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**Clinicians' Understanding of ICD-10 Diagnostic Criteria
For F62.0 Enduring Personality Change After
Catastrophic Experience**

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A thesis submitted in fulfillment of the requirements for the degree of
Doctor of Philosophy

School of Occupation and Leisure Sciences

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The University of Sydney

March 2006

DECLARATION

I declare that this thesis submitted in fulfillment of the requirements for the degree of Doctor of Philosophy is my own work completed under the guidance of my principal supervisor, Professor Gwynnyth Llewellyn and my associate supervisor, Professor Derrick Silove.

Ruth O. Beltran

ACKNOWLEDGEMENTS

Completing this thesis has been a very long, challenging, comfortable, and sometimes not so comfortable journey. I am indebted to a host of people in arriving at my destination having achieved the level of understanding of the work articulated in this thesis.

First of all, I would like to express my heartfelt thanks to my supervisors, Professor Gwynnyth Llewellyn and Professor Derrick Silove for their very competent and supportive guidance.

When Gwynnyth agreed to supervise me I expressed to her that I did not wish to be pressured into finishing my PhD in a hurry for reasons she and I are fully aware of. I admire and respect her for respecting my wishes. I was also acutely aware of my responsibilities as a student. Now that this thesis is complete I am sure Gwynnyth can sigh with big relief. As my primary supervisor Gwynnyth was such an expert guide and awesome challenger. She stretched my intellect from all corners in this thesis. With my writing, she was an editor in chief extraordinaire. She also assumed the role of a friend whenever I needed one in between PhD conversations.

Derrick started me in this PhD project. His expertise and mentorship in the area of psychiatry and organized violence provided me with ideas and insight to pursue in this project. This thesis is only the second of a three stage project that Derrick planned for EPCACE. My special thanks to Derrick's unit – the Psychiatry Research and Teaching Unit, University of New South Wales, based at Liverpool Hospital for the numerous supports extended for the expert opinion survey and this thesis. I benefited greatly from Zachary Steel's and Vijaya Manicavasagar's collegial support in this unit. I also owe Derrick his immense help and expert practitioner advice during my mental health crisis while life and this thesis were going on. As my first ports of call during that crisis, he and Gwynnyth provided very reassuring assistance.

I am indebted to the clinicians who participated in this study and the centre managers who paved the way for me to access them. The clinicians generously shared their experiences with me and these form part of the substance of this thesis.

The School of Occupation and Leisure Sciences provided me with a lot of help for this project – internal school grant, study leave, pre-completion grant, etc. Thank you! The company of the staff of the School and my academic

colleagues and their accomplishments in similar journeys were a source of motivation and encouragement.

Part of the growth of this project is indebted to the conceptual discussions I have had with my family at the dinner table when I had to describe my thesis in a language they can understand. One weekend I had a flash of “aha!” when Katrina and Alex facilitated my understanding of where this thesis is going using concept maps. I was so impressed to hear Katrina’s thoughts through her words while at the same time expressing them through her hand by drawing figures and lines and writing her spoken words.

I also received technical support from my children and their partners: Katrina for her help in editing the first draft and final formatting, Chris for his statistical support in the exploratory study, Alec and Luna for document scanning and printing. I am deeply grateful for their time and their willingness to help. Meanwhile Penelope and Amelie arrived in this world and provided another dimension to life in addition to this project. This thesis took the backstage when they were around. They are such a gem and provide so much joy. Time with them seems like an endless flow experience.

I am not sure whether I would have coped with the pressures of a PhD, full time work, and family life without the loving support and care of Alex. He made sure I had fun while doing my PhD. Thank you so much.

I thank my thesis examiners for their constructive critique and valuable comments and suggestions. Their expert validation of this fledgling project gave me such a boost.

This thesis is dedicated to the struggles of trauma survivors whose amazing spirit is deeply moving. However as an academic, a health professional, and a global citizen I can not rest and be complacent about this knowledge of survivors' resiliency.

“Apart from the inner qualities of the survivors, a primary condition for their rehabilitation is to live in a world free from fear, injustice and authoritative coercion” (de Wind, 1972, p.176).

I know that I need to do something more than a PhD thesis.

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CHAPTER 1

INTRODUCTION

Enduring personality change after catastrophic experience (EPCACE) is a diagnostic category included for the first time in 1992 in the ICD-10 (*International Statistical Classification of Diseases and Related Health Problems*, 10th revision) Mental and Behavioural Disorders Chapter as one of the adult personality disorders (WHO, 1992a).

The distorting impact of extreme trauma on personality functioning was already recognized in World War I veterans (Kardiner, 1959; Kardiner & Spiegel, 1947) and in survivors of the Nazi holocaust (Eitinger, 1959), prompting the introduction of terms such as the "concentration camp" or "KZ syndrome" (Chodoff, 1966) and the "survivor syndrome" (Niederland, 1968a). Clinical descriptions included not only symptoms of anxiety, chronic depression, widespread psychosomatic complaints and disturbances in cognition and memory, but also behavioural changes such as isolation, social withdrawal and the "musselman syndrome" of extreme apathy and regression. Other clinicians described a pattern of persisting anger and hostility in survivors who, it was suggested, had lost the capacity to modulate aggressive feelings that led to major social handicap and family dysfunction (de Wind, 1972).

Problems relating to explosive anger, interpersonal difficulties and feelings of mistrust which border on transient bouts of paranoia, continue to be described in elderly Holocaust survivors (Bower, 1994), in survivors of torture (Doerr-Zegers, Hartmann, Lira, & Weinstein, 1992; Silove, Tarn, Bowls, & Reid, 1991; Turner, Gorst, Unsworth, 1990), and in combat veterans (Parson, 1988).

In an attempt to systematise these observations and prior to the publication of ICD-10 in 1992 and the DSM-IV in 1994, it was suggested by clinician-researchers such as Horowitz and Marmar (Horowitz, Weiss, & Marmar, 1987; Marmar & Horowitz, 1988; Marmar, 1991) that there may be an identifiable "posttraumatic character disorder" following certain forms of severe trauma which is not captured by the term posttraumatic stress disorder. Following this suggestion, other clinician-researchers proposed the introduction of a category of "complex traumatic stress disorder", now referred to in the literature by various names such as complex posttraumatic stress disorder (complex PTSD) (Herman, 1992a), Disorder of Extreme Stress (DES) (Pelcovitz, van der Kolk, Roth, Mandel, Kaplan, & Resick, 1997), also known as Disorder of Extreme Stress Not Otherwise Specified (DESNOS) (Herman, 1993).

The PTSD diagnostic category has not satisfied all in the field. Thus, studies examining the feasibility of a group of trauma related symptoms not encompassed by PTSD diagnostic category have been published.

The complexity of adaptation to trauma has been highlighted in studies of specific symptoms including dissociation, somatization and affect regulation (van der Kolk, Pelcovitz, Roth, Mandel, McFarlane, & Herman, 1996) and in studies of psychiatric consequences of “ethnic cleansing” (Weine, Becker, Vojvoda, Hodzic, Sawyer, Hyman, Laub, & McGlashan, 1998). Although dissociation, somatization and affect regulation are listed as associated features of PTSD, studies have found that these symptoms tend not to occur in isolation but can co-occur in the same individual. Even those who no longer suffer from PTSD continue to exhibit the above symptoms. It therefore appears that PTSD as a diagnosis does not capture the complexity of the relationships of these symptoms in an individual. This finding has raised the possibility of an alternative diagnostic category and the need for alternative approaches.

Some studies (Jongedijk, Varlier, Schreuder, & Gersons, 1996) have identified symptoms that may differentiate DESNOS from simple PTSD. These symptoms are dissociation, conversion, despair and hopelessness, affect regulation, modulation of anger, suicidal preoccupation, feeling that nobody can understand, somatization and loss of previously held beliefs. One study (van der Kolk et al, 1996) also found that DESNOS coexisted with PTSD. Studies supporting the clinical utility of this symptom cluster for sexual abuse survivors (Dickinson, de Gruy, Dickinson, & Candib, 1998), US combat veterans (Newman, Orsillo, Herman, Niles, & Litz, 1995), and Dutch war veterans (Jongedijk, 1996) have been reported. A study conducted among US

war veterans showed DESNOS as a reliable predictor of poor inpatient treatment outcomes (Ford & Kidd, 1998).

Issues were raised by the above studies however. These include the lack of specificity of the DESNOS criteria and the difficulty of making a diagnosis of complex PTSD because of the absence of core symptoms and the presence of numerous diffuse and loosely connected ones. These studies have also yielded identification of various symptoms from different populations who experienced trauma. Despite some endorsement in principle for this new symptom cluster indicating complex PTSD, DESNOS as a diagnostic category was excluded in DSM-IV (*Diagnostic and statistical manual of mental disorders*, 4th ed.) (APA, 1994). Instead its identified features were included as associated features of PTSD (APA, 1994).

In contrast ICD-10 (WHO, 1992a, 1992b, 1993) included a new diagnostic category, EPCACE. This category includes the following criteria: pervasive hostility or mistrust, social withdrawal, feelings of emptiness or hopelessness, being chronically on edge and estrangement. The category specifies that the stress must be of such an extreme nature (for example, torture, and imprisonment in a concentration camp) so as to plausibly account for the observed personality changes, irrespective of the person's prior level of adaptation. Importantly, single or short-term life threatening events such as motor vehicle accidents are excluded as possible precipitating experiences.

EPCACE was also reviewed for consideration in DSM-IV. (See Shea's review, 1996). This review found evidence of personality pathology after experiencing extreme trauma which was characterised by a pattern of multiple symptomatology and maladaptive features. As Shea (1996) concluded, personality change can occur without pre-existing vulnerability, and there is some overlap of EPCACE with PTSD (Shea, 1996). Like DESNOS, EPCACE is not included in DSM-IV.

Studies on ICD-10 EPCACE are still in the early stage. One exploratory study conducted by the author and her colleague (Beltran & Silove, 1999), raised critical issues about the validity of EPCACE particularly the lack of specificity of the EPCACE criteria and the difficulty of operationalizing a broadly defined set of criteria. Furthermore, additional characteristics, behaviours and symptoms were identified by experts in the field. This suggests a more comprehensive array of adaptational changes that survivors of trauma experience than the current definition of EPCACE allows for. In other words, it appears that current EPCACE criteria are insufficient to encompass these changes. The aim of this study was to therefore examine the symptoms that clinicians observe in their clients and to determine whether these conform to or exceed current EPCACE criteria.

There is an ongoing debate about whether DESNOS (DSM) and EPCACE (ICD) are indeed one and the same. There is a recognizable similarity between DESNOS (DSM) and EPCACE (ICD) (Roth, Newman, Pelcovitz, van der

Kolk, & Mandel, 1997). Yet in a related matter comparing ICD-10 and DSM-IV criteria for posttraumatic stress, Peters, Slade, and Andrews (1999) concluded that ICD-10 criteria for Posttraumatic Stress Disorder cannot be assumed to be identical to DSM-IV criteria for the same disorder. It appears that discrepancies can arise from the way the criteria are defined and the inclusion or exclusion of a criterion in one system and not the other (Peters, Slade, & Andrews, 1999). Such a finding adds weight to the possibility that ICD-10 EPCACE is not the same as DESNOS. However, addressing the hypothesis that EPCACE is different to DESNOS is beyond the scope of this study. Instead, this study focuses attention on how trauma clinicians understand EPCACE. This is done by examining their experiences with, and observations of, their clients who present problems relating to potential personality change.

The criticisms leveled at EPCACE by experts in the exploratory study (Beltran & Silove, 1999) are fundamental given that this diagnostic category is relatively new in the standard international classification system (ICD). The issues raised by the experts in that study on reliability, validity and clinical utility are critical due to the impact of accurate categorization on the diagnostic and treatment process. With increasing numbers of people around the world subjected to situations of extreme stress, refinement of the criteria of EPCACE is urgently needed. In addition to personality changes, they also may suffer from a multiple array of adaptational problems. These are not currently encompassed by EPCACE criteria. As the exploratory study

demonstrated, the lack of well articulated criteria for a diagnostic category may undermine the confidence of clinicians in using the category for diagnostic and treatment purposes.

In order to clarify EPCACE criteria, the overall aim of this study was to examine how clinicians describe the symptoms that they observe in their clients which conform to or exceed the criteria of EPCACE. The specific research questions were: (1) how do clinicians describe typical personality changes they see in their clients using the EPCACE criteria? (2) Do clinicians identify any one or more symptom/s that could be considered as core criterion/criteria of EPCACE? (3) Do clinicians identify other behaviours, symptoms or character changes that are not encompassed by EPCACE criteria? The answers to these questions are essential to establishing the descriptive validity of this diagnostic category.

In this thesis, I employed Alfred Schutz' (Schutz, 1973) social phenomenological view to understand clinicians' perspective. Simply put, this view understands clinicians as social actors in their everyday world of trauma work. They experience and make sense of this world through their common-sense knowledge, or to use a Schutzian term, typifications. I also recognize that clinicians from various professional backgrounds who work closely with survivors of trauma, have their own unique view and perceptions about personality change that they see in their clients. However, the Schutzian perspective acknowledges that these potentially differing views and

perceptions are influenced by the cultural and social settings in which clinicians work (Schutz, 1973).

ICD-10 has two sets of documents describing the criteria for EPCACE. These are the Diagnostic Criteria for Research (DCR) (WHO, 1993) and Clinical Descriptions and Diagnostic Guidelines (CDDG) (WHO, 1992b). I use the ICD-10 EPCACE Clinical Descriptions and Diagnostic Guidelines (CDDG) and the Diagnostic Criteria for Research (DCR) as the primary tools for exploration in this thesis. I then employed Schutz's social phenomenological perspective to this thesis by producing an interpretative composite description of clinicians' understanding and interpretations (their typifications) of the criteria of EPCACE as seen in their clients and their critical appraisal of the utility of the EPCACE category. The research design is qualitative employing a focused in-depth interview method as the data collection procedure. In brief, to adequately explore clinicians' views and experiences about EPCACE, a semi-structured interview was conducted with those working in the area of torture and refugee trauma, war trauma and sexual assault trauma. Qualitative data analysis procedures guided by the "framework approach" outlined by Ritchie and Spencer (1994) were employed to analyse the data.

The thesis is arranged in the following manner. Chapter 2 provides an expanded discussion of the literature on personality and adaptational changes related to trauma, and highlights issues that provide direction for this study.

Chapter 3 elucidates the social phenomenological perspective and the methods and procedures employed to explore how clinicians understand EPCACE criteria. Chapter 4 presents the interpretative composite description of EPCACE criteria developed from the typification of clinicians and the clinicians' critique of EPCACE. The discussion chapter, Chapter 5, interprets the results of the study and the last chapter, Chapter 6, presents the conclusions and implications arising from this study.

The unique contribution of this thesis is the critical examination of a trauma related diagnostic category included for the first time in the WHO sponsored international classification system, ICD-10. This study, to the best of my knowledge is the first to critically examine the ICD-10 EPCACE criteria and to do so from the perspective of those required to work with these criteria in their daily practice. Implications for research, policy and clinical practice arise from the key findings of the strengths and limitations of the clinical utility of the EPCACE.

CHAPTER 2

LITERATURE REVIEW

In this chapter I examine the literature on what is currently known about the ICD-10 diagnostic category EPCACE – Enduring Personality Change After Catastrophic Experience. I start this chapter by broadly discussing the context within which the issues surrounding EPCACE are situated. In sections 2.1 to 2.3, I provide a brief background discussion of the two current classification systems of psychiatric disorders, ICD and DSM. In section 2.4 I provide an overview of the existing trauma syndromes contained in both classification systems. In sections 2.5 and 2.6 I discuss the evidence of personality changes identified in literature on combat trauma, sexual assault and trauma in the refugee population. Following this, I discuss issues surrounding the EPCACE category (sections 2.7 and 2.8) and go on to issues in relation to clinical diagnostic process (sections 2.9 and 2.10). In the final section, I present the need for and scope of this current study in light of the gaps in knowledge about EPCACE.

