and social justice. Current practices in narrative therapy. *The Counselling Psychologist*, *40*, 1033-1060.

Cooley, C, S. (1909). *Social organization.* New York: Scribner.

Corrigan, P. (2004). How stigma interferes with mental health care. *American Psychologist, 59*, 614-625.

Corrigan, P. W., & Miller, F. E. (2004). Shame, blame, and contamination: A review of the impact of mental illness stigma on family members. *Journal of Mental Health*, *13*, 537-548.

Corrigan, P. W., & Watson, A. C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry*, *1*, 16-20.

Council of Australian Governments. (2006). *National action plan on mental health: 2006-2011*. Retrieved from: www.coag.gov.au/meetings/140706/docs/nap_mental_health.pdf

Craig C.D. & Sprang G. (2010). Compassion satisfaction, compassion fatigue, and burnout in a national sample of trauma treatment therapists. *Anxiety, Stress & Coping, 23*, 319-339.

Crocker, J., & Lutsky, N. (1986). Stigma and the dynamics of social cognition. In S.C. Ainlay, G. l. Becker., & L. M. Coleman (Eds.). *The dilemma of difference* (pp. 95-121). New York: Plenum Press.

Crowdy, T. (2007). *Military misdemeanours: Corruption, incompetence, lust and downright stupidity*. Oxford: Osprey Publishing.

Cunningham, L. S., & Reich, J. J. (2009). *Culture and values: A survey of the humanities*. Boston: Cengage Learning.

Cushing, H. (1935). Psychiatrists, neurologists and the neurosurgeon. *Yale Journal of Biology and Medicine, 7*, 191-207.

Da Costa, J. M. (1871). On irritable heart; a clinical study of a form of functional cardiac disorder and its consequences. *The American Journal of the Medical Sciences*, 121, 2-52.

Danieli, Y. (2006). It was always there. In C. R. Figley (Ed.), *Mapping trauma and its wake: Autobiographic essays by pioneer trauma scholars* (pp. 33-46). New York: Brunner-Rutledge Psychosocial Stress Book Series.

Daniels, E. B. (1985). Nostalgia: Experiencing the elusive. In D. Ihde & H. J. Silverman (Eds.). *Descriptions: Selected studies in phenomenology and existential philosophy, 11,* (pp. 76-90). Albany: State University of New York Press.

Darbonne, A. R. (1967). Crisis: A review of theory, practice and research. *Psychotherapy: Theory, Research & Practice*, *4*, 49-56.

Darwall, S. (1998). Empathy, sympathy, care. *Philosophical Studies*, *89*, 261-282.

Davidson, L. (2003). *Living outside mental illness: Qualitative studies of recovery in schizophrenia*. New York. New York University Press.

Davidson, L., O'Connell, M., Tondora, J., Styron, T., & Kangas, K. (2006). The top ten concerns about recovery encountered in mental health system transformation. *Psychiatric Services*, *57*, 640-645.

Davies, J. (2012). *The importance of suffering: The value and meaning of emotional discontent*. London: Routledge.

Davis, K. (1948). *Human society*. New York: Macmillan.

Dawson, J. (2006). Fault-lines in community treatment order legislation. *International Journal of Law and Psychiatry*, *29*, 482-494.

Dawson, J. (2007). Factors influencing the rate of use of community treatment orders. *Psychiatry*, *6*, 42-44.

Denham, A. R. (2008). Rethinking historical trauma: Narratives of resilience. *Transcultural Psychiatry, 45*, 391-414.

Department of Human Services. (2015). *Carer payment*. Retrieved from: https://www.humanservices.gov.au/customer/services/centrelink/carer-payment

Dick, B. (2002). *Thesis resource paper: You want to do an action research thesis?* Chapel Hill: Interchange.

Dick, B. (2010). *Action research theses: Thesis resource paper. You want to do an action research thesis?* (Doctoral dissertation). Retrieved from: academia.edu.

Dixon, L., Lucksted, A., Stewart, B., Burland, J., Brown, C. H., Postrado, L., McGuire, C., & Hoffman, M. (2004). Outcomes of the peer-taught 12-week family-to-family education program for severe mental illness. *Acta Psychiatrica Scandinavica*, *109*, 207-215.

Dornyei, Z. (2009). The L2 motivational self system. In Z. Dornyei., & E. Ushioda (Eds.). *Motivation, language identity and the L2 self* (pp. 9-42). New York: Multilingual Matters.

Dorsey, J and Jaffe, J. (2007). *Body-mind mental health therapies: A guide to treatment*. Retrieved from: helpguide.org/mental/mind_body_therapy.htm.

Douglas, M. (1973). *Natural symbols*. New York: Random House.

Duan, C., & Hill, C. (1996). The state of empathy research. *Journal of Counseling Psychology*, *43*, 261-274.

Durkheim, E. (1965). *La divisione del lavoro*. [The division of the labor in society]. Comunità. Milano.

Ehrlich, P. (Ed.). (1891). *Farbenanalytische untersuchungen zur histologie und klinik des blutes* [Colour analysis of histology and clinic of Blood] (Vol. 1). Berlin: Hirschwald.

Eisen, J. (Ed.). (2001). *Suppressed inventions*. New York: Avery Publishing Group.

Elliott, S. (2012). The walls that did not come tumbling down: Are the early Neolithic walls of Jericho the first evidence of warfare? *The RUSI Journal*, *157*, 72-79.

Elsaesser, T. (2001). Postmodernism as mourning work. *Screen*, *42*, 193-201.

Epel, E., Daubenmier, J., Moskowitz, J. T., Folkman, S., & Blackburn, E. (2009). Can meditation slow rate of cellular aging? Cognitive stress, mindfulness, and telomeres. *Annals of the New York Academy of Sciences*, *1172*, 34-53.

Erichsen, J. E. (1867). *On railway and other injuries of the nervous system*. Philadelphia: Henry C. Lea.

Escalas, J. E., & Stern, B. B. (2003). Sympathy and empathy: Emotional responses to advertising dramas. *Journal of Consumer Research*, *29*, 566-578.

Evans, F. B. (1996). *Harry Stack Sullivan. Interpersonal theory and psychotherapy*. London: Routledge.

Falloon, I. R. (2003). Family interventions for mental disorders: Efficacy and effectiveness. *World Psychiatry*, 2, 20-28.

Fassin, D., & Rechtman, R. (2009). *The empire of trauma. An enquiry into the condition of victim hood*. New Jersey: Princeton University Press.

Fellner, J. (2006). Corrections quandary: Mental illness and prison rules. *Harvard Civil Rights-Civil Liberties Law Review*, *41*, 391-591.

Felman, S., & Laub, D. (1992). *Testimony: Crises of witnessing in literature, psychoanalysis and history*. New York: Routledge.

Ferster C.B., & Skinner, B. F. (1957). *Schedules of reinforcement*. New York: Appleton-Century- Crofts.

Figley, C. R. (Ed.) (1995). *Compassion fatigue: Coping with secondary traumatic stress disorder*. New York: Brunner/Mazel.