2.1 Systems of Classification of Mental Disorders

Nosology, the study and practice of classification of disorders and diseases, is a fundamental part of the theory and practice of medicine (Bogenschutz & Nurnberg, 2000). Psychiatric classification is an integral part of the conceptual framework of clinical psychiatry (Bertelsen, 1999). There are two standard

nosological systems that guide diagnostic practice in psychiatry. One is the Diagnostic and Statistical Manual of Mental Disorders (DSM) (APA, 1994) now in its fourth edition known as DSM-IV-TR (Text Revision) (APA, 2000) and the other is the International Statistical Classification of Diseases and Related Health Problems (ICD-10) system, in its tenth edition (WHO, 1992). DSM-IV is the system developed by the American Psychiatric Association for use in the United States and is widely accepted internationally while ICD-10, developed by the World Health Organization (WHO), is the official classification system used in Europe and in other parts of the world. Both systems were designed to correspond with each other using the same categories and codes (Bogenschutz & Nurnberg, 2000). Both systems are descriptive, based on explicit operational diagnostic criteria, are multi-axial in format and both claim theoretical neutrality (Bogenschutz & Nurnberg, 2000).

2.1.1 Categorical Diagnosis Systems

Classification can take either a categorical or dimensional system approach. With a categorical system, the disorder is either present or not present. With dimensional systems, there are no discrete categories. Individuals are described along continuous factors that usually have a normal distribution throughout the whole population.

Frances, First, and Pincus (1995) discussed the advantages and disadvantages of both systems in classifying mental disorders. According to these authors, a categorical strategy is most useful in classifying disorders that have clear

boundaries while a dimensional system is better for labeling borderline cases. Unfortunately, most mental disorders are characterized by unclear boundaries and heterogeneity within a category (Frances, First, & Pincus, 1995). In fact, DSM-IV makes no assumption that each diagnostic category is a completely discrete entity (APA, 1994). A disadvantage of the dimensional strategy is the difficulty of knowing which dimensions are most useful and accessible to measurement; there is also a concern that adapting this system may obscure what could in fact be distinct and independent categories (Frances, First, & Pincus, 1995).

A categorical system of classification is most frequently observed in medicine and psychiatry and DSM-IV and ICD-10 reflect this. However there is little evidence that such a system is more useful or valid than a dimensional system (Bogenschutz & Nurnberg, 2000; Frances, First, & Pincus, 1995). For example, the purported categorical nature of personality disorders has been questioned (Bogenschutz & Nurnberg, 2000) and has become the source of difficulties, one of which is the difficulty of arriving at a single diagnosis of personality disorder (Pichot, 1994). In contrast, a dimensional perspective of personality disorders is well accepted by clinicians and researchers alike as evidenced by studies supporting the dimensional classification of these disorders (McCrae, 1994; Widiger & Clark, 2000; Widiger & Sanderson, 1995).

Debates about the advantages or otherwise of categorical and dimensional models of defining personality disorders continue (see Cloninger, 1999;

Parker, 1998; Pukrop, Herpertz, Sabeta, & Steinmeyer, 1998; Trull, 2000).

Trull's (2000) recent review recommends that dimensional models of personality disorder complement the use of categorical models. He notes in sum that dimensional models help clinicians and researchers to understand the heterogeneity of symptoms and the lack of clear boundaries between categorical diagnoses (Trull, 2000).

The findings of Haslam's (2003) comprehensive qualitative review of all published taxometric studies of mental disorders indicates that some mental disorders such as eating disorders, melancholia, pathological dissociation tend to have discrete categories whilst dimensional models tend to be identified in general depression, generalized anxiety, posttraumatic stress disorder and for borderline personality disorder. It is interesting to note from this review that two other types of personality disorders, that is schizotypal and antisocial disorders, tended to be more categorical in structure (Haslam, 2003). This seems to suggest that personality disorders include a mixture of latent categories and dimensions or continua. Exclusive adherence to a polarized view may misrepresent some disorders and may omit many prominent features of psychiatric impairment and disability (Haslam, 2003). In the midst of these debates and findings, DSM-IV and ICD-10 have retained the use of the categorical system.

2.1.2 Levels of Criteria for Classification

In his review of nosological models in psychiatry, Pichot (1994) stated that criteria for classification in psychiatry and in medicine in general pertain to three levels: symptoms, mechanisms, and causes. Symptoms can be subjectively felt, include behavioural or somatic changes, and may also have temporal evolution. Mechanisms or pathogenesis include both neurophysiologic and biochemical brain processes and psychological mechanisms. Causes can belong to the psychological, social or biological spheres. According to Pichot (1994), the relationships between these three levels are complex. A syndrome, which is a combination of independent symptoms, is the expression of a mechanism; this mechanism may be triggered by one or several causes.

Pichot (1994) also noted that most nosological models are not homogeneous and may combine elements from two or three levels. This observation is demonstrated in DSM-IV and ICD-10. For example in ICD-10, EPCACE includes a list of symptom criteria and a list of examples of catastrophic events that are hypothesized causes of EPCACE; however, it does not include statements about mechanisms. Similarly in DSM-IV-TR, PTSD includes in its criteria exposure to a traumatic event and a list of symptoms that may be experienced as consequences of such exposure.

ICD-10 and DSM-IV provide a common language in psychiatry (Pichot, 1994; Shepherd, 1994). However, a common language does not guarantee

validity. In this situation, understanding which of the symptom criteria pertaining to a particular syndrome like EPCACE are significant becomes important for establishing clinical utility and valid use.

2.1.3 DSM and ICD

DSM-IV was published in 1994 (APA, 1994) and it is now in its revised text edition, known as DSM-IV-TR (APA, 2000). The history of the development of DSM-IV is well documented in these editions, in the DSM-IV Guidebook (Frances, First, & Pincus, 1995) and in a review of methods used to develop the DSM written by the chair of the DSM-IV Task Force (Frances & Egger, 1999).

In brief, the development of DSM-IV was spearheaded by a Task Force comprising a chairperson and vice-chairperson with 27 members. Work groups of 5 to 10 members researched each diagnosis supported by advisory groups of 50-100 members. According to Frances and Egger (1999), the expert consensus model is an important part of the development of the DSM-IV criteria. Members of all work groups were chosen to reflect psychiatric expertise, differing opinions and unresolved controversies with the ability to adopt a consensus view.

The task force conducted a three-stage empirical process that consisted of literature reviews, reanalysis of relevant unpublished data sets and field trials that compared DSM-III, DSM-III-R, ICD-10 and the proposed DSM-IV

criteria sets (Bogenshutz & Nurnberg, 2000; Frances, 1996; Frances & Egger, 1999). It has been argued that the use of a standard nomenclature like DSM - IV has facilitated reliability of diagnosis, communication and research on psychiatric illness (Frances & Egger, 1999). Whether or not this is the case, DSM in the DSM-III-R version for example, was translated into 13 languages and became a frequently observed but not exclusive mode in which research and clinical findings were reported (Foulks, 1996; Frances, 1996).

Although DSM-IV remains the standard nomenclature in the United States and has wide ranging influence in the practice of psychiatry worldwide, it is not without criticism. A common criticism relevant to this study relates to validity. According to Frances and Egger (1999) the DSM-IV's emphasis on observable criteria facilitates reliability without confirming the validity and clinical usefulness of the descriptive categories. According to Bogenshutz and Nurnberg (2000), the rates of co-occurrence between many of the DSM-IV diagnostic categories are higher than those found in any other branch of medicine. This brings into question whether the categories represent discrete entities or represent different aspects of larger symptom complexes or potential syndromes.

Wakefield (1997) leveled similar criticisms about the conceptual validity of DSM -IV. He noted that DSM-IV fails to distinguish a disorder from non-disorder (or problems of living) due to over inclusiveness of most of the criteria. This results in a marked tendency for increased false positives.

Similarly, Kirk & Kutchins (1992) critically questioned the scientific claims of DSM with a critique of the reliability and validity of DSM-IV.

Other criticisms leveled at DSM-IV focus on its atheoretical stance and its multiaxial system of diagnosis. These are discussed extensively by Bogenschutz and Nurnberg (2000). Conceptual issues related to DSM-IV and issues regarding its use have been comprehensively discussed by Frances, First, and Pincus (1995) and in the introductory chapter of DSM-IV-TR (APA, 2000). Its cultural application and utility have been extensively considered by Good (1996) and Kleinman (1996).

Interestingly, in contrast to ICD-10, DSM-IV provides only one set of diagnostic criteria for research and clinical purposes. This, it has been noted (Frances et al., 1995) has the major advantage of having greater generalizability of research findings into the clinical situation and promotes mutual agreement between researchers and clinicians.

In defining the future direction of DSM-IV, Frances and Egger (1999) suggested that there is a need to continue to validate the current descriptive categories whilst at the same time, “strive to define and operationalize all clinical phenomena, including functional interactions between the patient and his or her family and environment, as well as internal, intrapsychic phenomena” (p. 164). This echoes the earlier suggestions of Spitzer and Williams (1980) in relation to DSM-III that diagnostic criteria should address

all issues of validity – face, descriptive, predictive and construct. In response to recommendations such as these, this thesis aims to operationalize and refine the criteria of EPCACE and to contribute to its descriptive validity. Since the focus of this study however is a diagnostic category in ICD-10 rather than in the DSM system, I now turn to ICD-10.

Historically and as standard practice, to develop the Family of Classifications that includes ICD-10, the World Health Organization actively convenes meetings, fora and conferences involving representatives of different disciplines and various schools of thought in psychiatry from all parts of the world (Sartorius, 1992). Specifically, the developmental process behind ICD-10 involved the work of nine Collaborating Centres for the Classification of Diseases, specialty divisions (such as Mental Health) at both the headquarters and regional offices of the WHO, non-governmental organizations such as the World Psychiatric Association (WPA) and a miscellaneous panel of interested groups, advocacy groups and individuals, all working under the coordination of the WHO Unit on the Development of Epidemiological and Health Statistical Services (Bogenschutz & Nurnberg, 2000, p. 840).

Procedures for updating ICD-10 are well defined and proposals for changes are submitted to the WHO through a Collaborating Centre wherein such proposals for changes are examined. (See information on this website: <http://www.who.int/whosis/icd10/update.htm>, retrieved 12/05/2004).

ICD-10 (WHO, 1992a) was published in three volumes. Volume 1 Tabular List classifies and lists all the diseases. Volume 2 Instruction Manual includes guidance on the use of Volume 1 and history of the current classification system. Volume 3 Alphabetical Index includes the index itself and instructions for its use.

Relevant to this current study are the descriptions of diagnostic classes and categories included in Volume 1. In this volume, the Mental and Behavioural Disorders of relevance to this study are included in Chapter V and are coded with the letter F. The first digit after the letter F denotes 10 major classes of mental and behavioural disorders: F0 to F9. The second and third digits denote finer categories within a major class of disorder. For example, the code F62.0 denotes the mental and behavioural disorders chapter (F), disorders of adult personality and behaviour class (6), subclass of enduring personality changes, not attributable to brain damage and disease (2), and the specific category “enduring personality change after catastrophic experience” (0).

The description of F62.0 Enduring Personality Change After Catastrophic Experience in the ICD-10 Volume 1 includes brief statements about duration of the condition, stressor, characteristics of the condition, possible precedence of PTSD, list of catastrophic events and exclusion criterion. (See Appendix A for full description of EPCACE in ICD-10, Volume 1, Chapter V Mental and Behavioural Disorders).

Developed from Chapter V (F) of the ICD-10, the *ICD-10 Classification of Mental and Behavioural Disorders. Clinical Descriptions and Diagnostic Guidelines* (CDDG) (WHO, 1992b) was published and became available in 1992 for general clinical and educational use by psychiatrists and other mental health professionals. The development of CDDG went through several major drafts based on extensive consultations with panels of experts, national and international psychiatric societies and individual consultants. Field trials were conducted in 40 countries. The results of these trials were used in finalizing the clinical guidelines (Sartorius, 1992). Therefore EPCACE exists in two places. First, in ICD-10 Volume 1, Chapter V and in the CDDG. In comparison with Volume 1, the CDDG contains more elaborate and specific statements about the nature of the personality change and as expected, includes diagnostic guidelines. (See Appendix B for full description of EPCACE in *ICD-10 Classification of Mental and Behavioural Disorders. Clinical Descriptions and Diagnostic Guidelines*).

In 1993 the *ICD-10 Classification of Mental and Behavioural Disorders. Diagnostic Criteria for Research* (DCR) (WHO, 1993) was published. The DCR has also been extensively tested involving the work of researchers and clinicians from 32 countries. It provides more specific and more elaborated criteria for the diagnoses contained in the CDDG and was designed to be used in conjunction with CDDG (Sartorius, 1993; Sartorius, Bedirhan Üstün, Korten, Cooper, & van Drimmelen, 1995). CDDG and DCR are consistent and

compatible with one another but they differ in the degree of detail and specificity provided for each diagnostic category.

In the DCR description, as is the rule for users (WHO, 1993), the obligatory criteria are labeled with capital letters (A, B, C, etc.) and numbers are used to identify further groups of characteristics, of which only some are required for diagnosis. The criteria are clearly defined and are specified in more detail than in the more narrative equivalent statements in the CDDG. As an example see Appendix C for full description of EPCACE in *ICD-10 Classification of Mental and Behavioural Disorders. Diagnostic Criteria for Research* (DCR) (WHO, 1993).

Comparison of the field trials of ICD-10 DCR and ICD-10 CDDG found that inter-rater agreement on diagnostic assessments increases with the use of the research criteria found in DCR. Diagnostic assessments using DCR are more precise than those using CDDG, the diagnostic guidelines (Sartorius et al, 1995). This same field trial also showed however that clinician/researchers experienced difficulty in diagnosing the F6 (personality disorders) categories with over 50 % of clinician/researchers reporting moderate or low levels of confidence or ease of use (Sartorius et al, 1995). Although there was no data specifically reported about EPCACE, as one of the F6 categories it could be presumed that clinicians may also experience low levels of confidence or ease of use with this diagnostic category.

In Australia, the Australian Health Ministers' Advisory Council (AHMAC) unanimously endorsed the use of the Australian modification (AM) of the ICD-10 (ICD-10-AM) as the Australian standard for morbidity coding in health services as of 1 July 1998. The National Centre for Classification in Health (NCCH) is responsible for the development, introduction and maintenance of ICD-10-AM (NCCH, 1998, 2000, 2002a).

In 2002, NCCH published the first edition of *ICD-10-AM Mental Health Manual* designed for use by clinicians and aimed at improving the compatibility of information between community based and hospital based services. The Mental Health Manual integrates diagnostic tools and clinical guidelines into a classification (NCCH, 2002b).

The ICD-10-AM uses the same description for F62.0 Enduring Personality Change After Catastrophic Experience as the one included in ICD-10 Volume 1. The *ICD-10-AM Mental Health Manual* incorporates the description of F62.0 Enduring Personality Change After Catastrophic Experience contained in ICD-10 Volume 1 and a part of the diagnostic guidelines described in CDDG. It does not include other details previously included in CDDG such as the possibility of personality change without precedent PTSD and the statement about the exclusion of short term exposure to trauma. (See Appendix D for full description of EPCACE in *ICD-10-AM Mental Health Manual*).

In addition to Australia, other countries such as Cuba, China, India, Japan and Korea have adapted the ICD-10 Classification of Mental and Behavioral Disorders for local use (Bogenshutz & Nurnberg, 2000). The Nordic countries have done the same (Munk-Jørgensen, Bertelsen, Dahl, Lehtinen, Lindström, & Tomasson, 1999).

Criticisms about DSM-IV have also been raised about ICD-10. In the Nordic countries, the use of ICD-10 posed some difficulties in the clinical reasoning of clinicians. Munk-Jørgensen et al. (1999) identified the issue as difficulty of thinking/reasoning at different logical levels. One level is the phenomenological descriptive thinking required by the ICD-10 criteria and the other is the hermeneutic understanding and interpretation of these diagnoses in the choice of therapy needed by the individual client. In relation to the use of the research criteria, Munk- Jørgensen et al. (1999) also noted that from the Danish experience, the ICD-10-DCR fitted better with the practices learned using the DSM-III-R.

Jablensky's (1999) issues based paper investigating DSM-IV and ICD-10 classifications recognized that, in general, the operational definition and criteria contained in the current classification systems are rigorous. However as a by-product of this, the present classification systems have a poor ability to account for mixed or atypical cases.

Commenting specifically about ICD-10, estimates from clinical trials in Canada and the United States suggest that “goodness of fit” between the diagnostic criteria and the actual features of clinical cases is unsatisfactory in 18-22% of cases (Regier, Kaelber, Roper, Rae, & Sartorius, 1994, cited in Jablensky, 1999). Examining the results of the ICD-10 clinical field trial for mental and behavioural disorders in more detail, feasibility and suitability ratings for 8 out of 9 and 5 out of 9 types of personality disorders were rated low (kappa coefficients less than 0.40) by clinicians worldwide and clinicians in the United States and Canada respectively (Regier et al, 1994). For those diagnoses with low kappa coefficients, clinicians in general reported poor fit, low confidence in the use of the diagnoses, difficulty in making differential diagnoses and inadequate clinical description and diagnostic guidelines. EPCACE was not one of the personality disorders reported on in this field trial.

2.2 Concerns Regarding DSM and ICD about Trauma Related Disorders

There are a number of concerns reported in relation to DSM and ICD and classification of trauma related disorders, in particular PTSD, and concerns in relation to personality disorders.

2.2.1 Concerns in relation to Posttraumatic Stress Disorder

1. Lack of compatibility between ICD-10 and DSM-IV criteria for PTSD

Claims for compatibility exist between DSM-IV and ICD-10 (APA, 2000; Bogenschutz & Nurnberg, 2000); however Peters, Slade, and Andrews (1999) contend that ICD-10 criteria cannot be assumed to be identical to DSM-IV criteria for some disorders. These authors found that 48% of the discrepancies between the two nosological systems were due to the addition in DSM-IV of the criterion that requires that the symptoms of PTSD cause clinically significant distress or impairment (disability criterion) that is not present in the ICD-10 DCR. Andrews (2000) suggests that similar problems exist in other anxiety disorders.

2. Lack of agreement between ICD-10 DCR and ICD-10 CDDG

Another issue about PTSD concerns the use of the research criteria (DCR) and the diagnostic guidelines (CDDG). Lack of agreement between information specified in ICD-10 DCR and ICD-10 CDDG has been identified as an issue not only in PTSD but also in other anxiety disorders (Andrews, 1999). Bertelsen (1999) also noted the difficulty in making a diagnosis in relation to severity of depression because ICD-10 diagnostic guidelines and research criteria are not completely identical. Andrews (1999) contends that confusion would be lessened if these two WHO documents were in concordance. Furthermore, when ICD-10 is used PTSD is diagnosed more frequently than when using DSM-IV (Peters, Slade, & Andrews 1999).

Rosenman (2002) confirmed this finding noting that ICD-10 yields a PTSD diagnosis more than twice as often as DSM-IV.

3. Differences in emphasis placed on some criteria by DSM-IV and ICD-10

Comparison between the DSM-IV criteria for PTSD and the clinical descriptions and diagnostic guidelines (not the research criteria) of ICD-10 has been described by Yule, Williams, and Joseph (1999). Symptoms of avoidance and physiological arousal are not considered necessary in making a diagnosis of PTSD in ICD-10 although these are recognized as a frequent accompaniment to PTSD. This is not the case for DSM-IV. Both systems are in agreement that aside from the stressor criterion, intrusive recollections of the event or re-experiencing symptoms is the primary symptom in PTSD.

More recently, First and Tasman (2004) identified other differences between ICD-10 and the latest edition of DSM, DSM-IV-TR, in relation to PTSD. Both systems differ in the specificity/generality in their definition of the stressor criterion. DSM-IV-TR requires that symptoms persist for more than one month whereas ICD -10 criteria for research does not (First & Tasman, 2004).

4. Conceptual Confusions

Psychiatrists such as Burges Watson (1995) critiqued the shortcomings and conceptual confusions in the use of PTSD criteria in DSM-III-R and DSM-

IV. He pointed out the difficulty in measuring PTSD criteria; the complexity of understanding the varied ways by which symptoms can be expressed and described, such as in personal/relational terms, behavioural terms, psychosocial constructs, and cognitive and biological concepts; and, the need to understand social, psychological and biological discourses, and their influences in diagnosis and practice of psychiatry. Although not explicitly stated by this author, it seems safe to assume that these criticisms may also apply to PTSD criteria in ICD-10. It is concerns such as these that this current study tries to address by specifically uncovering the understanding of clinicians in relation to their observations and subsequent descriptions of the symptom criteria of EPCACE.

2.2.2 Concerns in relation to Personality Disorder

To reiterate, EPCACE is included in ICD-10 and classified as a personality disorder (WHO, 1992). This diagnostic category is not in DSM-IV, although DSM-IV does include personality disorder.

Conceptual and empirical issues in the study of personality disorders are well documented (see Cloninger & Sverakic, 2000; Dahl & Andreoli, 1997; Millon & Davis, 1995). Some of the issues identified by these authors include the difficulty of defining personality disorders depending on the theoretical perspective adopted whether this be, for example, cognitive, behavioural or another; the debate about using either a categorical or dimensional approach; the difficulty of drawing the boundaries between normal and abnormal

personality; the influence of culture and differing role expectations on behavioural patterns; and sometimes the difficulty of determining whether the behaviour pattern is a longstanding trait problem (Axis II disorder) or as a symptom of an existing mental illness (Axis I). Following are some issues from this suite of concerns about personality disorders that are relevant to this thesis.

1. Over inclusiveness of criteria

Wakefield (1997), in his critique, suggested that over inclusiveness of its diagnostic criteria is the basic problem of DSM-IV. He cited the example of the diagnosis of personality disorders as lacking in specific criteria and thus covering a range of normal personality variation. He surmises that this leads to failure in distinguishing what is a disorder and what is not. According to this author, the inclusion in most DSM diagnoses of the impairment requirement as a criterion does not solve the problem of false positives. It also does not offer any real guidance in deciding whether the level of impairment is sufficient to imply a disorder. He also views the impairment requirement as redundant with the symptom criteria “forming a useless tautology” (Wakefield, 1997, p.642).

Pfohl (1996) offers a different view from Wakefield. He sees the advantage of a criterion that requires a disorder to cause a significant functional impairment and personal distress on the individual. He suggests that it is a useful tool for dealing with cultural variations in traits simply because some traits or

behaviours are adaptive in some societies and not in others. He also suggests that the impairment criterion is useful in determining when treatment is needed.

2. Reliability Issue

Based on European experience, Bertelsen (1999) claims that the F6 group in ICD-10, which is the criteria for personality disorders, is the one that is most difficult to apply with any satisfactory degree of reliability. According to Bertelsen (1999), reasons for this vary depending on the criterion. One reason for the difficulty is that some of the criteria are difficult to establish from information gained from the patient. This necessitates the need for additional information from key informants using a special interview. However, Dahl and Andreoli (1997) pointed out that problems arise when accounts of the patient and other informants differ from each other. There is a need to have a systematic method of integrating discrepant information. Another difficulty contributing to the reliability issue is the requirement that the disorder be stable, inflexible and permanent. This makes clinicians hesitate to diagnose personality disorders, suggesting an inability to change that is stigmatizing (Bertelsen, 1999).

3. Contextual validity

The cultural constructionist point of view put forward by Mezzich, Otero-Ojeda, and Lee (2000) asserts that personality disorders are based on Anglo-American conceptions of personhood and codes of appropriate behaviour.

Thus it is a cultural interpretation of behaviour rather than a disorder or illness per se. This viewpoint also contends that personality disorder as a construct exists due to the medicalization of undesirable social behaviour. Accordingly, transformation in the values of society changes the discourse in relation to such behaviour and determines whether they are called disease, sin or crime. Given the disparity between cultural conceptions of personhood across societies, Mezzich et al. (2000) argues that the contextual validity of personality disorders would be subject to question. In this regard, Pfohl's (1996) suggestion that a significant functional impairment and personal distress be present is of particular importance. Otherwise the diagnostic category may be used for those who are considered 'difficult' as well as those presenting with a disorder.

4. Stability of Personality Disorder

Both ICD-10 and DSM-IV imply a definition of personality as enduring patterns of perceiving, relating to and thinking about the environment and oneself that are manifested in a range of personal and socio-cultural contexts. In turn, these enduring patterns are only problematic and become disorders when they are inflexible, maladaptive and cause significant functional impairment or subjective distress.

The central tenet that the dysfunction is persistent, pervasive, enduring and stable remains in the latest editions of the ICD and DSM classification systems despite the debate in relation to this diagnosis. In contrast however, a

review by Grilo and McGlashan (1999) found that few data support the tenet about the stability of personality disorder and suggest that personality disorders demonstrate only modest to moderate stability. This review indicated that personality disorders can improve over time and can benefit from specific treatments (Grilo & McGlashan, 1999). This finding challenges the assumption that personality disorders are enduring and stable over time. This debate over stability or otherwise of personality disorder has particular relevance to diagnostic categories such as EPCACE.

5. Distinction between Personality Disorder vs. Personality Change

Reflecting on the name of the diagnosis - Enduring Personality Change after Catastrophic Experience - the distinction between personality disorder and personality change is important to recognize. The Pocket Guide to the ICD-10 classification of mental and behavioural disorders differentiates between personality disorders and personality change (Cooper/WHO, 1994).

Accordingly these two conditions are stated to vary in their timing and mode of emergence.

Personality disorders are defined as developmental conditions that appear in late childhood or adolescence and continue into adulthood, not secondary to another mental disorder or to brain disease, and may precede and coexist with other disorders. In contrast, personality change is acquired usually during adult life, following severe or prolonged stress, extreme environmental

deprivation, serious psychiatric disorder or brain diseases or injury (Copper/WHO, 1994).

In somewhat the same manner, the DSM-IV-TR guidelines indicate that a diagnosis of personality disorder is only warranted when the onset is no later than early adulthood. DSM-IV-TR also specifies that personality changes as an outcome of general medical conditions, substance abuse or catastrophic experience do not warrant a diagnosis of personality disorder. Instead, DSM-IV-TR suggests that when personality changes appear and persist after exposure to extreme stress, PTSD should be considered as a diagnosis (APA, 2000). It is not surprising that the DSM adopts this view because it does not include an enduring personality change category in its system, thus not allowing the possibility of a separate diagnostic category. However in view of the important distinctions between personality disorder and personality change discussed above that are noted in DSM-IV and ICD-10 Pocket Guide, it becomes problematic that EPCACE currently remains classified under the broader rubric of personality disorder.

6. Personality Disorder as a pejorative label for trauma survivors

Criticisms and objections to the use of the label “personality disorder” to diagnose survivors who manifest the complex symptoms of repeated and prolonged traumatization have been raised and identified in the literature (Allen, Coyne, & Huntoon, 1998; Beltran & Silove, 1999; Herman, 1992a, 1993). For example Allen, Coyne and Huntoon (1998) suggested that use of

such label in the context of trauma is stigmatizing, pejorative and “adding insult to injury by blaming the victim” (p.292).

Resistance to using the label “personality disorder” may be due in part to health professionals’ adherence to a long held assumption that no bad events can destroy good character once formed in childhood (Shay, 1996). Shay (1996) contends that this assumption is no more prominent than in the controversy as to whether DSM-IV should admit to the possibility of posttraumatic personality changes following severe, prolonged trauma. Shay posed the question starkly: “Can any workings of bad luck produce cruel or evil actions in a good person?” (Shay, 1996 in <http://www.sidran.org/shay.html> retrieved in 12/01/2004).

2.3 Classification Systems: Other Issues

Jablensky (1999), in commenting about classification systems in psychiatry, discussed the advantages that an internationally shared framework of concepts, rule-based classification and explicit criteria offer the field of psychiatry. These advantages include greater diagnostic agreement/reliability among clinicians, improved statistical reporting on morbidity, services, treatments and outcomes; increased diagnostic standards in research, provision of an international reference system for education in psychiatry, and improved communication with consumers, carers and the public by demystifying psychiatric diagnosis and making its logic more transparent. On

the other hand, he also pointed out that the majority of the current diagnostic criteria remain provisional and some could be considered arbitrary in a sense that their definitions are based on expert consensus and best estimate without the additional benefit of hard evidence from research. Frances, First, and Pincus (1995) had reminded the users of the classification systems such as DSM-IV that there is the tendency to reify the diagnostic categories as if truly representing real independent disease entities. They argued that clinicians and others needed to realize that diagnostic categories reflect only the current state of knowledge and understanding at that time during the drafting of the versions of the classification systems. Regular revisions attempt to reflect evolving understanding of categories. Evolving understanding however needs to be built on solid empirical evidence and in particular the face and clinical utility of the classification systems categories.

In summary, the current versions of DSM and ICD remain the standard classification systems in psychiatry in different parts of the world.

Recognizing the advantages and limitations of the dimensional system, both classifications have remained basically categorical and claim compatibility with each other. Notwithstanding the politics and the debates on the development and use of DSM and ICD, both systems justify their legitimacy by providing a uniform language by which clinicians and researchers can communicate.

However, despite this facility and the claim that the criteria contained in both systems possess a level of rigour, others still contend that the common

language which clinicians use to refer to the same things is still poorly operationalized in clinical reality. The validity and clinical usefulness of the classification systems have been questioned and calls for finer definition and operationalization of criteria for some of the categories included in both systems have been put forward. The advantage and disadvantage of adapting separate clinical guidelines and research criteria or using one set of criteria for both clinical and research purposes have been discussed.

With respect to the purpose of this study for examining EPCACE, regrettably to date there is no data reported on EPCACE in ICD-10 field trials. Based on Jablensky's (1999) view, it could be inferred that EPCACE is in an arbitrary status without the benefit of hard evidence from research. The exploratory study by Beltran and Silove (1999) and the current study represent attempts to build the hard evidence in relation to this diagnostic category.

2.4 Posttraumatic Stress Disorder (PTSD) and other Traumatic Stress Disorders in the Current Classification Systems

In order to appreciate the place of EPCACE within the group of traumatic stress disorders in the current diagnostic classification system, this section presents an overview of developments in traumatic stress disorders, particularly PTSD.

2.4.1 Beginning of PTSD

Posttraumatic stress disorder (PTSD) was first included in the official nomenclature in 1980 in DSM-III (APA, 1980) and has afforded clinicians and researchers a useful concept to approach the psychological impact of traumatic and catastrophic stress. Survivors' reactions to traumatic stress and injuries have been recognized as early as the 17th century and have been known by different names such as shell shock, war neurosis, neurasthenia and traumatic neurosis (Kinzie & Goetz, 1996; Trimble, 1985; van der Kolk, Weisaeth, & van der Hart, 1996). By the mid 19th century, the phenomenon of psychological trauma and its consequences had already been recognized by pioneering clinicians in the field.

Historical accounts of trauma in psychiatry and the beginnings of PTSD are well documented. For example, the historical analysis of van der Kolk et al. (1996), explored the 19th century beginnings of theorizing about the aetiology of trauma starting from the works of physicians on whiplash injuries or what was referred to as "railroad spine" through to the works of Sigmund Freud on war neurosis and up to the recognition of PTSD. Their historical account was followed by an up to date comprehensive literature review of scientific findings and current understanding of the clinical phenomenology of PTSD (van der Kolk et al., 1996). Similarly, comprehensive as well as brief accounts (Flora, 2002; Kinzie & Goetz, 1996; Saigh & Bremner, 1999; Wilson, 1995; Young, 2000) have traced the historical evolution of PTSD criteria from as early as 17th century to DSM-IV and the history of the classification of

traumatic stress reactions within the ICD and DSM systems (Brett, 1993, 1996).