Figley, C. R. (1999). Compassion fatigue: Towards a new understanding of the costs of caring. In B. H. Stamm (Ed.), *Secondary traumatic stress: Self-care issues for clinicians, researchers and educators* (2nd ed., pp. 3-28). Lutherville, MD: Sidran Press.

Figley, C. R. (2002). Compassion fatigue: Psychotherapists' chronic lack of self care. *Journal of Clinical Psychology*, *58*, 1433-1441.

Finkel, T., & Holbrook, N. J. (2000). Oxidants, oxidative stress and the biology of ageing. *Nature*, *408*, 239-247.

Finkelhor, D., Ormrod, R. K., &Turner, H.A. (2007). Poly-victimization: A neglected component in child victimization. *Child Abuse & Neglect*, *31*, 7-26.

Freud, S. (1896). Zur atiologie der hysterie (The origin of hysteria). London: Imago.

Folkman, S. (1984). Personal control and stress and coping processes: A theoretical analysis. *Journal of Personality and Social Psychology*, *46*, 839-852.

Ford, J. D. (2009). *Posttraumatic stress disorder: Scientific and professional dimensions*. San Diego: Academic Press.

Foucault. M. (1961). *Histoire de la folie* [The history of madness]. London: Routledge.

Foucault, M. (1972). *Power/knowledge. Selected interviews and other writings, 1972-1977.* New York: Pantheon Books.

Foucault, M. (1981). "'*Omnes et singulatim': vers une critique de la raison politique*." [Omnes and singulatim ': Towards a critique of political reason]. Paris: Gallimard.

Foucault, M. (1988). *Madness and civilization: A history of insanity in the age of reason*. New York: Vintage.

Fultz, J., Schaller, M., & Cialdini, R. B. (1988). Empathy, sadness, and distress. Three related but distinct vicarious affective responses to another's suffering. *Personality and Social Psychology Bulletin*, *14*, 312-325.

Furman, W., & Buhrmester, D. (1985). Children's perceptions of the personal relations of their social networks. *Developmental Psychology*, *21*, 1016-1024.

Gair, S. (2012). Feeling their stories. Contemplating empathy. Insider/outsider positioning's and enriching qualitative research. *Qualitative Health Research, 22*, 134- 143.

Gallant, T. W. (1991). *Risk and survival in ancient Greece: Reconstructing the rural domestic economy.* Stanford: Stanford University Press.

Garrison, E. P. (1991). Attitudes toward suicide in ancient Greece. *Transactions of the American Philological Association, 121*, 1-34.

Garton, S. (1994). Sound minds and healthy bodies: Re-considering eugenics in Australia, 1914-1940. *Australian Historical Studies*, *26*, 163 -181.

Goffman, E. (1963). *Stigma: Notes on a spoiled identity*. New York. Simon and Schuster.

Goleman, D. (1995). *Emotional Intelligence. Why it can matter more than IQ.* London: Bloomsbury.

Gollins, T. (2001). Male carers: A study of the inter-relations between caring, male identity, and age. *Sheffield online papers in social research shop*. Retrieved from: http://www.shef.ac.uk/socst/Shop/gollins.pdf

Gomm, R. (1996). Mental health and inequality. In R. Gomm., T. Heller., R. Muston., S Pattison., & J. Reynolds (Eds.). *Mental health matters: A reader* (pp. 110-120). Basingstoke: Macmillan Education.

Greenberg, S. A., Shuman, D. W., & Meyer, R. G. (2004). Unmasking forensic diagnosis. *International Journal of Law and Psychiatry*, *27*, 1-15.

Grob, G, N. (1991). Origins of DSM-I: A study in appearance and reality. *The American Journal of Psychiatry, 148,* 421-431.

Grohol, J. M. (2013). DSM-5 changes: PTSD, trauma and stress-related disorders. Retrieved from: http://pro.psychcentral .com/dsm-5-changes-ptsd-trauma-stress-reated-disorders/004406.html

Guerin, B. (2004). *Handbook for analysing the social strategies of everyday life*. Reno: Context Press.

Hagen, E. H. (2003). The bargaining model of depression. In P. Hammerstein (Ed.). *Genetic and cultural evolution of cooperation* (pp. 95-123). Cambridge: MIT Press.

Hårde, A. (2005). The emergence of warfare in the early bronze age: The Nitra group in Slovakia and Moravia, 2200-1800 BC. *Warfare, Violence and Slavery in Prehistory, British Archaeological Reports (International Series)*, *1*, 87-105.

Hartup, W. W. (2009). Critical issues and theoretical viewpoints. In R, H. Kenneth., W. M. Bukowski., & B. Laursen., (Eds.). *Handbook of peer interactions, relationships, and groups. Social, emotional, and personality development in context* (pp. 3-19). New York: Guilford Press.

Heider, F. (1944). Social perception and phenomenal causality. *Psychological Review*, *51*, 358-374.

Hellawell, D. (2006). Inside-out: Analysis of the insider-outsider concept as a heuristic device to develop reflexivity in students doing qualitative research. *Teaching in Higher Education*, *11*, 483-494.

Hemmings, R. (2005). "The blameless physician": Narrative and pain, Sassoon and Rivers. *Literature and Medicine*, *24*, 109-126.

Henderson, J. (2004). *Deinstitutionalisation and the construction of community care in Australian mental health policy*. Melbourne: Australian Sociological Association and La Trobe University.

Herman, J. L. (1992). Complex PTSD: A syndrome in survivors of prolonged and repeated trauma. *Journal of Traumatic Stress*, *5*, 377-391.

Herman, J. L. (1992). *Trauma and recovery*. New York: Basic Books.

Herman, J. L. (1995). Crime and memory. *Journal of the American Academy of Psychiatry and the Law Online*, *23*, 5-17.

Herman, J. L. (1997). *Trauma and recovery: The aftermath of violence from domestic abuse to political terror*. New York: Basic Rooks.

Herman, J. (2000). *The case of trauma and recovery. Conversation with Judith Herman MD*. Conversations with History: Institute of International Studies, UC Berkeley. Retrieved from: https://www.youtube.com/watch?v=USTKmffoQms

Herrman, H., Saxena, S., & Moodie, R. (2005). *Promoting mental health: concepts, emerging evidence, practice.* A report of the World Health Organization, Department of Mental Health and Substance Abuse in collaboration with the Victorian Health Promotion Foundation and the University of Melbourne. World Health Organization.

Hobfoll, S. E. (1998). *Stress, culture and community. The psychology and philosophy of stress*. New York: Plenum Press.

Hofer, J. (1688). Dissertatio medica de nostalgia [Medical dissertation on nostalgia] (C. Anspach Trans). *Bulletin of the History of Medicine*, *2*, 376-91.

Hogan, R, (1982). A socioanalytic theory of personality. In R. A. Dienstbier., & M. M. Page (Eds.). *Personality: Current theory and research* (pp. 55-89). Nebraska Symposium on Motivation. Lincoln: University of Nebraska Press.