2.4.2 Traumatic Stress Disorders in ICD-10 and DSM-IV

The DSM-IV and ICD-10 systems include a spectrum of traumatic stress disorders. Within the DSM system, acute stress disorder and posttraumatic stress disorder are categorized under the Anxiety Disorders class (see DSM-IV-TR {APA, 2000} for a full description of these diagnostic categories). Within the ICD-10 system, acute stress reaction and posttraumatic stress disorder are classified under neurotic stress-related and somatoform disorders class, while enduring personality change after catastrophic experience is classified under Disorders of Adult Personality and Behaviour.

2.4.3 Progress in PTSD: Research and Practice

The last two and a half decades have seen the expansive growth in the number of clinical and research studies in the field of trauma and PTSD. The phenomenon of trauma and its consequences has been investigated from various perspectives including epidemiological studies on PTSD (Creamer, Burgess, & McFarlane, 2001; de Jong, Komproe, Van Ommeren, El Masri, Araya, Khaled, Van de Put, & Somasundaram, 2001; Kulka, Schlenger, Fairbank, Hough, Jordan, Marmar, & Weiss, 1990; McFarlane, Clayer, Bookless, 1997; Rosenman, 2002; see also epidemiological reviews: Breslau, 2001; Davidson & Fairbank, 1993; De Girolamo & McFarlane, 1996a, 1996b); and, studies that examined comorbidity of PTSD with other mental disorders

(Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995; McGorry, Chanen, McCarthy, Van Riel, McKenzie, & Singh, 1991; Momartin, Silove, Manicavasagar, & Steel, 2004).

There are numerous studies on PTSD arising from various traumatic events and experiences such as trauma of combat and the experiences of Vietnam veterans and prisoners of war (see reviews by Boman, 1990, and Cozza, 2005; Engdahl, Dikel, Eberly, & Blank, 1997; O'Toole, Marshall, Schureck, & Dobson, 1999; Solomon, 2001); natural disasters (Carr, Lewin, Webster, & Kenardy, 1997; Green & Lindy, 1994; Katz, Pellegrino, Pandya, Ng, & DeLisi, 2002; McFarlane, 1993); terrorism (see review by Lee, Isaac, & Janca, 2002); studies examining PTSD in relation to sexual assault and abuse (Green, 1993; Harvey & Herman, 1992; Herman, 1992b; Roth & Lebowitz, 1988), torture and refugee trauma (Basoglu, Mineka, Paker, Aker, Livanou, & GÖk, 1997; Mollica & Caspi-Yavin, 1992; Silove, Steel, McGorry, Miles, & Drobny, 2002; Silove, Tarn, Bowles, & Reid, 1991; Steel, Silove, Phan, & Bauman, 2002; Turner, Bowie, Dunn, Shapo, & Yule, 2003); and mass human rights violations and the ongoing trauma of asylum seeking (Silove & Schweitzer, 1993; Silove, Sinnerbrink, Field, Manicavasagar, & Steel, 1997; Steel, Silove, Bird, McGorry, & Mohan, 1999).

From a lifespan perspective, PTSD studies have not only focused on adults (Acierno, Kilpatrick, & Resnick, 1999; Yule, Williams, & Joseph, 1999) but also on children and adolescents (Feeny, Foa, Treadwell, & March, 2004;

Pynoos & Nader, 1993; Saigh, Yasik, Sack, & Koplewicz, 1999; Terr, 1995; Yule, 2001); older people (Bramsen, Van Der Ploeg, 1999; Falk, Hersen, Van Hasselt, 1994); the general population (Helzer, Robins, & McEvoy, 1987; Yule, 2001); women (Foa & Street, 2001; Ramsay, Feder, Rivas, Carter, Davidson, Hegarty, Taft, & Warburton, 2005); and various demographic groups (Norris, 1992).

Assessment (Blanchard & Buckley, 1999; March, 1999; Sparr & Pitman, 1999; Weathers & Keane, 1999) and treatment approaches have continued to develop and be examined (McFarlane & Yehuda, 2000; McNally, 1999; Schwartz, 1990). See for example reviews on behavioural and cognitive behavioural interventions (Meadows & Foa, 1999); and early intervention and psychological debriefing (Dheal, 2000; Rose, Bisson, & Wessely, 2002). Broad conceptual treatment approaches applied to specific populations such as survivors of disasters (Raphael & Wilson, 1993) and torture (Vesti & Kastrup, 1995) have been explored. Literature on pharmacological treatment of PTSD abounds (Berlant, 2001; Friedman, 1993; Sutherland & Davidson, 1999).

There is no shortage of theoretical models on PTSD. Information, emotional and cognitive processing paradigms (Creamer, Burgess, & Pattison, 1992; Dalgleish, 1999; Foa, Steketee, & Olav Rothbaum, 1989), two-factor stress response model (Horowitz, 1986), integrative psychosocial model (Williams & Joseph, 1999), integrative two-factor model (Everly, 1995), vulnerability model (McFarlane, 1990), dissociative mechanisms model (Spiegel & Cardena,

1990), and the resiliency model (Flach, 1990) have all been examined as possible explanations for the aetiology, and hence the treatment of PTSD.

Psychoneurobiology and genetics (see reviews of Burgess Watson, Hoffman, & Wilson, 1988; Friedman, 1991; Hagh-Shenas, Goldstein, & Yule, 1999; True & Pitman, 1999; Yehuda, 1998, 2001), have also been given attention in the conceptual and research literature and have lent strong support to PTSD. The cultural aspect of PTSD has also been the subject of extensive exploration (see reviews of de Silva, 1999; and also edited book of Marsella, Friedman, Gerrity, & Scurfield, 1996 on this topic).

2.4.4 PTSD and Personality Trait

Of relevance to the current study, is the linking of personality with PTSD. Williams' (1999) review of theoretical advances and empirical evidence on personality and posttraumatic stress disorder, examined the effects of personality on the individual's vulnerability to develop PTSD, how personality characteristics affect the course of PTSD, how personality can be affected by the experience of PTSD and whether a personality style is identical with PTSD. Williams (1999) tentatively concluded that a certain personality trait (neuroticism) may predispose an individual to the development of a severe and enduring PTSD and this same trait helps to maintain this disorder.

Williams' (1999) finding confirmed the findings of Reich's review (1990) almost a decade earlier. Reich cited the prospective studies done by

McFarlane (1986, 1987, 1988, cited in Reich, 1990) in which evidence was found that associates the personality trait neuroticism with predisposition toward PTSD. Reich (1990) found that evidence for this personality factor predisposing toward PTSD was fragmentary, although trending towards a positive direction. Reich also noted the highly emotionally charged issue of personality trait as a contributory factor in PTSD. This is thought problematic due to the stigma attached to mental illness and the tendency to “blame the victim” for having developed PTSD subsequent to experiencing a traumatic event.

More recent findings (Lecic-Tosevski, Gavrilovic, Knezevic, & Priebe, 2003) in a civilian population indicate that personality traits have a direct and independent influence on the development of PTSD. Personality traits also interact with previous traumatic experiences and exposure to traumatic events in terms of impact on specific symptoms of PTSD such as avoidance and intrusion. This suggests then a potential link between PTSD, personality and personality disorders.

2.4.5 PTSD and Personality Disorders

Miller (1992) in his review of the long-term effects of torture on former prisoners of war summarized the work of Green, Lindy and Grace (1985, cited in Miller, 1992) which identified several possibilities for explaining the relationship between posttraumatic stress disorder and character pathology. These hypothesized relationships include the possibility that: character

pathology and PTSD are independent of each other; character pathology may predispose individuals to develop PTSD; character pathology may function as a selector for those who find themselves in potentially high risk traumatic situations and survive as a result of trauma; and character pathology may develop as a result of the trauma itself. This last relationship most closely aligns with the ICD-10 EPCACE category.

One aspect of the relationship between PTSD and personality disorders that has attracted research attention is the relationship of borderline personality disorders (BPD) with PTSD. This has been the subject of theoretical and research explorations where trauma history is implicated in the development of personality disorders (Gunderson & Sabo, 1993; Kudler, 1993). However, trauma history is neither a sufficient nor a necessary condition for the development of borderline personality disorder; 20-40% of individuals with BPD have no apparent history of trauma (Gunderson & Sabo, 1993).

Recent findings from a study of ninety-four non-treatment seeking veterans of Operation Desert Storm (Axelrod, Morgan, & Southwick, 2005) which employed a combined prospective/retrospective design, indicate that pre existing features of borderline personality disorder accounted for a significant amount of variance in PTSD symptoms 6 months post war; combat trauma exposure accounted for 10% of the variability in borderline personality features beyond the variability accounted for by prewar borderline personality disorder features; and that PTSD symptoms measured at one month post

conflict accounted for variability in borderline personality disorder features at 6 months above and beyond the variability accounted for by prewar borderline personality features, war trauma, and age. This study suggests a complex relationship between trauma, PTSD symptoms and features of borderline personality disorder. The latter appears to be a risk factor for the development of PTSD and a consequence of living with the disruptive and debilitating effects of PTSD symptoms (Axelrod, et al., 2005). A limitation of this study was the dependence on self report measures of combat trauma experiences, PTSD symptoms and borderline personality disorder features. It also depended on retrospective account of prewar personality functioning.

Borderline personality disorder is not the only type of personality disorder implicated with PTSD. McFarlane's (2004) latest findings identified other personality disorders such as schizoid, anxious, avoidant and anankastic as co-morbid with PTSD. He hypothesized the possibility that these personality types may be adaptations to the chronic conditions of PTSD and not as pre-existing conditions (McFarlane, 2004).

2.4.6 Influence of PTSD on Personality

As to the effects of PTSD on personality, Williams (1999) found that much of the research literature in this area focuses on negative changes and mostly among Vietnam Veterans. Again, this is consistent with Reich's (1990) earlier findings. Reich's review concluded that patients who suffer from chronic PTSD have some tendency toward deleterious personality changes. He posits

that this change may have something to do with an individual's attribution of meaning placed on the traumatic event. At one extreme, some sufferers adjust to life with paranoia. At the other, what might appear as a normal adjustment to life is saddled with preoccupation with recurrent thoughts or images which leaves no energy left for work and relationships. According to Reich (1990), prior schemas about the world are so disrupted that sufferers spend their time and energy trying to cope with the emotional imbalances that these may cause.

The later findings of Scott, Stradling, and Lee (1997, cited in Scott & Stradling, 2001) suggest that about two years post trauma patients with PTSD are characterised more with deleterious personality changes than with symptoms of PTSD. Relatives capture this phenomenon by describing their family member as "they are not the person they were before" (Scott & Stradling, 2001, p. 42). These authors described the cognitive aspects of personality change manifested by patients with chronic PTSD (2 years or more post trauma) as having a negative view of self, a negative view of others and negative beliefs. Reich (1990) suggested that further delineation of the nature of personality changes is an area of urgent need for future research.

In contrast to potential negative personality changes, there are also indications in Williams' (1999) review of empirical evidence of positive adaptational changes related to coping and resilience factors. Her findings are consistent with earlier findings on survivors of the Jewish holocaust (Kahana,

Kahana, Harel, & Rosner, 1988; Robinson, Rapaport, Durst, Rapaport, Rosca, Metzger, & Zilberman, 1990). Williams (1999) also noted that attributions of personality change are relatively more common in sufferers of chronic PTSD and their relatives. More importantly, her overall findings showed that theory and research on the effects of PTSD on personality suggest there is a lack of clear distinction between a chronic disorder and personality change, a lack of longitudinal studies with various trauma populations, and difficulty disentangling and mapping the relationships of various personality factors with PTSD without the use of a common framework.

2.4.7 Other Developments in PTSD

It is worth noting at this point that the conduct of research studies on PTSD on a wider scale and the dissemination of knowledge derived from these studies has been facilitated by the use of criterion-based diagnosis of PTSD which, as discussed earlier, has provided a common language for clinicians and researchers to communicate. Parallel with the progress in research studies undertaken worldwide, there are publications such as the *Journal of Traumatic Stress* and *PTSD Research Quarterly* and professional organizations such as the International Society of Traumatic Stress Studies and its national affiliates worldwide founded to focus on study, collaboration, exchange and dissemination of knowledge on trauma and its effects. An expert consensus guideline for the treatment of PTSD has also been published (Foa, Davidson, & Frances, 1999).

In summary, the inclusion of PTSD in DSM-III relabeled a phenomenon which was previously described in the literature by various names. Scientific and clinical interest in PTSD and its consequences have steadily grown in the last two and a half decades. Of relevance to the current study is the interaction of PTSD and personality factors. Personality traits may have a direct and indirect influence on PTSD but may not be sufficient to explain the development of PTSD without considering previous life stressors and trauma exposure. Personality disorders may be a risk factor for the development of PTSD or may be a consequence of chronic PTSD.

It appears that the relationship between personality factors, trauma exposure, PTSD symptoms and the subsequent impact of these on personality is more complex than can be suggested by considering the impact of each factor alone. In considering the influence of PTSD on personality functioning, positive adaptational as well as negative changes have been identified in the literature. For deleterious influences on personality it appears that the effects go beyond the classic symptoms of PTSD. Individuals tend to present a more chronic and complex clinical picture than that which PTSD encompasses and which resembles more closely those of personality changes and difficulties. The next section therefore reviews the literature on trauma and personality change.

2.5 Trauma and Personality Change

The impact of trauma on personality and the distortions and changes it brings on personality functioning had been observed and studied as early as post World War I. Following World War II there was renewed interest in enduring personality change particularly related to concentration camp survivors, war veterans and refugees. The characteristic symptoms and manifestations of these changes and the names attributed to these symptom complexes are now discussed.

2.5.1 Concentration Camp Syndrome and Survivor Syndrome

The work of Eitinger (1964) with Holocaust survivors of concentration camp internment in Norway and Israel serves as a significant landmark for the subsequent conceptualization of complex PTSD (Herman, 1992a; see discussion on complex PTSD in this chapter) and on whose work the ICD-10 Enduring Personality Disorder after Catastrophic Experience was based (Weisaeth, 1997). Eitinger's study included six groups of concentration camp survivors – 3 in Norway and 3 in Israel totaling more than 600 people.

Among the syndromes identified by Eitinger from this study included what he called the concentration camp syndrome and chronic neurotic reactions.

Concentration camp syndrome was characterized by difficulties in memory and concentration, increased fatigue, dysphoria, emotional instability, sleep disturbances, feelings of inadequacy, amotivation, irritability and nervousness, vertigo and headaches. Chronic neurotic reactions included sleep

disturbances, anxiety, depression, hypersensitivity and difficulties in functioning and relationships. Eitinger (1964) argued that the profound changes in personality in this group of survivors can only be explained as an outcome of a trauma of the magnitude of the Holocaust independent of premorbid personality.

Chodoff (1966) reviewed the long-term personality alterations in people who experienced internment in concentration camps during Nazi occupation. These alterations were manifested as tendency toward seclusion, social isolation, helplessness and apathy, and suspiciousness, hostility and mistrust. In this same review, Chodoff (1966) also discussed the long-term psychiatric consequences in terms of symptomatology. These included anxiety, startle reaction, psychosomatic symptoms, phobia, obsessive rumination, depression and survival guilt. All these manifestations were referred to as “concentration camp syndrome” with anxiety, depression and survival guilt as core symptoms.

Notwithstanding these effects, Chodoff (1966) cited the work of Lifton (1961) on the long-range positive effects of brainwashing in concentration camps. Paradoxically, in some cases survivors developed emotional strength, empathy, greater flexibility and confidence in relationships as a result of their trauma experience. Chodoff’s review also emphasized the overriding role of traumatic events as a factor in personality change over the influence of individual personality factors. This was evident in studies of concentration

camp survivors although it was recognized that information about the premorbid personality and developmental experiences of these survivors were not always available to permit a conclusive finding.

Niederland (1968a) described the multiple symptoms of what he called “survivor syndrome” manifested by survivors of Nazi persecution. Similar to Eitinger (1964) and Chodoff (1966), he described manifestations which included anxiety, disturbances of cognition and memory, chronic depressive states, tendency to isolation, withdrawal, and brooding seclusion; psychotic and psychosis-like symptoms; alterations of personal identity; psychosomatic conditions; and “living corpse” appearance or behaviour (Niederland, 1968a, p. 313). Niederland (1968a) attributed great importance to this latter manifestation which he described as early as 1961 (cited in Niederland, 1968a) and which was also observed by Lifton (1963, as cited in Niederland, 1968a) and De Wind (1968, as cited in Niederland, 1968a). To these observers, this manifestation indicated a pervasive psychological scar on the whole personality.

Niederland’s (1968b) description of the core symptoms of survivor syndrome is similar to Chodoff’s (1966) characterization of core symptoms of concentration camp syndrome. Neiderland (1968b) identified reactive chronic depression, anxiety syndrome and survivor guilt with the latter having a depressive component and a persecutory component. The depressive component is manifested through complete withdrawal, apathy, brooding

seclusion, depression and permanent feeling of loss and sadness. The persecutory component is manifested through constant fear, vigilance and paranoid reactions. On the other hand, Niederland (1968b) also suggested delayed positive after effects of experiencing traumatic events that are consistent with Lifton's report (1961, cited in Chodoff, 1966).

Krystal and Niederland (1968) conducted a correlational study of 149 cases selected at random to study in more detail the clinical features of the survivor syndrome. They found that in 97% of this population, anxiety was the most predominant chronic complaint. This was manifested in chronic tendency to worry, vigilance and multiple phobias, diffused fears about persecutions and an expectation of catastrophe. Sleep disturbances were reported by 71% of the cases with nightmares, a common experience. Almost half of the population had disturbances of memory and cognition. Also included in this group of disturbances were the persistent feelings of being different from others and from one's previous self, being a completely different person or being of different species or character, a feeling of being totally changed in relation to one's inner and outer worlds. Chronic depression was manifested in masochistic trait disturbances (79%) and survivor guilt (92%). To ward off depression, most of the survivors tended to be addicted to work. These authors also noted the agitated type of depression that survivors showed which was associated with anxiety. Survivors also had strong fixations to feelings of helplessness, social withdrawal and isolation. There was also a high rate of somatization (55-60%) among the younger age group (15-30 years old)

with 30% for the whole group. The most frequent psychosomatic or somatopsychic problems included problems directly related to muscle tension, syndromes of pain, syndromes of headaches, allergic like reactions and anxiety equivalents, for example, jumpiness and irritability, nervousness, palpitations and hyperventilation. It is worth noting that in this study, Krystal and Niederland (1968) found that in 79% of the cases, heredity and personal disposition were ruled out as factors to mental illness.

In summing up the after effects endured by concentration camp survivors Krystal (1968) described a variety of symptoms. These included disturbances of affect which came in the form of chronic reactive aggression, depression associated with survivor guilt, somatization, loss of ability to enjoy life, inability to trust others or to display any initiative, and general blocking of affect. Characterological changes included masochistic tendencies and passive-aggression. Krystal (1968) also observed that many of the survivors tended to manifest sexual dysfunction and decreased ability to enjoy and initiate sex. In many cases, severe cognitive deficits in memory and intellectual functioning were found. Survivors showed marked decrease of interest in anything outside work and home routines and displayed severe social withdrawal. Self-hatred as a phenomenon was attributed to damage to survivor's self respect as a result of persecution.

Bychowski's (1968) clinical observations appear consistent with those of Eitinger (1964), Chodoff (1966), Krystal (1968) and Niederland (1968a,

1968b). He described the major changes and alterations in the personalities of survivors of Nazi concentration camps and ghettos. There were several common features. One was depression characterized by guilt, apathy, hopelessness and resignation, emptiness and loneliness that resulted from failure to resolve losses and grief. The depression was also shaded with estrangement and blunting of affect. Chronic anxiety was another feature that manifested itself in cardiac symptoms, disturbances of consciousness, hypersensitivity to various noises and stimuli, agitation and panic. Another common feature was somatization which included hypertension, arteriosclerosis and premature senility, all of which were at a relatively young age. Last but not least were aggression, hostility and rage that were believed to be related to the mechanism of identification with the aggressor.

In a later publication, Eitinger (1969) identified in 227 concentration camp survivors in Norway that 43% suffered from chronic anxiety associated with nightmares and severe sleep disturbances. Again it was extrapolated from this study that premorbid personality had no importance to play in the aetiology of anxiety symptoms. These findings are consistent with the findings of Krystal and Niederland (1968).

De Wind (1972) singled out the symptom of emotional withdrawal as the core of concentration camp syndrome. According to de Wind, this withdrawal acted as a protection against aggression provoked by torture in concentration camps. There were several ways by which survivors dealt with this aggression.

For some, the aggression that was provoked by torture was directed towards the self ending up in suicide or extreme passivity also referred to as “Musselman” state (de Wind, 1972; Krystal, 1968; Niederland, 1968). Some survivors dealt with their aggression by identifying with the aggressor and took on roles and duties that gave them a position of authority in concentration camps. Some inmates suppressed their aggression and used this energy to endure hard labour and boring work in camps (de Wind, 1972).

Kleber and Brom’s review (1992) presented a summary description of the symptoms of the concentration camp syndrome which they described as a “constellation of chronic symptoms” (p. 99). These symptoms include fear which manifested in many ways: chronic dejection and despair, irritability related to unexpressed anger and aggression expressed in the form of rage; recurrent intrusive memories, reduced psychological resilience characterized by cognitive problems, lack of vitality and inability to function in daily living, nightmares and sleep disturbances and psychosomatic complaints.

In a later study Bower (1994) confirmed the existence of concentration camp syndrome in Holocaust survivors of more than 30 years after the event. This was based on his psychiatric assessment of survivors seeking compensation from the German government for persecution suffered during 1939-1945. The majority of the 200 cases he examined (87% of the under 16 group and 84% of the over 20 group) was categorized as having concentration camp syndrome.

Bower (1994) identified five nuclear syndromes that were exhibited by survivors in various combinations and degrees. These syndromes were: depression which included sadness, despair, self-accusation, withdrawal, (1) apathy, recurrent memories of persecution, suicidal ideation, no initiative, sleep disturbance; (2) anxiety which included fears, phobias, sweating, tremor, palpitations, fainting, tension, feelings of unreality, breathing difficulties; (3) somatization which included headaches, tiredness, weight loss or gain, appetite disturbance, sexual inadequacy, heart complaints, backache, abdominal complaints; (4) intellectual disturbance which included memory loss, decline in intellectual functions, poor concentration and attention, inability to plan or make decisions; and, (5) contact abnormalities which included aggression, suspicion, explosive behaviour, irritability, hypersensitivity, paranoid ideation, frank sociopathic behaviour.

Bower's (1994) work also revealed that a third of the population he studied showed work disability and that contact abnormalities (aggression) occurred three times more often in the younger group than in the older group. This led Bower to conclude that those survivors who experienced persecution in childhood exhibited three times more aggression than those survivors who experienced an identical trauma as adults. Bower (1994) also concluded that the concentration camp syndrome constituted a personality change based on an existential trauma of unknown dimensions.

Symptoms and personality changes which characterize concentration camp syndrome do not manifest only among individuals; they also become evident in families of survivors later in life. Danieli (1985) described the long term and intergenerational effects of victimization on Holocaust survivors and their children. Based on her clinical work on Holocaust survivors and their families, Danieli (1985) identified and described four types of survivors' families in which some of the above symptoms were characteristically evident. In "victim families", depression, worry, mistrust and fear of the outside world and clinging within the family was common. Somatization and guilt also persisted. In "fighter families", family members were contemptuous of any dependency in themselves and in others, which had an impact on their peer and marital relationships. In "numb families", constriction of affect was markedly evident and for "families of those who made it", members tended to deny the traumatic events and the effects of these events on them which resulted in inner numbing, isolation and somatization. Danieli (1985) warned however that this categorization could not be considered pure and mutually exclusive but pointed out the heterogeneity of responses and differential long-term effects of the so-called survivor syndrome.

More recently, Silove (1999a) in his book review of Krell's and Sherman's (1997) edited book, *Medical and Psychological Effects of Concentration Camps on Holocaust Survivors*, stated that this publication challenged some of the traditional concepts (e.g. "survivor guilt", "identification with the aggressor") used to understand the dynamics of psychological trauma in Holocaust

survivors. In effect, these concepts do not appear to do justice to the extreme situations that survivors faced where taken for granted notions of ethical choices did not exist. Krell (1997, cited in Silove, 1999a) was also critical of the medicalization of normative responses in extreme catastrophic situations and suggested that a broader conceptualization of the consequences of extreme psychological trauma would be more useful than viewing these as a psychopathology. Silove (1999a) commented that the idea of whether catastrophic experience can bring about enduring personality changes in survivors “was as current in the early Holocaust literature as it is today” (p.254).

It is evident from the literature reviewed in this section that there is a pattern of commonality and consistency as well as multiplicity in the symptoms identified by various authors. There seems to be an agreement on anxiety, depression and somatization as core symptoms. Although survival guilt as a core symptom has been identified, it appears that its features are related to depression. In brief, there are identifiable clusters of symptoms that characterize concentration camp syndrome. Bower’s (1994) five nuclear syndromes appear to capture most of the observations and findings of various authors.

Independent of Bower (1994) three other symptom clusters can be identified from the literature reviewed in this section namely, (1) estrangement which includes alterations of personal identity, persistent feelings of being different

from the self and from others, feelings of having been totally changed; (2) affect disturbances which include blunting of affect, blocking of affect and emotional withdrawal; and (3) character changes which include masochistic tendencies, passive-aggression and tendencies toward sociopathic behaviour. Difficulties in functioning relate to relationship and work, the latter due to disability or addiction to work. There is a strong assertion that all these changes are the outcome of massive trauma affecting the existential aspects of one's life and are difficult to attribute to premorbid personality factors. Some of the characteristics of these symptom clusters or syndromes can also be typical adaptations for families of survivors.

Although most of the early studies done on concentration camp syndrome consisted of thorough clinical observations and descriptive and correlation research, these studies were not specifically designed to examine personality change in survivors. Rather, these were designed to examine and document symptoms and other consequences of extreme trauma, one of which is its effect on personality and character. It should be noted that there was no reliable information on premorbid personality functioning of survivors in these observations and studies.

2.5.2 War Related Trauma, Torture, Refugee Experiences and Personality Change: Torture Syndrome and Posttraumatic Character Disorder

War related trauma is experienced by those who engage in combat such as those in the military, those involved in militia or guerilla movements and by civilians caught in the midst of the event. Kardiner (1959), in discussing neuroses in WW I and WWII veterans as an outcome of experiencing combat trauma, identified a chronic syndrome that became incorporated into the personality and consisted of characteristic symptoms including an altered conception of oneself in relation to the outer world, constant catastrophic dreams, irritability and startle pattern, explosive aggressive reaction patterns and marked decrease in general level of functioning including cognitive ability.

More recently, Horowitz (1986) and colleagues (Horowitz, Weiss & Marmar, 1987; Marmar, 1991; Marmar & Horowitz, 1988) delineated a syndrome among Vietnam Veterans called posttraumatic character disorder that manifested all the prototypical symptoms of PTSD but was further complicated by alcohol and drug abuse, psychosomatic problems and characterological disturbances. Accordingly with this disorder, the trauma experience enables the formation of persisting personality schema that organizes one's view of life post trauma.

In addition, and also in relation to Vietnam Veterans, Parson (1988) suggested the concept of posttraumatic self-disorder as the core psychological injury in

which the experience of extreme stress can lead to maladaptation and destruction of the self-structure. This fragmented self-structure manifests as diminished or virtually non-existent adult ambitions, ideals, self-caring skills, empathy, introspection and ineffective ability to manage tensions and conflicts.

The advent of civil wars in various parts of the world has seen the movement of people seeking refuge in safe places around the globe. Many of these people have been subjected directly or indirectly to various forms of torture, terrorism and mass human rights violations. Mental health professionals have begun to witness and report the immediate and long term consequences of this traumatization on refugee survivors which echo earlier findings. For example, Eitenger in 1959 in his work with WWII refugees in Norway, pointed to the interaction of isolation and feelings of insecurity as contributory factors to the total breakdown of personality. He noted that isolation resulted in confusional states with disturbances of consciousness whilst feelings of insecurity affected the refugees' relationship with their environment and brought about self-doubt. When projected with aggressive feelings, this resulted in persecutory delusions, jealousy reactions and conversion symptoms (Eitinger, 1959).

In more recent years, Turner and Gorst-Unsworth (1990) presented a descriptive framework that characterized the psychological consequences of torture in refugee survivors. Long-term sequelae included chronic anxiety,

depressive reactions, somatic symptoms and existential dilemma, of which the latter has personal and broader social and political dimensions. Somatic symptoms included chronic hyperventilation and cognitive impairments which may be due to disturbed emotional state and/or organic damage. Sexual dysfunction was often reported whilst its mechanisms remained unclear. For example, Lunde, Rasmussen, Wagner and Lindholm (1981) found that in 17 men who were subjected to torture, 29% had sexual dysfunction. Note that these long term sequelae are similar to the ones identified in concentration camp survivor syndrome.

Doerr-Zegers, Hartmann, Lira, and Weinstein (1992) described the psychopathology of torture survivors who presented complex syndromes that were difficult to classify within DSM-III anxiety and depression diagnostic categories. In addition to anxiety and depressive symptoms, torture survivors displayed mistrust bordering on paranoia, insecurity about their own capacities and a marked loss of interest not usually manifested by patients with anxiety disorders. These authors found that torture survivors had lost their energy for living evidenced by marked decreased capacity to work and an inability to deal with the usual demands of life situations particularly in the area of interpersonal relationships. These researchers also observed severe cognitive difficulties in survivors and impoverishment of emotions and affective life. They suggested that torture and concentration camp experiences have the capacity to modify the personality structure and dispositions of survivors.

2.5.3 Victimization and Personality Change: -Victimization Sequelae Disorder

Conceptualizations such as those described above not only capture the experiences of people who have been interned in concentration camps, refugee survivors of torture and other forms of human rights violations, survivors of the Holocaust, and WWI and WWII veterans. Ochberg (1993) proposed a similar categorization called “victimization sequelae disorder” (p.782) based on his work with victims of cruelty and violent crime including physical violence, psychological abuse and sexual abuse. Symptoms in this category included sense of ineffectivity in one’s environment, belief of permanent damage to oneself due to the victimization experience, feeling of isolation, inability to trust and be intimate with others including sexual inhibition, over suppression or over expression of anger, minimization and/or amnesia for the experiences, belief that one deserved to be victimized, vulnerability to re-victimization, adopting the distorted beliefs of the perpetrator and idealization of the perpetrator.

What stands out from the symptoms observed in war veterans, refugee survivors of torture, the Holocaust and from people who have been victimized, is the altered sense of oneself that survivors experience. This phenomenon appears to be related to the destruction of self structure (Parson, 1988) that may bring about self doubt and insecurity about one’s capabilities and manifests in maladaptive behaviours towards the self, others

and the wider environment. In other words, the experience of extreme trauma can alter one's beliefs about oneself and one's existence in the wider world. This altered sense of self is akin to the experience of estrangement identified in the previous section on concentration camp survivors.