Hollins, K. (2000). Between two worlds: the social implications of cochlear implantation for children born deaf. In J. Hubert (Ed.). *Madness, disability and social exclusion: The archaeology and anthropology of difference* (pp. 180-195). London: Routledge.

Holmes, J. (1999). Ethical aspects of psychotherapies. In S. Bloch., P. Chodoff., & S. A. Green. (Eds.). *Psychiatric ethics* (3rd ed.). New York: Oxford University Press.

Homans, G. C. (1951). *The human group*. New York: Routledge.

Hooker, K., Monahan, D., Shifren, K., & Hutchinson, C. (1992). Mental and physical health of spouse caregivers: The role of personality. *Psychology and Aging, 7*, 367-375.

Horowitz, M. (2006). A life in but not under stress. In C. R., Figley (Ed.) *Mapping trauma and its wake. Autobiographic essays by pioneer trauma scholars. Psychosocial Stress Series.* (pp. 85-94). New York: Routledge.

Hochschild, A. R. (1995). The culture of politics: Traditional, postmodern, cold-modern, and warm-modern ideals of care. *Social Politics: International Studies in Gender, State & Society*, *2*, 331-346.

Houts, A. C. (2000). Fifty years of psychiatric nomenclature: Reflections on the 1943 War Department Technical Bulletin, Medical 203. *Journal of Clinical Psychology*, *56*, 935-967.

Howorth, P. (2000). The treatment of shellshock. Cognitive therapy before its time. *The Psychiatrist*, *24*, 225-227.

Humphrey, L, L., & Benjamin, L. S. (1986). Using structural analysis of social behaviour to assess critical but elusive family processes. A new solution to an old problem. *American Psychologist*, *41*, 979-989.

Huneman, P. (2008). Montpellier vitalism and the emergence of alienism in France (1750-1800): The case of the passions. *Science in Context*, *21*, 615-647.

Hunt, C. K. (2003). Concepts in caregiver research. *Journal of Nursing Scholarship*, *35*, 27-32.

Ironside, W. (1980). Conservation-withdrawal and action-engagement: On a theory of survivor behaviour. *Psychosomatic Medicine, 42*, 163-175.

Jeffreys, D., & Tait, J. (2000). Disability, madness, and social exclusion in dynastic Egypt. In J. Hubert (Ed.). *Madness, disability and social exclusion: The archaeology and anthropology of difference* (pp. 87-95). London: Routledge.

Jemeka, R., Trupin, E., & Chiles, J. A. (1989). The mentally ill in prisons: A review. *Hospital and Community Psychiatry, 40,* 481–491.

Jenkins, S. R., & Baird, S. (2002). Secondary traumatic stress and vicarious trauma: A validational study. *Journal of Traumatic Stress*, *15*, 423-432.

Jones, F. D. (1995). Psychiatric lessons of war**.** In R. Zajtchuk (Ed.). *War psychiatry. The textbook of military medicine* (pp. 1-33). Washington: Office of The Surgeon General United States of America.

Jones, E. (2006). Historical approaches to post-combat disorders. *Philosophical Transactions of the Royal Society of London B: Biological Sciences*, *361*, 533-542.

Jordan, J. V. (1992). *Relational resilience (Work in Progress No. 57).* Wellesley: Stone Center Working Paper Series.

Kahill, S. (1988). Symptoms of professional burnout: A review of the empirical evidence. *Canadian Psychology, 29*, 284-297.

Kahn, J. P. (2013). *Angst: Origins of anxiety and depression*. New York: Oxford University.

Kate, N., Grover, S., Kulhara, P., & Nehra, R. (2013). Caregiving appraisal in schizophrenia: A study from India. *Social Science & Medicine*, *98*, 135-140.

Kazdin, A. E., & Blase, S. L. (2011). Rebooting psychotherapy research and practice to reduce the burden of mental illness. *Perspectives on Psychological Science*, *6*, 21-37.

Kennedy, C. H., & McNeil, J. A. (2006). A history of military psychology. In C. H. Kennedy & E. A. Zillmer (Eds.). *Military psychology: Clinical and operational applications* (pp. 1-17). New York: Guildford.

Kessler, R. C., Aguilar-Gaxiola, S., Alonso, J., Chatterji, S., Lee, S., Ormel, J., Bedirhan Üstün T., & Wang, P. S. (2009). The global burden of mental disorders: An update from the WHO World Mental Health (WMH) surveys. *Epidemiologia e Psichiatria Sociale*, *18*, 23-33.

Kilby, J. (2002). Redeeming memories: The politics of trauma and history. *Feminist Theory*, *3*, 201-210.

Kirmayer, L. K. (1996). Landscapes of memory: Trauma, narrative, and dissociation. In P. Antze & M. Lambeck (Eds.). *Tense past: Cultural essays in trauma and memory* (pp. 172-198). New York: Routledge.

Kiselica, M. S., & Robinson, M. (2001). Bringing advocacy counselling to life. The history, issues and human dramas of social justice work in counselling. *Journal of Counseling and Development*, *79*, 387-397.

Kishur, G. R. (1984). *Chiasmal effects of traumatic stressors: The emotional costs of support*. Unpublished master's thesis. Purdue University.

Kisiel, C. L., Fehrenbach, T., Torgersen, E., Stolbach, B., McClelland, G., Griffin, G., & Burkman, K. (2014). Constellations of interpersonal trauma and symptoms in child welfare: Implications for a developmental trauma framework. *Journal of Family Violence*, *29*, 1-14.

Kleining, G., & Witt, H. (2001). Discovery as basic methodology of qualitative and quantitative research. Retrieved from: http://www.qualitative research.net/index.php/fqs/article/view/977/2130.

Kraemer, H. C. (2007). DSM categories and dimensions in clinical and research contexts. *International Journal of Methods in Psychiatric Research, 16*, 8-15.

Krell, R. (1984). Holocaust survivors and their children: Comments on psychiatric consequences and psychiatric terminology. *Comprehensive Psychiatry*, *25*, 521-528.

Kymalainen, J. A., & Weisman de Mamani, A. G. (2008). Expressed emotion, communication deviance, and culture in families of patients with schizophrenia: a review of the literature. *Cultural Diversity and Ethnic Minority Psychology*, *14*, 85-91.

La Berge, A. F. (1992). *Mission and method: The early nineteenth-century French public health movement*. Cambridge: Cambridge University Press.

Lakeman, R. (2008). Practice Standards to improve the quality of family and carer participation in adult mental health care: An overview and evaluation. *International Journal of Mental Health Nursing, 17,* 44-56.

Lanzetta, J. T., & Englis, B. G. (1989). Observers' vicarious emotional responses. *Journal of Personality and Social Psychology*, *56*, 543-554.

Lasiuk, G. C., & Hegadoren, K. M. (2006). Posttraumatic stress disorder part I: Historical development of the concept. *Perspectives in Psychiatric Care*, *42*, 13-20.

Lasswell, H. (1930). *Psychopathology and politics*. Chicago: University of Chicago Press.

Lauder, W., Kroll, T., & Jones, M. (2007). Social determinants of mental health: the missing dimensions of mental health nursing? *Journal of Psychiatric and Mental Health Nursing, 14,* 661-669.

Lawn, S., Barbara, A., Walsh, J., Springgay, M., & Sutton, P. (2013). *The bond we share: Experiences of caring for a person with mental and physical health conditions*. Croatia: INTECH Open Access Publisher.

Lazarus, R, S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.

Leach, E. (1976). *Culture and communication: The logic by which symbols are connected. An introduction to the use of structuralist analysis in social anthropology*. Cambridge University Press.

Leed, E. (2000). Fateful memories: Industrialized war and traumatic neuroses. *Journal of Contemporary History*, *35*, 85-100.

Lefley, H. P. (1996). *Family caregiving in mental illness*. Thousand Oaks: Sage Publications.

Leifman, S. (May, 2010). History of mental illness. [Video file] Retrieved from: www.youtube.com/watch?v=8yxYAQvGV78

Leiss, W. (2011). Modern science, enlightenment, and the domination of nature: No exit?. *Critical ecologies: The Frankfurt school and the contemporary environmental crisis* (pp. 25-26). Retrieved from: http://www.uta.edu/huma/agger/fastcapitalism/2_2/leiss.html

Lemke, T. (2001). 'The birth of bio-politics': Michel Foucault's lecture at the Collège de France on neo-liberal governmentality. *Economy and society*, *30*, 190-207.

Levenson, J. D., & Halpern, B. (1980). The political import of David's marriages. *Journal of Biblical Literature*, *99*, 507-518.

Lewin, K. (1936). A dynamic theory of personality: Selected papers. *The Journal of Nervous and Mental Disease*, *84*, 612-613.

Lewin, K. (1939). Field theory and experiment in social psychology: Concepts and methods. *American Journal of Sociology*, *44*, 868-896.

Lewin, K. (1952). *Field theory in social science*. London: Tavistock.

Leys, R. (2000). *Trauma: A genealogy*. Chicago: University of Chicago Press.

Lifton, R. J. (1973). *Home from the war. Vietnam veterans: Neither victims nor executioners*. Oxford: Simon & Schuster.

Lifton, R. J. (1979). *The broken connection: On death and the continuity of life*. Washington, DC: American Psychiatric Press.

Lightfoot, K. G. (1995). Culture contact studies: Redefining the relationship between prehistoric and historical archaeology. *American Antiquity*, *60*, 199-217.

Light, E., Kerridge, I., & Robertson, M. (2012). Out of sight, out of mind: Making involuntary community treatment visible in the mental health system. *The Medical Journal of Australia, 196*, 591-593.

Light, E., Kerridge, I., Ryan, C., & Robertson, M. (2012). Community treatment orders in Australia: rates and patterns of use. *Australasian Psychiatry*, *20*, 478-482.

Lindemann, E. (1944). Symptomatology and management of acute grief. *American Journal of Psychiatry*, *101*, 141-148.

Linden W., Earle T. L., Gerin W. and Christenfeld N. (1996). Physiological stress reactivity and recovery: Conceptual siblings separated at birth? *Journal of Psychosomatic Research, 42*, 117-135.

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, *27*, 363-385.

Lowenthal, D. (1975). Past time, present place: Landscape and memory: *Geographical Review*, *65*, 1-36.

Lunch W. L., & Sperlich P. W. (1979). American public opinion and the war in Vietnam. *The Western Political Quarterly*, *32*, 21-44.

Lyotard, J. F. (1984). *The postmodern condition: A report on knowledge*. Minnesota: University of Minnesota Press.

Machado, N., & Burns. T. (1998). Complex social organization: Multiple organizing modes, structural incongruence, and mechanisms of integration. *Public Administration, 76*, 355–386.

Maddi, S. R., Harvey, R. H., Khoshaba, D. M., Lu, J. L., Persico, M., & Brow, M. (2006). The personality construct of hardiness, III: Relationships with repression, innovativeness, authoritarianism, and performance. *Journal of Personality*, *74*, 575-598.

Magoro, P, Q., Gripp, R., Mcdowell, D, J., & Miller, I, W. (1978). *The mental health industry: A cultural phenomenon*. New York: John Wiley and Sons.

Markus, H. (1977). Self-schemata and processing information about the self. *Journal of Personality and Social psychology*, *35*, 63-78.

Markus, H. R., & Kitayama, S. (1991). Culture and the self: Implications for cognition, emotion, and motivation. *Psychological Review*, *98*, 224-253.

Markus, H., & Nurius, P. (1986). Possible selves. *American Psychologist*, *41*, 954-969.

Martinez, D. B. (2005). Mental health care after capitalism. *Radical Psychology*, *4:*2.

Maslow, A. H. (1943). A theory of human motivation. *Psychological Review*, *50*, 370-396.

Mayes, R., & Horwitz, A. V. (2005). DSM-III and the revolution in the classification of mental illness. *Journal of the History of the Behavioral Sciences*, *41*, 249-267.

McCann, I. L., & Pearlman, L. A. (1990). Vicarious traumatization: A framework for understanding the psychological effects of working with victims. *Journal of Traumatic Stress*, *3*, 131-149.

McCann, I. L., & Pearlman, L. A. (1992). Constructivist self-development theory: A theoretical framework for assessing and treating traumatized college students. *Journal of American College Health*, *40*, 189-196.

McFarlane, A. C., & De Girolamo, G. (1996). The nature of traumatic stressors and the epidemiology of posttraumatic reactions. In B. A. Van der Kolk., A. C. Mcfarlane., & L. Weisaeth (Eds.). *Traumatic Stress. The effects of overwhelming experience on mind, body and society* (pp. 129-154). London: Guilford Press.

McFetridge, G., Aldana, J., Hardt, J., & Slavinski, Z. (2004). *Peak states of consciousness: Theory and applications (Vol. 1). Breakthrough techniques for exceptional quality of life*. Hornby Island: Institute for the Study of Peak States Press.

McKnight, J. (1977). Professional service business. *Social Policy*, *8*, 110-116.

Mead, S., & Hilton, D. (2003). Crisis and connection. *Psychiatric Rehabilitation Journal*, *27*, 87-94.

Memmi, A. (1986, May-June). Racism today-us and them. *Unesco Courier*, p. 14.

Mendelssohn, K. (1971). A scientist looks at the pyramids: Engineering evidence connected with the building of the great pyramids suggests conclusions that go far beyond the problems of pyramid design. *American Scientist*, *59*, 210-220.

Mendelson, G. (1987). The concept of posttraumatic stress disorder: A review. *International Journal of Law and Psychiatry*, *10*, 45-62.

Merton, R. K. (1957). *A social theory and social structure*. New York: The Free Press.

Mithen, S. (1996). *The prehistory of the mind. A search for the origins of art, religion and science*. London: Thames and Hudson.

Moen, P., Robison, J., & Dempster-McClain, D. (1995). Caregiving and women's well-being: A life course approach. *Journal of Health and Social Behavior*, *36*, 259-273.