Similarly, Bower's (1994) five nuclear syndromes appear consistent with the observations and findings in these groups of survivors. Similar to concentration camp/survivor syndrome, affect disturbances and characterological disturbances have also been identified. Consistent with observations of concentration camp survivors, marked decrease in general level of functioning in the areas of interpersonal relationships and work have also been noted. Sexual dysfunction appears as a consistent observation across groups (Bower, 1994; Krystal, 1968; Ochberg, 1993; Turner & Gorst-Unsworth, 1990). Although subsumed under somatization (Bower, 1994) with its mechanisms remaining unclear (Turner & Gorst-Unsworth, 1990), sexual dysfunction may be related to the inability to trust and be intimate with others (Ochberg, 1993) as an outcome of having been victimized through internment in concentration camps, torture, physical violence, psychological abuse, and sexual abuse. Doerr-Zegers et al. (1992) suggest that torture and concentration camp experiences have the capacity to modify the personality structure and dispositions of survivors. The difficulty of attributing these changes to pre-morbid personality remains however.

In sum, there are several proposed syndromes that describe the long-term consequences of severe trauma on personality functioning. These are referred to by various names such as concentration camp syndrome, survivor syndrome, torture syndrome, posttraumatic personality disorder and victimization sequelae disorder. Most of the studies reviewed in this section were not designed to specifically examine personality changes in survivors. The literature includes theoretical formulations based on descriptive studies as well as extensive clinical observations. Despite this diversity, symptom clusters are consistent across these syndromes. The last diagnostic category that relates to personality functioning which was considered for inclusion in DSM-IV and has attracted considerable attention in the research literature on trauma is discussed here. This category is complex posttraumatic disorder.

2.6 Complex Posttraumatic Stress Disorder (Complex PTSD) or Disorders of Extreme Stress Not Otherwise Specified (DESNOS)

Herman (1992a, 1992b, 1993) reviewed the evidence for the existence of complex posttraumatic stress disorder considered for inclusion in DSM -IV but excluded in the final version under the name of Disorders of Extreme Stress Not Otherwise Specified (DESNOS). In her review, Herman contended that complex PTSD captures the experiences of survivors of prolonged repeated trauma such as those in prisons, concentrations camps, slave labour camps and conditions such as ritual abuse in some religious cults, organized sexual exploitation in brothels and in some families. Herman

asserted that the current PTSD formulation at that time was limited in that the criteria were derived from observations and studies of circumscribed events such as combat, disaster and rape (Herman, 1992a, 1993).

Herman's review (1992a, 1992b, 1993) identified three broad areas of disturbance that included symptoms, character changes and repetition of harm. The multiple array of symptoms picture identified somatization, dissociation and changes in affect that include rage, depression, self-hatred and chronic suicidality as prominent features. Character changes include pathological changes in relationships such as dependency, passivity, helplessness, intense attachment in or extreme withdrawal from relationships and pathologic changes in identity and sense of self. Survivors also suffer from the so-called repetitive phenomena that makes them vulnerable and at risk of repeated harm or repeated victimization. These can be self-inflicted or at the hands of others (Herman, 1992a, 1992b, 1993).

Herman's (1992a, 1993) conclusion offered empirical support for the concept of complex PTSD in survivors of prolonged, repeated trauma. The primary sources for the development of complex PTSD formulation were clinicians working with survivors of sexual and domestic abuse. As Herman (1992a, 1993) suggested, input must be sought from those working primarily with survivors of political persecution and imprisonment to get a broader picture of the phenomenon before finalizing the criteria. To these, input from people working with survivors of prolonged combat could be added.

Given that complex PTSD or DESNOS has not been given an official status in the DSM diagnostic nomenclature, conceptual application and research on it has been ongoing in the areas of sexual abuse and childhood trauma (Adshead, 1994; Allen, Coyne, & Huntoon, 1998; Allen & Huntoon, 1999; Dickinson, de Gruy, Dickinson, & Candib, 1998; Josephs, 1996; Rorty & Yager, 1996; Zlotnick, Zakriski, Tracie Shea, Costello, Begin, Paerlstein, & Simpson, 1996); sexual and physical abuse (Roth, Newman, Pelcovitz, van der Kolk, & Mandel, 1997); combat veterans (Ford & Kidd, 1998; Jongedijk, Carlier, Schreuder, & Gersons, 1996; Newman, Orsillo, Herman, Niles, & Litz, 1995; Shay & Munroe, 1998); refugee survivors of torture and ethnic cleansing (Weine, Becker, McGlashan, Laub, Lazrove, Vojvoda, & Hyman, 1995; Weine, Becker, Vojvoda, Hodzic, Sawyer, Hyman, Laub, & McGlashan, 1998); and, in individuals with other trauma histories (Newman, Riggs, Roth, 1997). Among the literature cited only those articles that are most relevant to this thesis are reviewed in the sections that follow – Sections 2.6.1 to 2.6.3.

2.6.1 Sexual and Physical Abuse, Childhood Trauma and Complex PTSD

Examining the link between trauma and violence, Adshead's (1994) descriptive pilot study of sixteen female cases referred to a forensic service and selected at random suggests that aggression (hostility, anger and irritability) and dangerous behaviour (harm to self and to others) in adulthood is linked with a history of childhood sexual and/or physical abuse and that the

women participants also manifested symptoms similar to the long-term sequelae of abuse described by Herman (1992). Adshead (1994) also cited the work of Goodwin, Cheeves, and Connell (1988) that described the effects of childhood incest in adulthood. Goodwin et al (1988, cited in Adshead, 1994) used the acronym FEARS which stands for fear and anxiety, ego constriction, anger dyscontrol, repetitions and sadness. For severe cases, similar to the cases identified by Adshead, Goodwin et al (1988) used the term “severe FEARS” (cited in Adshead, p.246) to describe fugues, ego splitting, antisocial behaviours, reenactments and suicidality in women suffering from severe sequelae of long term abuse. Although Adshead’s (1994) pilot study was not specifically intended to examine complex PTSD symptoms in these women, symptoms were identified which are similar to those described by Herman (1992).

The findings of Zlotnick et al. (1996) comparing women with and without histories of childhood sexual abuse lend support to the idea that complex PTSD or DESNOS characterize the symptoms manifested by adult survivors of childhood sexual abuse. Women with histories of childhood sexual abuse showed increased severity on somatization, dissociation, hostility, anxiety, alexithymia, social dysfunction, maladaptive schemas, self-destruction and adult victimization. This study also suggested that dissociation, revictimization and somatization, which have been found to be significant predictors of a history of sexual abuse, may form the core symptoms of DESNOS for sexual abuse survivors. This correlation study relied on self reports of early abuse

with no verifiable archival data. The sample was limited to a clinical population which limits generalizability of results to women in the general population.

The symptoms of dissociation, somatization and affect dysregulation that were identified by Herman (1992a, 1992b, 1993) however do not fall within the current PTSD category but are listed as associated features of PTSD and as a separate diagnosis (Dissociative Disorder in DSM). In the DSM-IV PTSD field trial study, van der Kolk, Pelcovitz, Roth, Mandel, McFarlane and Herman (1996) found that these symptoms tended not to occur in isolation but could be found together in the same individuals particularly those with early onset (before age 14), and repeated and prolonged trauma. In this study, about 97% of those diagnosed with complex PTSD were also diagnosed with PTSD. This study also found that even those who no longer suffered from PTSD continued to exhibit this triad of symptoms. These authors underscored the complex somatic, cognitive, affective and behavioural effects of psychological trauma and the difficulty of capturing the complex adaptations to traumatic life experiences through a list of symptoms or symptom clusters or through use of co-morbid diagnoses.

van der Kolk (1996) provided a list of the long term effects of interpersonal trauma which included: “generalized hyper arousal and difficulty in modulating arousal manifested in aggression against self and others, inability to modulate sexual impulses and problems with social attachments- excessive

dependence or isolation; alterations in neurobiological processes involved in stimulus discrimination which lead to problems with attention and concentration, dissociation and somatization; conditioned fear responses to trauma-related stimuli; shattered meaning propositions which includes loss of trust, hope and sense of agency, and loss of thought as experimental action; social avoidance which leads to loss of meaningful attachments and lack of participation in preparing for future” (p.184). Using empirical findings, this author provides a cogent explanation of how interpersonal trauma in childhood can bring about problems in regulating emotions such as anger, anxiety, and sexual impulses. Self destructive behaviours such as self-mutilation and drug abuse, he notes, are the survivor’s symptomatic ways of attempting to self-regulate. Extreme arousal is usually accompanied by dissociation and somatization.

As part of the DSM-IV field trials for PTSD, Roth et al. (1997) examined the occurrence of complex PTSD in victims of sexual and/or physical abuse using the Structured Interview for Disorders of Extreme Stress (SIDES), a measure developed to assess this constellation of symptoms which include alterations in regulation of affect and impulses, attention or consciousness, self-perception, perception of the perpetrator, relations with others, systems of meaning; and somatization (Pelcovitz, van der Kolk, Roth, Mandel, Kaplan, & Resick, 1997). The results indicated that subjects who were both sexually and physically abused had the highest risk (14.5 times more likely) of having a diagnosis of complex PTSD when compared to patients who were

not both sexually and physically abused. From this study it also appears that symptoms of complex PTSD had better specificity for sexual abuse.

Roth et al. (1997) also discussed some of the methodological and conceptual issues driving the on-going professional debate about the construction of complex PTSD. Firstly, they drew attention to the fact that the sensitivity and specificity of the symptoms included in the construct and the relationships of the symptom clusters with one another had not been established prior to the conceptualization and instrument development for this construct thus affecting the reliability of the SIDES. Secondly, they recognized the similarity of this symptom complex with EPCACE. This suggests that greater specificity and sensitivity is desirable for both complex PTSD and its apparently closely related category EPCACE.

An empirical study by Dickinson et al. (1998) in a primary care setting used cluster analytic techniques to determine if a relatively homogeneous subgroup of ninety nine treatment seeking abused women could be identified to fit the hypothesized symptoms of complex PTSD. This study found that subjects with childhood histories of severe sexual abuse and physical abuse manifest the constellation of symptoms fitting the description of complex PTSD.

Although statistically robust, the study sample was biased towards somatization given the patients presented at a primary care setting for medical problems. Complex PTSD symptoms assessed in this study were limited to dissociation and somatization.

Using personality assessments such as the MCMI-III (Millon Multiaxial Clinical Inventory) and Adult Attachment Scale and Childhood Trauma questionnaire in one hundred and sixty-six women admitted for specialized inpatient treatment of trauma related disorders, the findings of Allen et al. (1998) were consistent with Herman's formulation of complex PTSD with prominence in somatization and profound alterations of identity and interpersonal relationships. Their correlational findings also suggest that more pervasive and repeated abuse was related to higher severity of symptoms. The above reviews also suggest that complex PTSD is linked with a childhood history of sexual and physical abuse (Herman, 1992a, 1992b, 1993; Adshhead, 1994; van der Kolk, 1996).

2.6.2 Combat Veterans and Complex PTSD or DESNOS

There have also been attempts to examine the phenomenon of complex PTSD among combat veterans. In a study of 10 treatment-seeking male combat veterans in the US, Newman et al. (1995) found that all the clinical sample technically met the criteria for DES (Disorder of Extreme Stress – another acronym for DESNOS) as assessed using the SIDES and all the participants also met the criteria for PTSD. The DES symptoms applicable to this group included problems with affect regulation, amnesia for important life events, feeling as if one is permanently damaged, feeling as if no one understands, feeling unable to trust, despair, feeling a loss of life's meaning.

These symptoms were not part of PTSD criteria. The DES criteria were also noted as not requiring severity of symptoms for diagnosis, hence its sensitivity. However, the criteria were seen to lack specificity and may therefore result in over-inclusiveness. Other findings of this study indicate that the majority of the sample had histories of childhood physical or sexual abuse or both, leading to the inference that childhood trauma rather than combat trauma may be an influential predisposing factor for DES. It should be pointed out that sampling for this study was very limited (N=10) and that concerns about the reliability of the SIDES (Roth et al. 1997) noted earlier, remain.

An exploratory descriptive investigation of complex PTSD among twenty eight outpatient Dutch war veterans was conducted by Jongedijk et al. (1996) and supported the findings of van der Kolk et al. (1996) and Newman et al. (1995) that DESNOS is associated with PTSD and does not exist as a separate diagnostic category. This led the authors to support the use of the term “complex PTSD”. With the use of the SIDES as a measure, the DESNOS symptoms identified in the study, that differentiated simple PTSD from complex PTSD included dissociation, conversion, despair and hopelessness, affect regulation, modulation of anger, suicidal preoccupation, feeling that nobody can understand, somatization and loss of previously held beliefs. These authors believe that although diagnosis of DESNOS or complex PTSD may be difficult as there are no core symptoms, only numerous and loosely connected ones, it is still important to distinguish

complex PTSD from other disorders for therapeutic purposes. This descriptive study was also limited by its small sample size precluding further statistical analysis. No inter-rater reliability of the SIDES was conducted.

Research on DESNOS with war veterans, has also focused on treatment models and treatment outcomes. Ford's and Kidd's (1998) research with war veterans seeking treatment for chronic posttraumatic stress disorder in an inpatient setting, also found strong correlation of childhood trauma with DESNOS. More striking is the finding that DESNOS was shown to be a solid and strong predictor of poor inpatient PTSD treatment outcome using measures of quality of life and anxiety.

The treatment model used by Shay and Munroe (1996) in their work with male Vietnam Veterans with chronic posttraumatic stress disorder and enduring personality change, lead to a further belief that the veterans' enduring posttraumatic character change of damage to previous good character imposes the greatest social, economic, political and clinical costs. The key issue for these veterans at the core of this treatment model is their incapacity for social trust. Veterans in this treatment setting also exhibited extreme narcissism in addition to the bio-psychosocial changes that Herman (1992a, 1992b, 1993) conceptualized as complex PTSD or DESNOS.

2.6.3 Refugee Survivors of Torture and Genocide and DESNOS

The findings of Weine et al. (1995, 1998) shed light on the phenomenon of complex PTSD or DESNOS among Bosnian refugee survivors of genocidal trauma. Based on standardized psychiatric assessments including the SIDES and testimony of 20 survivors of ethnic cleansing from Bosnia being resettled in the US, the authors' clinical observations of marked changes in memory, identity, and core relationships suggest that these broader range of psychiatric symptoms and consequences to massive psychic trauma are not addressed by current PTSD diagnostic criteria (Weine et al, 1995).

However this same group of researchers (Weine et al., 1998) with twenty four participants found that there was no sufficient evidence amongst Bosnian refugee survivors to support the current construct of DESNOS. 17% to 33% of the participants in their 1998 study met specific DES symptom criteria. However, no subject fulfilled criteria for all six required symptom categories. These authors suggested that DESNOS may be more applicable to survivors of prolonged early life traumas supporting Herman's earlier formulations (1992a, 1992b, 1993) rather than to adult survivors of prolonged, repeated, multiple traumas of torture and genocide for which DESNOS was hypothesized to occur rather than a simple PTSD. Despite these findings the authors still believe that a broader posttraumatic formulation than PTSD is needed to encompass the changes documented by the DES instrument in findings from other studies and in other realms of trauma such as those previously discussed in this chapter. Weine et al. (1998) concluded that the

concept of posttraumatic personality change may not be the best model to understand the marked changes in adult refugee survivors of genocidal trauma.

Similar to other studies reviewed in this section, the Weine et al. (1998) study is constrained by small sample size. The authors also questioned the ethno-cultural relevance of research instruments such as the SIDES to the Bosnian population. They warned against too much emphasis on personality change in survivors of state sponsored organized violence without the evidence to support such formulations. The danger associated with this, according to the authors, is the risk of misconstruing as neurosis, the distressing and agonizing existential, cultural, moral and social dilemmas experienced by survivors. This could limit clinicians and researchers from broadly understanding the psychiatric consequences of state sponsored human rights violations.