Morreale, S. P., Spitzberg, B. H., & Barge, J. K. (2007). *Human communication: Motivation, knowledge, and skills*. Belmont: Thompson Wadsworth.

Morrow, M., Hankivsky, O., & Varcoe, C. (2004). Women and violence: The effects of dismantling the welfare state. *Critical Social Policy*, *24*, 358-384.

Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods, 1(2)*, 13-22.

Murthy, S. S. N. (2003). The questionable historicity of the Mahabharata. *The Electronic Journal of Vedic Studies*, *10(5)*, 1-15.

Myers, A. B. (1870). *On the etiology and prevalence of diseases of the heart among soldiers*: *The Alexander Prize essay*. London. John Churchill and Sons.

Myers, C. (1915). A contribution to the study of shell shock. Being an account of three cases of loss of memory, vision, smell, and taste, admitted into the Duchess of Westminster's War Hospital, Le Touquet. *The Lancet*, *185*, 316-320.

Nastasi B, K., & Schensul, S. L. (2005). Contributions of qualitative research to the validity of intervention research. *Journal of School Psychology*, *43*, 177-195.

Nelson, B.S., & Wright, D. W. (1996). Understanding and treating post-traumatic stress disorder symptoms in female partners of veterans with PTSD. *Journal of Marital and Family Therapy*, *22*, 455-467.

O'Hagan, M. (2003*). Force in mental health services. International user/ survivor perspectives*. Keynote address. World Federation for Mental Health Biennial Congress, Melbourne. Retrieved from: http://www.maryohagan.com/resources/Text_Files/ Force%20Paper.pdf

O'Hagan, M. (2010). Leadership for empowerment and equality: A proposed model for mental health user/survivor leadership. *International Journal of Leadership in Public Services, 5(4)*, 34-43.

Olsen, D. P. (2003). Influence and coercion: Relational and rights-based ethical approaches to forced psychiatric treatment. *Journal of Psychiatric and Mental Health nursing*, *10*, 705-712.

O'Neal, J. C. (1998). Auenbrugger, corvisart, and the perception of disease: The Johns Hopkins University Press. *Eighteenth-Century Studies, 31*, 473-489.

O'Neal, J. C. (2007). Understanding and interpreting confusion: Philippe Pinel and the invention of psychiatry. *Lumen: Selected Proceedings from the Canadian Society for Eighteenth-Century Studies*, *26*, 243-258.

Orlinsky, D. E. (1989). Researchers' images of psychotherapy: Their origins and influence on research. *Clinical Psychology Review*, *9*, 413-441.

O'Sullivan, L. (2012). The time and place of nostalgia: Re-situating a French disease. *Journal of the History of Medicine and Allied sciences*, *67*, 626-649.

Owen, A, R, G. (1971). *Hysteria, hypnosis and healing. The work of J.M. Charcot*. London: Dobson Books.

Oxford Dictionaries (2016). Oxford University Press. Retrieved from: https://www.oxforddictionaries.com/

Pakenham, K. I., Bursnall, S., Chiu, J., Cannon, T., & Okochi, M. (2006). The psychosocial impact of caregiving on young people who have a parent with an illness or disability: Comparisons between young caregivers and non-caregivers. *Rehabilitation Psychology*, *51*, 113-126.

Pardess, E. (2005). Training and mobilizing volunteers for emergency response and long-term support. *Journal of Aggression, Maltreatment & Trauma*, *10*, 609-620.

Parkes, K. R. (1994). Personality and coping as moderators of work stress processes: Models, methods and measures. *Work & Stress*, *8*, 110-129.

Paris, B. J. (2009). *Bargains with fate: Psychological crisis and conflicts in Shakespeare and his plays*. New Jersey: Transaction Publishers.

Patel, V., Flisher, A. J., Hetrick, S., & McGorry, P. (2007). Mental health of young people: A global public-health challenge. *The Lancet*, *369*, 1302-1313.

Paulson, D. S., & Krippner, S. (2007). *Understanding PTSD in war veterans including women reservists and those coming back from Iraq*. Westport: Praeger.

Pavalko, E. K., & Woodbury, S. (2000). Social roles as process: Caregiving careers and women's health. *Journal of Health and Social Behavior*, *41*, 91-105.

Paynter, R. (1989). The archaeology of equality and inequality. *Annual Review of Anthropology, 18*, 369 -399.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, *30*, 583-594.

Pearlman, L. A., & Saakvitne, K. W. (1995). Treating therapists with vicarious traumatization and secondary traumatic stress disorders. In C. R. Figley (Ed.). *Compassion fatigue: Coping with secondary traumatic stress disorder in those who treat the traumatized*. *Psychosocial Stress Series* (pp. 150-177). London: Brunner Mazel.

Pedersen, D (2002). Political violence, ethnic conflict, and contemporary wars: Broad implications for health and social well-being. *Social Science & Medicine*, *55*, 175-190.

Peele, R., & Chodoff, P. (1999). The ethics of involuntary treatment and deinstitutionalisation. In S. Bloch., P. Chodoff & S. A. Green. (Eds.). *Psychiatric Ethics.* (3rd ed.). (pp. 423-440). New York: Oxford University Press.

Peña, D. G. (2011). Structural violence, historical trauma, and public health: The environmental justice critique of contemporary risk science and practice. In L. M. Burton., S. P. Kemp., M. Leung., S. A. Matthews., & D. T. Takeuchi (Eds.). *Communities, neighbourhoods, and health* (pp. 203-218). New York: Springer.

Pepys, S. (1666). *The diary of Samuel Pepys*. H. B. Wheatley (Ed.). (1952). London: Bell. Retrieved from: https://archive.org/details/diaryofsamuelpep10pepy

Perry, H. S. (1982). *Psychiatrist of America: The life of Harry Stack Sullivan*. New York: W.W. Norton and Company.

Phillips, J. (1985). Distance absence and nostalgia. In D. Ihde., & H. J. Silverman (Eds.). *Descriptions: Selected studies in phenomenology and existential* philosophy, 11, **(**pp. 64-75). Albany: State University of New York Press.

Piedmont, R. L. (1999). Does spirituality represent the sixth factor of personality? Spiritual transcendence and the five-factor model. *Journal of Personality*, *67*, 985-1013.

Pilgrim, D., & Rogers, A. (1999). *A sociology of mental health and illness*. (2nd ed.). Philadelphia: Open University Press.

Pilgrim, D., & Rogers, A. (2009). Survival and its discontents: The case of British psychiatry. *Sociology of Health & Illness*, *31*, 947-961.

Pilgrim, D., Rogers, A., & Bentall, R. (2009). The centrality of personal relationships in the creation and amelioration of mental health problems: the current interdisciplinary case. *Health*, *13*, 235-254.

Pitman, R, K., Sparr, L., Saunders, L, S., & McFarlane., A. C. (1996). Legal issues in post-traumatic stress disorder. In B. A. Van der Kolk., A. C. McFarlane., & L. Weisaeth (Eds.). *Traumatic stress. The effects of overwhelming experience on mind, body and society*, (pp. 378-397). London: Guilford Press.