In response to the tensions and debate concerning categorization and adequate criteria described above, Silove (1999b) proposed a multisystem/multilevel approach to understanding the varied psychosocial consequences of torture, mass human rights violations and refugee trauma. This approach focuses on the adaptive responses of refugees and their communities in recovery from their experiences. Silove (1999b) suggested that the experience of extreme trauma challenges the individual's and community's adaptive capabilities for safety, attachment, sense of justice, sense of identity and role and maintaining one's sense of faith and meaning.

Silove's (1999b) review highlighted the long term effects of war and mass human rights violations that impact on these adaptive systems. For example, the threat to life that survivors experienced in the initial trauma tends to become pervasive in their day-to-day functioning subsequently undermining their sense of safety in their environment. Separations and losses brought by war, torture and refugee experiences bring about grief and cultural dislocations that pose enormous challenges on attachment and interpersonal bonds in the context of relationships, family and the wider community. Silove cited the phenomena of traumatic grief (Horowitz et al., 1997, cited in Silove, 1999b), cultural bereavement (Eisenbruch, 1991, cited in Silove, 1999b), and separation anxiety (Manicavasagar et al., 1997, cited in Silove, 1999b) as overwhelming reaction patterns associated with traumatic losses, separations and dislocations.

Silove (1999b) noted that torture, with its intent to dehumanize, humiliate and degrade its victims, engenders a sense of injustice that finds its expression in chronic anger, ongoing rage and aggression. Experience of extreme cruelty leaves survivors with existential perplexities that challenge their trust, faith and long held beliefs and values, cutting them off even more from their attachments thus perpetuating feelings of alienation and emotional withdrawal. Being subjected to oppressive methods and torture techniques can distort one's identity and self concept. The refugee experience can lead to loss of roles and status and loss of cultural identity which can perpetuate feelings of helplessness and hopelessness.

Silove (1999b) asserted that repair of adaptive systems that enable survivors to feel safe and secure, to recover and maintain the integrity of their interpersonal bonds, to repair and maintain the effectiveness of the mechanisms of justice, to stabilize their roles and identity and to re-establish the continuity of their belief systems that promote a sense of existential meaning, should be the focus of psychosocial rehabilitation. It is hypothesized that the repair of these adaptive systems appear to address the symptom clusters included in concentration camp syndrome, survivor syndrome, victimization sequelae disorder, DESNOS or complex PTSD and affected by them. Silove's (2000) later review on trauma and forced relocation, highlighted the inadequacy of PTSD criteria to encompass the broad and diversified experiences manifested by survivors of mass violence and human rights abuses. He also noted that specification of DESNOS and EPCACE are attempts to address this issue.

To sum up this section, complex PTSD has been referred to under various names such as complex PTSD (or CP), complicated PTSD, disorders of extreme stress (DES) and disorders of extreme stress not otherwise specified (DESNOS) (Roth et al. 1997). Although not included as an official category in DSM-IV, the symptom constellation was included as associated features of PTSD (APA, 1994). Preliminary evidence supports the presence of DESNOS in adult survivors of early life trauma of sexual and physical abuse and in adult survivors of combat or war zone trauma with childhood histories of abuse.

However, there is variability in the identification of core symptoms or what appear to be prominent symptoms. DESNOS however was not supported in findings among adult refugee survivors of genocidal trauma (Weine et al., 1998). Some of the studies reviewed in this section are limited by sampling constraints and the doubtful reliability and validity of the SIDES. It is debatable whether complex PTSD or DESNOS or even the concept of personality change is the best model to encapsulate the consequences of repeated, multiple, coercive trauma experienced by adult refugee survivors. I now review the diagnostic category included in ICD-10 that purports to describe personality change as a consequence of extreme trauma.

2.7 ICD-10 Enduring Personality Change after Catastrophic Experience (EPCACE)

Prior to the publication of DSM-IV a literature review on EPCACE was conducted by the DSM-IV Task Force for the purpose of determining whether there was empirical support for including it in DSM-IV (see Shea, 1996). The review sought to find out whether there was evidence of personality pathology after catastrophic experience and, if so, whether it was characterized by specific maladaptive traits, it occurs in the absence of preexisting personality disturbance and its relationship with PTSD (Shea, 1996).

The literature reviewed by Shea (1996) covered three types of trauma. This included prolonged torture or victimization that covers experiences of concentration camp survivors and prisoners of war, combat and other traumatic events such as natural and human-made disasters. Conclusions from Shea's (1996) review indicate that there was evidence consistent with the presence of personality pathology after catastrophic experience. Common features included "isolation, withdrawal and feelings of alienation; pervasive apathy, emptiness and hopelessness; identity disturbance; problems with management of hostility and aggression; and distrust and suspiciousness" (Shea, 1996, p.856). Evidence also suggests that personality changes can occur in the absence of preexisting personality disturbance or preexisting vulnerability. It is also likely that pre-existing individual vulnerabilities interact with the nature and severity of the trauma in producing permanent changes in personality. However, such changes can also manifest after severe trauma in people who are normally adjusted with no pre-existing personality disturbances.

It was also clear from Shea's (1996) review that there was some overlap in criteria between PTSD and EPCACE. The overlap included increased vigilance, irritability, estrangement and emotional numbness. EPCACE symptoms were often manifested within the context of somatic, behavioural, and cognitive symptoms many of which resemble PTSD criteria. Shea (1996) noted that to what extent the criteria for these two diagnostic categories overlap remains to be determined.

Shea (1996) also found that people with chronic PTSD tended to develop deleterious personality changes. It was also evident from this review that the then current DSM-III-R PTSD diagnosis did not encompass the range of symptoms and disturbances relative to extreme and prolonged trauma (Shea, 1996). She concluded that the use of retrospective assessment of pre-trauma personality in the studies reviewed was a methodological limitation. Similar to some of the studies reviewed in this chapter, Shea (1996) also recognized that most studies were not designed to study personality change in people who experienced catastrophic stress but were mostly conducted to focus on symptoms of traumatic stress (Shea, 1996). Nevertheless the identification of symptoms and difficulties experienced by survivors not encompassed by existing trauma related diagnoses had been extensive that it could no longer be ignored.

2.8 Exploratory Study on EPCACE: Beltran, R., & Silove, D. (1999).

Expert opinions about the ICD-10 category of enduring personality change after catastrophic experience. *Comprehensive Psychiatry*, 40, 396-403.

The publication of ICD 10 criteria of Enduring Personality Change after Catastrophic Experience (WHO, 1992a, 1992b, 1993) and the absence of subsequent published research on this category provided the impetus for an exploratory study conducted by this author in collaboration with Silove (Beltran & Silove, 1999). This study involved a questionnaire survey of

international experts, to investigate their opinions about the notion of posttraumatic personality change in adults. This survey focused on key aspects of the ICD-10 EPCACE category such as whether respondents endorsed the introduction of the diagnosis; whether they used the diagnosis in their practice; which features of the EPCACE criteria were most salient in making a diagnosis of posttraumatic personality change; the types and characteristics of traumatic events that were most likely to cause EPCACE; and the possible limitations of the ICD-10 diagnosis.

Since a survey of expert opinions can rarely be fully representative, a sufficiently diverse array of respondents who were likely to offer a wide range of ideas and insights were included (Seltiz, Wrightsman, & Cook, 1976). Questionnaires were distributed to participants presenting papers to a section on Organized Violence and Refugee Mental Health at an international conference convened by a large world mental health organization in 1995. Papers included topics on political violence, torture, refugee trauma and other human rights abuses. Where possible, the first author approached presenters personally to request that they completed anonymous questionnaires which were returned in sealed envelopes. Those presenters who could not be approached in person were surveyed by mail after the conference.

The pool of potential respondents was enlarged by writing to contributors to five major textbooks on traumatic stress published in the 1990s. Prospective participants were selected on the basis that their contributions focused on

human-engendered trauma or abuses. In addition, the 1994 and 1995 issues of four leading English-language psychiatric journals and one specialized traumatic stress journal were scanned for contributors of articles in the area of human engendered trauma, and questionnaires were sent to all relevant authors. One reminder letter was sent to those who did not respond to the first communication.

A brief questionnaire was devised to investigate the opinions of experts in the field about the notion of posttraumatic personality change in adulthood. Demographic questions were about respondent's occupation, specialty area and years of experience in the field. Questions which focused on key aspects of the ICD-10 category EPCACE including whether respondents believed that adults can develop enduring personality change following trauma, the types and characteristics of traumatic events that were most likely to lead to personality change in adults, which criteria of EPCACE they considered as core and other features they believed should be included as criteria, whether they were confident about using the diagnosis of EPCACE in their practice, and the possible limitations of the ICD-10 diagnosis. Each questionnaire item included a set of closed options, as well as an open-ended section in which respondents were encouraged to expand on their views.

Twenty four of the 143 envelopes were returned either because of incorrect addresses or because those approached ($n = 9$) did not feel experienced enough to respond meaningfully. Of the remaining 119 experts approached,

67 returned completed questionnaires, representing a response rate of 56.3%. Based on volunteered information and postmarks it was estimated that 45% of the respondents were from the USA, 10% from the United Kingdom and the remainder from countries representing most of the major regions of the world. Respondents included clinical psychiatrists (37%), psychologists (21%) and psychotherapists/counsellors (21%), with the remainder identifying themselves as other mental health professionals or academics with clinical interests. The length of experience of respondents in their professions ranged from four to 38 years (mean = 16 years, SD = 8.0). Although the majority recognized the phenomenon of posttraumatic personality change, few (16%) used the specific diagnosis of EPCACE in their practice. This was thought to be possibly due to the recent introduction of the category when the survey was conducted or because many practitioners adhered to the DSM system in which there is no such category.

The rank ordering obtained for endorsed symptoms of EPCACE suggested that “a hostile or mistrustful attitude towards the world” was regarded as the most important feature, a finding which is consistent with the level of salience ascribed to these characteristics throughout the literature reviewed in this chapter on the psychological responses to concentration camp internment (Bower, 1994; Bychowski, 1968; Krystal, 1968) and victimization and human rights violations (Doerr-Zegers et al. 1992; Eitinger, 1959; Ochberg, 1993; Silove, 1999a, 1999b). In contrast, estrangement and social withdrawal were ranked lowest. One possible explanation is because these were regarded as too

difficult to operationalize or non-specific. Somewhat surprisingly, feelings of emptiness or hopelessness ranked second even though it could be expected that such symptoms would be common in other disorders such as depression.

Several respondents pointed to the lack of specificity of EPCACE criteria and the potential overlap of features with other psychiatric disorders, raising the possibility that this new EPCACE category may not represent a cohesive or unique syndrome. This concern paralleled that which had been expressed earlier about DES or complex PTSD by several investigators (Jongedijk et al., 1996; Newman et al., 1995; Roth et al., 1997; Zlotnick et al., 1996). These concerns however are prevalent in any attempt to derive typologies or classification in the complex area of personality disorders in general (Gabbard, 1997; Westen, 1997).

As predicted by the findings of others (e.g. Malt, Schnyder, & Weisaeth, 1996) torture and concentration camp experiences were rated by most of the respondents as being experiences that were likely to result in EPCACE, with both categories of trauma receiving 90% or greater endorsement. Between 50% and 75% of respondents endorsed war exposure, sexual assault, hostage situations and domestic violence, but only approximately one quarter agreed that natural disasters or motor vehicle accidents could lead to such psychological consequences. Such responses broadly support the criteria specifying intentional human violence as the principal cause of EPCACE in ICD-10. The absolute exclusion of other traumatic events such as motor vehicle accidents

may be excessively rigid. At this time, I and my colleague (Beltran & Silove, 1999) concluded that it may be more appropriate to propose a probabilistic model in regard to different categories of trauma, that is, certain types of trauma (e.g. torture) are more likely to lead to personality change than others (e.g. natural disasters).

The characteristics of trauma with greater influence of increasing risk of personality change and nominated by approximately 50% of respondents were that it was prolonged (repeated or sustained); undermined the person's integrity; was life threatening; induced shame or guilt; and, was intentional and/or malicious. Slightly fewer respondents agreed that injustice or the violating aspects of the trauma were important. Such findings suggest that respondents did not make clear distinctions between events that were life threatening and which were generally associated with risk of PTSD and those that were associated with more complex psychological consequences such as guilt, shame and feelings of being unfairly victimized.

The compilation of spontaneous descriptors in this study provided a comprehensive list of adaptational changes that were regarded as salient in survivors of trauma (Beltran & Silove, 1999). When assigned to post hoc categories, meaningful clusters emerged which included impulse control problems and loss of moral constraints; altered perceptions of the self and reduced self-esteem; somatization; guilt; hostility; anxiety, depression and impaired modulation of affect; a tendency towards revictimization and passivity;

reduced capacity for intimacy; poor coping and existential despair; and impaired learning and concentration. Some of these descriptors had been included in previously proposed categories such as the concentration camp syndrome, victimization syndrome, complex PTSD or DESNOS. Whether respondents were influenced by the literature in proposing these features or whether they had observed such characteristics first-hand in the clinical setting could not be determined by the method used in the study.

Several respondents raised critical issues about the theoretical underpinnings and validity of EPCACE. These included whether personality could be fundamentally altered by events in adulthood; the problem in making accurate retrospective judgments about whether personality had indeed changed and whether the identified trauma was the responsible event; difficulty in operationalizing complex phenomena such as “estrangement”, and the lack of specificity of several of the EPCACE criteria; whether or not EPCACE was simply a manifestation of chronic PTSD; and, whether the diagnosis was valid in the transcultural setting. To these concerns could be added the risk of stigmatizing trauma survivors with a label of “personality change” that could be regarded as pejorative or demeaning.

The exploratory study conducted by myself and Silove (1999) was not without its limitations. The first as noted earlier, was that 45% of the respondents were from the USA and used the DSM rather than ICD which may have influenced their responses. The second was that other mental health professionals such as

nurses, social workers and occupational therapists who work with traumatized populations were under represented in the sample.

Despite these limitations, the study found that a substantial proportion of trauma experts working in the field of human engendered violence recognized the possibility that certain traumas can result in personality change. Questions were raised however about the specificity and poor operationalization of the criteria of EPCACE in ICD-10. As well a more comprehensive array of adaptational changes were recognized than the criteria permitted. These concerns directly influenced the conceptualization of the current study. Prior to turning to the research design needed to address these concerns, the process of diagnosis in clinical practice is explored.

2.9 Clinicians and Clinical Diagnostic Process in Psychiatry

Diagnosis is a fundamental concept in medicine and psychiatry. Diagnosis is about identification of a disorder; it is also a process; and it is an outcome. Further it attempts to characterize the patient's entire clinical condition. Diagnostic categories, by default, offer, even set guidelines by which clinicians observe, think, remember and act. It is therefore vital that criteria for diagnosis are well defined.

One of the sources of unreliability in the diagnostic process is criterion variance (Spitzer & Williams, 1980). According to Spitzer and Williams

(1980), this occurs in two ways. One, when criteria are not explicit and clinicians are forced to use their own personal concepts to describe the disorders; and two, when differences exist in definitions of terms that clinicians use. Furthermore in psychiatry as Jablensky (1999) noted, diagnosis is still very much dependent on the clinicians' ability to elicit information from the client, to listen and the patient's readiness to communicate subjective experience. Rarely does diagnosis depend primarily on objective signs and tests. Rather, the evidence required is phenomenological and descriptive of behaviours, thoughts and feelings that require communication, semiotic analysis and introspection on the part of the clinicians (Jablensky, 1999). This underscores the importance of having a well defined set of descriptive criteria for diagnosis if the aim is to achieve as reliable as possible diagnostic outcome. Jablensky asserts (1999) as did Strauss (1996) before him that inter-subjectivity is intrinsic to the discipline, and further posits that it is debatable whether the subjective element in psychiatric diagnosis can ever be replaced and if it could, at what cost. The previous discussion of categories such as PTSD and the inclusion of EPCACE as a personality disorder provide one example of the importance of understanding the subjective or clinician element in psychiatric diagnosis.