Platt, S. (1985). Measuring the burden of psychiatric illness on the family: An evaluation of some rating scales. *Psychological Medicine*, *15*, 383-393.

Porges, S. W. (2001). The polyvagal theory: Phylogenetic substrates of a social nervous system. *International Journal of Psychophysiology*, *42*, 123-146.

Porter, D. (Ed.). (1994). *The history of public health and the modern state*. Amsterdam: Rodopi.

Porter, D. (1998). New approaches to the history of health and welfare. *Bulletin of the History of Medicine*, *72*, 83-93.

Powdermaker, F., & Frank, J. (1953). *Group psychotherapy*. Cambridge, MA: Harvard University Press.

Prugh, D. G., & Harlow, R. G. (1961). " Masked deprivation" in infants and young children. *Public Health Papers*, *14*, 9-29.

Radey, M., & Figley, C. R. (2007). The social psychology of compassion. *Clinical Social Work Journal*, *35*, 207-214.

Radstone, S. (2007). Trauma theory: Contexts, politics, ethics. *Paragraph*, *30*, 9-29.

Ramsey, M. (1994). Public health in France. In D. Porter, (Ed.). *The history of public health and the modern state* **(**pp. 45-118.). Amsterdam: Rodopi.

Raphael, B. (2006). Life, trauma and loss. In C. R. Figley (Ed.). *Mapping trauma and its wake: Autobiographic essays by pioneer trauma scholars*. *Psychosocial Stress Series*. (pp. 153-168). New York: Routledge.

Ray, S. L. (2008). Evolution of posttraumatic stress disorder and future directions. *Archives of Psychiatric Nursing*, *22*, 217-225.

Repper, J., & Perkins, R. (2003). *Social inclusion and recovery. A model for mental health practice.* London: Elsevier Science.

Repper, J., & Perkins, R. (2009). Recovery and social inclusion. In P. Callaghan., J. Playle, & L. Cooper (Eds.). *Mental Health Nursing Skills* (pp. 85-95). Oxford: Oxford University Press.

Reynolds, B., & Seeger W. M. (2005). Crisis and emergency risk communication as an integrative model. *Journal of Health Communication*, *10*, 43-55.

Ribeiro, O., Paúl, C., & Nogueira, C. (2007). Real men, real husbands: Caregiving and masculinities in later life. *Journal of Aging studies*, *21*, 302-313.

Rieff, P. (1968). *The triumph of the therapeutic: Uses of faith after Freud*. New York. Harper Torchbooks.

Rivers, W. H. R. (1918). The repression of war experience. *Proceedings of the Royal Society of Medicine*, *11*, 1-20.

Rocco, C. (1994). Between modernity and postmodernity: Reading dialectic of enlightenment against the grain. *Political Theory*, *22*, 71-97.

Rolfe, T., Sheehan, B., & Davidson, R. (2008). Are consumers on community treatment orders informed of their legal and human rights? A West Australian study. *International Journal of Mental Health Nursing*, *17*, 36-43.

Rosen, G. (1972). Percussion and nostalgia. *Journal of the History of Medicine and Allied Sciences*, *27*, 448-450.

Rosenbloom, D. J., Pratt, A., C, &Pearlman, L. A. (1999). Helpers responses to trauma work: Understanding and intervening in an organization. In B. H. Stamm (Ed.). *Secondary traumatic stress. Self- care issues for clinicians, researchers, and educators*, (2nd ed.). (pp. 65-79). Maryland: Sidran Press.

Rosenhan, D, L. (1973). On being sane in insane places. *The American Association for the Advancement of Science, 179*, 250-258.

Roth, T. L., & Sullivan, R. M. (2005). Memory of early maltreatment: Neonatal behavioural and neural correlates of maternal maltreatment within the context of classical conditioning. *Biological Psychiatry*, *57*, 823-831.

Sabin-Ferrell, R., & Turpin, G. (2003). Vicarious traumatization: Implications for the mental health of workers. *Clinical Psychology Review*, *23*, 449-480.

Safran D. (1990) Towards a refinement of cognitive therapy in light of Interpersonal Theory. *Clinical Psychology Review, 10*, 87-105.

Salmon, T. W. (1917). The care and treatment of mental diseases and war neuroses: Shell shock in the British army. *Mental Hygiene, 1*, 509-547

Sapir, E. (1934). Personality. *Encyclopaedia of the Social Sciences*, *12*, 85-88.

Sapir, E. (1936-37). The contribution of psychiatry to an understanding of behavior in society. *American Journal of Sociology, 42*, 862-870.

Saunders, J, C. (2003). Families living with severe mental illness: A literature review. *Issues in Mental Health Nursing*, *24*, 175-198.

Savage, S., & Bailey, S. (2004). The impact of caring on caregivers' mental health: A review of the literature. *Australian Health Review, 27*, 103-109.

Schetzer, A. (2016, May 22). In search of the least worst option. *Sunday Age*, p. 27.

Schmiedebach, H. P. (1999). Post-traumatic neurosis in nineteenth-century Germany: A disease in political, juridical and professional context. *History of Psychiatry, 10*, 27-57.

Scott, J. P. (1989). *The evolution of social systems. Monographs in psychobiology. An integrated approach (Vol. 3)*. New York: Gordon and Breach Science.

Shah, A. J., Wadoo, O., & Latoo, J. (2010). Psychological distress in carers of people with mental disorders. *British Journal of Medical Practitioners*, *3(3)*, 18-25.

Shakespeare, W. (1942). *The complete plays and poems of William Shakespeare*. Boston: Houghton Mifflin Company.

Shapiro, M. J. (1969). Rational political man: A synthesis of economic and social-psychological perspectives. *American Political Science Review*, *63*, 1106-1119.

Shaw, I. (Ed.). (2000). *The Oxford history of ancient Egypt*. Oxford: Oxford University Press.

Shay, J. (1994). *Achilles in Vietnam. Combat trauma and the undoing of character*. New York: Scribner.

Shay, J. (2002). *Odysseus in America. Combat trauma and the trials of homecoming*. New York: Scribner.

Sheldon, A., Traustadóttir, R., Beresford, P., Boxall, K., & Oliver, M. (2007). Disability rights and wrongs? *Disability & Society*, *22*, 209-234.

Shin, D. H. (2011). Understanding e-book users: Uses and gratification expectancy model. *New Media & Society*, *13*, 260-278.

Shoda, Y., Mischel, W., & Peake, P. K. (1990). Predicting adolescent cognitive and self-regulatory competencies from preschool delay of gratification: Identifying diagnostic conditions. *Developmental Psychology*, *26*, 978-986.

Sieber S, D. (1974). Toward a theory of role accumulation: *American Sociological Review*, *39*, 567-578.

Slade, M., Amering, M., Farkas, M., Hamilton, B., O'Hagan, M., Panther, G., Perkins, R., Shepherd, G., Samson, T., & Whitley, R. (2014). Uses and abuses of recovery: Implementing recovery-oriented practices in mental health systems. *World Psychiatry*, *13*, 12-20.

Slade, M., Adams, N., & O'Hagan, M. (2012). Recovery: past progress and future challenges. *International Review of Psychiatry, 24*, 1-4.

Smith, M. (1945). Social situation, social behaviour, social group. *Psychological Review, 52*, 224-229.

Smith, M. S. (1998). The heart and innards in Israelite emotional expressions: Notes from anthropology and psychobiology. *Journal of Biblical Literature*, *117*, 427-436.

Smith, R. (2008). *Social security as a developmental institution? Extending the solar case for the relative efficacy of poor relief provisions under the English old poor law. Brooks World Poverty Institute Working Paper.* Manchester. University of Manchester.

Snow, N., & Austin, W. J. (2009). Community treatment orders: The ethical balancing act in community mental health. *Journal of Psychiatric and Mental Health Nursing*, *16*, 177-186.

Snyder, W. U. (1947). The present status of psychotherapeutic counselling. *Psychological Bulletin*, *44*, 297-386.

Snyder, C. R. (1988). From defences to self-protection: An evolutionary perspective. *Journal of Social and Clinical Psychology*, *6*, 155-158.

Somers, M., & Gibson, G, D. (1994). Reclaiming the epistemological ‘other’: Narrative and the social constitution of identity. In C. Calhoun (Ed.). *Social theory and the politics of identity* (pp. 37-99). Oxford: Blackwell.

Spinazzola, J., Blaustein, M., & Van Der Kolk, B. A. (2005). Posttraumatic stress disorder treatment outcome research: The study of unrepresentative samples? *Journal of Traumatic Stress*, *18*, 425-436.

Spitzer, R. L., & Wakefield, J. C. (1999). DSM-IV diagnostic criterion for clinical significance: Does it help solve the false positives problem? *American Journal of Psychiatry*, *156*, 1856-1864.

Sprott, W. J. H. (1958). *Human groups*. Harmondsworth: Penguin Books

Stamm, B. (2005). *The professional quality of life scale: Compassion satisfaction, burnout & compassion fatigue/secondary trauma scales*. Lutherville: Sidran Press.

Stam, R., & Spence, L. (1983). Colonialism, racism and representation. *Screen*, *24(2)*, 2-20.

Stanford Encyclopedia of Philosophy. (2005). *The Metaphysics Research Lab, Center for the Study of Language and Information*. Retrieved from: https://plato.stanford.edu/

Stearns, A. W., & Schwab, R. S. (1943). Five hundred neuro-psychiatric casualties at a naval hospital. *Journal of the Maine Medical Association*, *34*, 81-89.

Stepping Up (2007). *A social inclusion action plan for mental health reform: 2007-2012*. Retrieved from: http://www.sahealth.sa.gov.au/wps/wcm/connect/8ea68b804308c5cfb076fa2cf7cfa853/steppingupmentalhlthreform0712-socinclusion-2010.pdf?MOD=AJPERES

Stern, D. (1985). *The interpersonal birth of the infant*. New York: Basic Books.

Sullivan, H. S. (1937). A note on the implications of psychiatry, the study of interpersonal relations, for investigations in the social sciences. *American Journal of Sociology*, *42*, 848-861.

Sullivan, H. S. (1942). Psychiatry, the army, and the war. *Psychiatry*, *5*, 435–442.

Sullivan, H. S. (1948). Towards a psychiatry of peoples. *Psychiatry*, *11*, 105-116.

Sullivan, H. S. (1953). *The interpersonal theory of psychiatry* (H. S. Perry, & M. G. Gawell, Eds.). New York: Norton and Company.

Sullivan, H. S. (1954). *The psychiatric interview*. (H. S. Perry, & M. G. Gawell, Eds.). New York: Norton and Company.

Sullivan, H. S. (1956). *Clinical studies in psychiatry*. (Eds.). (H. S. Perry, M. G. Gawell, & M. Gibbon, Eds.). New York: The Norton Library.

Sullivan, H. S. (1962). *Schizophrenia as a human process*. New York: Norton & Company.

Sullivan, H.S. (1964). *The fusion of psychiatry and social sciences.* New York: Norton.

Sullivan, R. M. (2003). Developing a sense of safety. *Annals of the New York Academy of Sciences*, *1008*, 122-131.

Szasz, T. S. (1970). *Ideology and insanity. Essays on the psychiatric dehumanisation of man*. Maryland: Penguin.

Szasz, T. S. (1973). *The myth of mental illness. Foundations of a theory of personal conduct*. St Albans: Paladin

Szasz, T. S. (1974). *The myth of mental illness* (Rev. ed.). New York: Perennial.

Szasz, T. S. (1977). *Theology of medicine: The political-philosophical foundations of medical ethics*. New York: Harper & Row.

Szmukler, G. (1996). From family 'burden' to caregiving. *The Psychiatrist*, *20*, 449-451.

Szmukler, G. (2008). Treatment pressures, coercion and compulsion in mental health care. *Journal of Mental Health*, *17*, 229-231.

Szmukler, G., & Appelbaum, P. S. (2008). Treatment pressures, leverage, coercion, and compulsion in mental health care. *Journal of Mental Health*, *17*, 233-244.

Sztompka, P. (2004). The trauma of social change: A case of post-communist societies. In J. C. Alexander., R. Eyerman., B. Giesen., N. Smelser., & P. Sztompka. (Eds.). *Cultural trauma and collective identity* (pp. 155-195). Berkeley: University of California Press.

Talbot, I., & Verrinder, G. (2010). Health promotion in context: Primary health care and the new public health. In L. Talbot & G. Verrinder (Eds.). *Promoting health: The primary health care approach*, (4th ed). (pp. 1-31) Marrickville. Elsevier Australia.

Tedeschi, R, G., & Calhoun L, G. (1995). *Trauma and the transformation. Growing in the aftermath of suffering*. Thousand Oaks: Sage publications.

Teghtsoonian, K. (2009). Depression and mental health in neoliberal times: A critical analysis of policy and discourse. *Social Science & Medicine*, *69*, 28-35.

Thoits, P. A. (2003). Personal agency in the accumulation of multiple role-identities. In P. J. Burke, T. J. Owens, R. T. Serpe, and P. A. Thoits (Eds.). *Advances in identity theory and research* (pp. 179-194). Boston: Springer.

Thomas, G. (2011). A typology for the case study in social science following a review of definition, discourse, and structure. *Qualitative Inquiry*, *17*, 511-521.

Tick, E. T. (2005). *War and soul. Healing our nations veterans from Post-Traumatic Stress Disorder*. Wheaton: Quest Books.

Trevarthen, C. (2001). The neurobiology of early communication: Intersubjective regulations in human brain development. In A.F. Kalverboer & A Gramsbergen (Eds.). *Handbook on brain and behavior in human development* (pp. 841-882). Dordrecht: Kluwer Academic Publishers.

Turner, R.H. (1988). Personality in society: Social psychology's contribution to sociology. *Social Psychology Quarterly*, *51*, 1-10.

Tyrka, A. R., Price, L. H., Kao, H-T., Porton, B., Marsella, S. A., & Carpenter, L. L. (2010). Childhood maltreatment and telomere shortening: Preliminary support for an effect of early stress on cellular aging. *Biological Psychiatry*, *67*, 531-534.

United Nations. (1991). *Principles for the protection of persons with mental illness and for the improvement of mental health care*. Retrieved from: http://www.un.org/esa/ socdev/enable//rights/wgrefa12.htm

Valent, P. (1995). Documented childhood trauma (Holocaust): Its sequelae and applications to other traumas. *Psychiatry, Psychology and Law*, *2*, 81-89.

Valent, P. (2002). Diagnosis and treatment of helper stresses, traumas, and illnesses. In Figley, C. R. (Ed.). *Treating compassion fatigue* (pp. 17-37). New York: Brunner-Routledge.

Valent, P. (2007). Eight survival strategies in traumatic stress. *Traumatology*, *13*, 4-14.

Van Der Hart, O., Nijenhuis, E., Steele, K., & Brown, D. (2004). Trauma-related dissociation: Conceptual clarity lost and found. *Australian and New Zealand Journal of Psychiatry*, *38*, 906-914.

Van der Kolk, B. A. (1996). Trauma and memory. In B. A. Van der Kolk., A. C. McFarlane & L. Weisaeth (Eds.). *Traumatic stress: The effects of overwhelming experience on body, mind and society* (pp. 279-302). New York: Guilford Press.

Van der Kolk, B. A. (2000). Posttraumatic stress disorder and the nature of trauma. *Dialogues in Clinical Neuroscience*, *2*, 7-22.

Van der Kolk, B. A. (2002). In terror's grip: Healing the ravages of trauma. *Cerebrum*, *4*, 34-50.

Van der Kolk, B. A., Weisaeth, L. & Van der hart, O. (1996). History of trauma in psychiatry. In B. A. Van der Kolk., A. C. McFarlane & L. Weisaeth (Eds.). *Traumatic stress: The effects of overwhelming experience on body, mind and society* (pp. 47-76). London: Guilford Press.

Van der Walt, C. (2011). Hearing Tamar's voice: How the margin hears differently. Contextual readings of 2 Samuel 13:1-22. *Lectio difficilior. European Journal for Feminist Exegesis*, *2*, 1-25.

Viljoen, J. (2001). Deconstructing secondary trauma and racism at a south African Police station. (Unpublished master's thesis). University of South Africa. Pretoria

Vischer, R. (1873). On the optical sense of form: A contribution to aesthetics. *Empathy, form, and Space: Problems in German Aesthetics*, *1893*, 89-124.

Wachtel, P. L. (1972). Cognitive style and style of adaptation. *Perceptual and Motor Skills*, *35*, 779-785.

Wadsworth, Y. (1998). What is participatory action research? Action Research International, Paper 2. *Action Research International*. Retrieved from: http://www.aral.com.au/ari/p-ywadsworth98.html

Waerness, K. (1987). On the rationality of caring. In A. S. Sassoon (Ed.). *Women and the state* (pp. 207-234). London: Hutchinson.

Watts, L., & Hodgson, D. (2015). Assessing the needs of carers of people with mental illness: Lessons from a collaborative study. *Practice*, *28*, 235-252.

Watson, J. B. (1913). Psychology as the behaviourist views it. *Psychological Review*, *20*, 158-177.

Weitz, R. (2007). *The sociology of health, illness, and health care: A critical approach* (4th ed.). Belmont CA: Thompson Wadsworth.

Wessely, S. (2005). Risk, psychiatry and the modern military. *The British Journal of Psychiatry, 186*, 459-466.

White, L. (1949). Energy and the evolution of culture. In L. White (Ed.). *The Science of Culture* (pp. 363-393). New York: Farrar, Strauss & Giroux.

Whiteford, H. A., & Buckingham, W. J. (2005). Ten years of mental health service reform in Australia: Are we getting it right? *Medical Journal of Australia*, *182*, 396-400.

Whiteford, H., Buckingham, B., & Manderscheid, R. (2002). Australia's national mental health strategy. *The British Journal of Psychiatry*, *180*, 210-215.

Wilcock, A. A. (2007). Occupation and health: Are they one and the same? *Journal of Occupational Science*, *14*, 3-8.

Wiles, J. (2003). Informal caregivers' experiences of formal support in a changing context. *Health and Social Care in the Community*, *11*, 189-207.

Wilson, J. P., Lindy, J. D., & Raphael, B. (1994). Empathic strain and therapist defense: Type I and II CTRs. In J. P. Wilson, & J. D. Lindy (Eds.). *Countertransference in the treatment of PTSD* (pp. 31-61). New York: Guilford Press.

Winter, J. (2000). Shell-shock and the cultural history of the great war. *Journal of Contemporary History*, *35*, 7-11.

World Health Organization. (1948). *Constitution of the World Health Organization*. *Basic Documents*. Geneva: World Health Organization.

World Health Report (2001). *Mental health: New understanding, new hope*. Geneva: World Health Organization.

World Health Organisation. (2013). *International Classification of Diseases (ICD)*. Retrieved from: http://www.who.int/classifications/icd/en/

World Health Organisation (2015). *International Statistical Classification of Diseases and Related Health Problems 10th Revision*. Retrieved from: http://apps.who.int/classifications/icd10/browse/2015/en

Wooley, C. F. (1982). Jacob Mendez Dacosta: Medical teacher, clinician, and clinical investigator. *American Journal of Cardiology, 50*, 1145-1148.

Wright, H. (1986). The evolution of civilizations. In D. J. Meltzer, D. D. Fowler & J. A. Sabloff (Eds.). *American Archeology Past and Future* (pp. 323-365). Washington, DC: Smithsonian Inst. Press.

Wynne, L., Singer, M., & Toohey, M. (1976). Communication of the adoptive parents of schizophrenics. In J. Jorstad & E. Ugelstad (Eds.), *Schizophrenia 75: Psychotherapy, family studies, research* (pp. 413-452). Universitetsforlaget: Oslo.

Yalom, I. D. (1975). *The practice of group psychotherapy* (2nd ed.). New York: Basic Books.

Yinger, J. (1965). *Toward A field theory of behaviour: Personality and social structure*. New York: Mcgraw-Hill.

Young, I. M. (1990) *Justice and the politics of difference*. Princeton: Princeton University Press.

Youniss, J. (1980). *Parents and peers in social development: A Sullivan/Paiget perspective*. Chicago. University of Chicago Press.

Zeegers, P. (2002). A revision of the Biggs' study process questionnaire (R-SPQ). *Higher Education Research and Development*, *21*, 73-92.

Zimmering, R., Munroe J., and Gulliver S, B. (2003). Secondary traumatisation in mental health care providers. Retrieved from: http://www.psychiatrictimes.com/ptsd/content/article/10168/47641