Assessing and diagnosing personality disorders are particularly challenging and divergences exist between clinical and research methods in this aspect. Westen (1997) conducted an initial small survey of 52 clinicians, before replicating this with a random national survey of 1,901 experienced

psychiatrists, psychologists and clinical social workers in the USA to find out the extent to which current personality measures derived from DSM criteria mirror the clinical diagnostic process. Clinicians were asked to rate five methods for diagnosing personality disorders in order of importance and the extent to which they relied on these methods to diagnose personality disorders. These methods were: “(1) asking direct questions derived from DSM-IV, (2) listening to the way patient describes interactions with significant others, (3) observing patient’s behaviour, including with you, (4) speaking with significant others, and (5) administering questionnaires” (Westen, 1997, p.898).

Westen (1997) found that in assessing and diagnosing personality disorders, clinicians valued and relied primarily on listening to patients describe their interpersonal interactions and on observing the patient’s behaviour with the interviewer. Clinicians in Westen’s study (1997) also found direct questioning based on research instruments using DSM-IV criteria less useful in comparison to the observation of patients’ behaviour during the interview and the description of patients’ interactions with significant others. Through observing patients’ interactions and listening to their narratives about their lives, clinicians were able to pick up and identify enduring personality patterns such as problems with relatedness, work, self-esteem and chronic sub clinical depressive traits which, they believed, would not have been identified otherwise using direct questioning based on research instruments using DSM-IV criteria.

Some studies such as those of Egan, Nathan, and Lumley (2003) and Zimmerman and Mattia (1999) have contradicted Westen's findings asserting that semi-structured interviews and structured measures have more sensitivity and specificity in diagnosing personality disorders than unstructured clinical interviews. Westen (2001) countered this argument by critiquing the methodological flaws of the Zimmerman et al. (1999) study and suggesting alternative procedures. His critique focused on the study's flaw of biasing the clinicians with prior information about the patients before clinician assessment; using intake diagnoses as an index as clinicians are often reluctant to diagnose patients with personality disorders during a brief intake procedure; and, focusing only on borderline personality disorder for which structured interviews have the best validity and reliability data (Westen, 2001). Westen (2001) suggested that to counteract these effects for a more reliable study, a personality disorder, for example narcissistic personality disorder, which the criteria are not so accessible by direct questioning needed to be selected.

Horowitz (1998) in agreeing with Westen's (1997) findings was critical of the definitions of personality disorders included in DSM-IV noting that such definitions have a poor basis in empirical reality and lead to a menu-driven approach to diagnosis. Further, he noted that funded research in this area "tend(s) to reify rather than revise the system" (p.1464). Horowitz (1998) commented that Westen's findings highlighted the "need to be flexible and active at arriving at new research methods and tools" (p.1464) as current

definitions of personality disorders in DSM do not lead to development of good measures and are not helpful in developing treatment plans.

In conjunction with the development of ICD-10, a measure called International Personality Disorder Examination (IPDE) to assess personality disorder according to ICD-10 and DSM-IV criteria was developed and field tested (see full report of its development and psychometric properties in Loranger, Janca, & Sartorius, (Eds.), 1997). The IPDE is a semi-structured interview intended to be used internationally with questions derived from ICD-10 and DSM-IV criteria and dependent on self-report. No data on the use of this instrument in assessing EPCACE is reported in the field trial (Loranger, 1997). Although the instrument was generally accepted and found by clinicians as useful in the field trials, Dahl and Andreoli (1997) suggest the clinician sample was biased as they all had commitment to the project. Given the findings of Westen (1997) regarding the preferred method of clinicians in assessing and diagnosing personality disorders, it remains speculative whether other clinicians would find IPDE more useful and preferable to other methods.

Alternative assessment tools to measure personality disorders have been researched and proposed (Westen & Shedler, 1999 a&b). An example of this method is called the Shedler-Westen Assessment Procedure or SWAP-200 (Westen & Shedler, 1999a). This assessment includes 200 personality-descriptive statements that reflect the personality disorders diagnostic criteria

in DSM, literature on personality and personality disorders and from observations of clinicians and pilot studies conducted by the assessment developers. These statements are written on separate index cards. The assessment uses the Q-sort method which requires clinicians to sort or arrange the cards into 8 categories on the basis of how the statements apply to the client from those that are not descriptive (0 score) to those that are highly descriptive (score of 7) (Westen & Shedler, 1999a).

The procedures included in the SWAP-200 enable quantification of clinician's observations and inferences. The personality disorder score indicates the extent to which the clinician's observations match any diagnostic prototype which can be reported dimensionally. The SWAP-200 also enables the clinician to construct a narrative description of a patient's most salient diagnostic features based on the items with the highest values. This narrative description has the advantage of being anchored on SWAP items that have clear, consensually understood meanings (Westen & Shedler, 1999a).

2.10 Clinician Response to Diagnostic Criteria

As Frances and Egger (1999) remind us, DSM categories are shaped by the current state of knowledge and measurements about psychiatric disorders. The effective use of any classification system hinges on this knowledge. Sartorius (1992) wrote similarly about ICD-10 stating that "A classification is a way of seeing the world at a point in time" (p.vii Preface, The ICD-10

Classification of Mental and Behavioural Disorders, WHO, 1992). For these reasons, according to Frances and Egger (1999), researchers must use diagnostic criteria as a means to move beyond the confines of the current classification. Clinicians on the other hand must combine clinical judgement and comprehensive multidimensional assessment and treatment with diagnostic categories. These authors describe an effective clinician as knowing the symptoms, the diagnostic categories and the predictive power of each diagnosis at the same time as being aware of the limitations of a categorical approach to diagnosis. In real life they conclude, patients do not fit neatly into diagnostic categories. Therefore, clinicians must continue to use clinical judgment and consider individual patient's personal history.

In the context of increasing interest and support for classification systems, it becomes critical that the current DSM and ICD systems are understood accurately, including their strengths and their limitations. Diagnostic reification of these systems appears to be a danger to be avoided at all costs. There are two serious apprehensions expressed as an adverse side effect of the current categorical systems of DSM-IV and ICD-10. The first is that this may result in the uncritical belief that these classification systems are the true and only way of viewing psychiatric illness (Jablensky, 1999). The second is that classification systems are seen as a panacea to the question of complexity and human variability and may result in the mechanical application of the criteria (Bertelsen, 1999). Both WHO (1992) and APA (2000) have offered caveats in regards to the importance of clinicians not employing the

diagnostic systems in a mechanical fashion without considering individual and cultural differences.

Appearance, naming, and definition of disease, illnesses and disorders are not trivial processes and have important consequences. Clinicians are at the forefront of these processes. Daily they encounter difference and variability as well as conformity and consistency. In one sense, they are charged by the diagnostic process to create order according to predefined categories out of what might be described as the chaotic disorder of the human condition.

Use of clinicians' descriptions is one way of validating psychiatric diagnosis and in turn, bringing order to psychological disturbances (Robins & Guze, 1970). Despite the presence of sophisticated measures and use of external validators such as DNA studies, Positron Emission Tomography, Magnetic Resonance Imaging and advances in cognitive neuroscience and methods of measuring brain electrical activity, an editorial in the *American Journal of Psychiatry* written by N.C.A. (1995) asserts that diagnosis and its validation "must begin with careful clinical description" (p.161).

2.11 The Need for and Scope of this Study

Given the complex nature of manifestation of personality changes and the lack of understanding of the relationships between the identified symptoms and characteristics of these changes identified in this review and the findings

of the exploratory study (Beltran & Silove, 1999), I considered the critical next step was to ask clinicians about their clinical observations of EPCACE criteria and how these criteria manifest in their clients.

From this review it is clear that there is scarcity of literature on EPCACE and studies on it are just beginning. There are only two articles published specifically relating to EPCACE. There are no empirical studies to date on validity. For a diagnostic category like EPCACE in ICD-10, some validity questions need to be asked. Which of the criteria pertaining to a particular syndrome like EPCACE are significant? Are there any relationships between these criteria? This current study will examine how clinicians interpret the symptom criteria of EPCACE contained in the CDDG.

It has been more than a decade since EPCACE was included in ICD-10. As a formally categorized phenomenon it is relatively under studied. As Frances and Egger (1999) pointed out, there is a need to continue to validate current descriptive categories whilst at the same time, strive to define and operationalize all clinical phenomena, including functional interactions between the patient and his or her family and environment, as well as internal, intrapsychic phenomena. The aim is to refine the criteria and to begin to identify the most salient criterion so that individual cases can be understood and managed. These assertions are most relevant to the current state of knowledge about EPCACE.

As suggested by Kraus (1996), psychiatric diagnosis must deal with reality on various levels: physical/biological level to consider biological factors underlying psychopathology; psychological level to deal with complex, experiential, subjective, phenomenological reality – the illness as experienced by the person; social level which deals with the reality of social facts, actions or judgments by an authority that have the impact of fact. This thesis addresses the social level, that is, the reality of the judgment of clinicians about a social fact, which is the diagnostic category. It also deals with the psychological level to the extent in which clinicians describe the phenomenon of EPCACE as experienced by their clients seen through the clinicians' eyes. This study does not deal with the biological level of the phenomenon.

This study seeks to validate the symptom criteria of EPCACE from the clinician's point of view. It is therefore important that the focus of this EPCACE study is the typification/characterization of the symptom criteria of EPCACE through clinicians' descriptions and to find out from clinicians whether there is an identifiable core symptom in this category.

Operationalization of the symptoms criteria will provide a richer clinical description of the criteria and will lead towards a better understanding of the varied ways by which symptoms are expressed and described.

The inclusion of EPCACE as a diagnostic category with specific criteria in ICD-10 assumed that it is categorical. This current study does not seek to prove whether EPCACE is a categorical or a dimensional disorder. Rather, this study seeks to operationalize the EPCACE symptoms criteria and in

doing so identify prominent features that may be relevant in the future understanding of the classification of this disorder.

From this literature review, it is apparent that varying descriptions of EPCACE exist, contained in the following documents:

1. ICD-10, Volume 1 – Tabular List, Chapter 5 Mental and Behavioural Disorders (WHO, 1992a)
2. ICD-10 Classification of Mental and Behavioural Disorders. Clinical Descriptions and Diagnostic Guidelines (CDDG) (WHO, 1992b)
3. ICD-10 Classification of Mental and Behavioural Disorders. Diagnostic Criteria for Research (DCR) (WHO, 1993).
4. ICD-10-AM Mental Health Manual (NCCH, 2002)

The first three of these are published by WHO and the last is published and adapted for use in Australia.

Although ICD-10 and DSM-IV have provided a common language in psychiatry (Pichot, 1994; Shepherd, 1994) and enhanced the reliability of diagnosis, there are issues and concerns identified from this review regarding diagnostic criteria that need to be addressed. These include inadequate clinical description and diagnostic guidelines, lack of agreement between CDDG and DCR in ICD-10, and complexity of understanding the varied ways symptoms are expressed and described.

Issues and concerns discussed in this review about ICD and DSM in relation to PTSD and personality disorders criteria include over-inclusiveness of criteria, reliability, contextual validity, stability of personality disorder, distinction between personality disorder and personality change, and personality disorder as a pejorative label for trauma survivors.

For EPCACE criteria, the issue of the criteria being too general and poorly operationalized was also discussed. As noted in this review, one of the problems identified in the ICD-10 field trials with the goodness of fit between diagnostic criteria and actual features of clinical cases is the inadequacy of CDDG. There is also the question whether the CDDG and DCR versions of EPCACE criteria are in agreement. It is beyond the scope of this study to address the DCR version. In this study the question is whether clinicians find the criteria of EPCACE contained in the CDDG adequate and easy to use by examining how the symptom criteria of EPCACE are identified and described by clinicians. Validation of a diagnostic category must start with a careful clinical description. The next chapter describes how I proceeded to embark on this task.

CHAPTER 3

METHOD

In this chapter I describe the research perspective, methods and procedures I used to conduct this study.

3.1 Aim of the Study and Specific Research Questions

In order to seek descriptive validation of EPCACE criteria, the overall aim of this study was to examine how clinicians describe the symptoms which conform to or exceed the criteria of EPCACE that they observe in their clients. The specific research questions were:

- (1) How do clinicians describe typical personality changes they see in their clients using the EPCACE criteria?
- (2) Do clinicians identify any one or more symptom/s that could be considered as core criterion/criteria of EPCACE?
- (3) Do clinicians identify other behaviours, symptoms or character changes that are not encompassed by EPCACE criteria?

3.2 Social Phenomenological Perspective

The ideas of Alfred Schutz, who provided a sociological orientation to phenomenology, has influenced this study [see Alfred Schutz (1973). *Collected*

Papers Volume 1 The Problem of Social Reality. Edited and introduced by Maurice Natanson. The Hague: Martinus Nijhoff. Schutz' work originally published in 1953]. According to Schutz (1973), human beings experience the everyday social world as a socially meaningful reality. In our day to day interactions, we see a person doing something or we hear a person say something and we understand the meanings of those actions and words. This social world also has an inter-subjective nature. This means that although we experience the world in our own individual consciousness, it is not a private world, and hence not entirely personal.

Human beings or “actors” as referred to by Schutz, have a common and shared experience of the social world (Schutz, 1973). This is what makes communication possible. This shared objective nature of everyday life is something humans as social actors take for granted. For Schutz, everyday life is a taken for granted reality. This is because, according to him, as socialized human beings, we possess common-sense knowledge of the everyday world in which we live in and of which we are a part. We experience the social world as a given. It is out there, outside of us and it pre-exists any of us (Schutz, 1973).

However, this given world has to be interpreted and to be made sense of by each of us, through our experiences. Common sense knowledge or “stock of knowledge at hand” (Schutz, 1973, p.7) enables us to categorize and name the things we experience. The concepts that comprise our common sense

knowledge are referred to by Schutz as “typical” (p.7). Typification refers to what is standard or typical among a group of events, actions, objects or things. According to Schutz, typifications are to a certain extent, socially derived and socially approved, and “the pattern of typical constructs is frequently institutionalized as a standard of behaviour, warranted by traditional and habitual mores and sometimes by specific means of so-called social control, such as the legal order” (p.19).

As members of society, we possess a stock of typification which enables us to see the world as familiar. These typifications are embodied in the language that we share with others. Thus Schutz’s concern is with the structure of the social world as experienced by individuals, and how that experience is socially constructed and organized (Schutz, 1973).

Schutz introduced the concept of multiple realities by contrasting the structure and organization of knowledge in the world of everyday reality with the world of dreams and the world of fantasies and of particular relevance here, the world of scientific theorizing. Schutz claims that there are differences between the structure and organization of knowledge in everyday life and that of knowledge in social science. Common sense, the everyday knowledge of actors in their social world, is a first or basic degree concept. Social science constructs about the everyday world are known as second degree constructs, they are “constructs of the constructs made by the actors on the social scene” (Schutz, 1973, p.59) which already have meaning in

common sense terms. Hence, the methods and procedures of social science should be suited to grasp the nature of multiple realities. Social science concepts should relate to the concepts by which actors understand social actions, events or objects if science is to reproduce in a scientifically useful way the common sense understanding of actors. Schutz (1973) also recognized that actors are influenced by their individual biographies, the particular situation they are in, and by the actions of other actors in the situation.

Schwartz and Wiggins (1987) in discussing the role of typifications in psychiatric diagnosis assert that skilful clinicians are able to diagnose their patients because they are able to typify their patients as exhibiting the features of a mental disorder. Schwartz and Wiggins (1987) argue that typifications “orient and guide the first steps in diagnosis” (p.76). These authors regard the ability to typify as a preconceptual skill that renders a list of diagnostic criteria meaningful. They maintained that classification schemes such as DSM and ICD are explicit articulations of typifications and that the ability to comprehend the meaningfulness of classificatory criteria and concepts used to describe various mental disorders depends upon a prior ability to typify the disorders. As they state: “The process of defining a concept simply renders explicit what one already knows through typifications” (Schwartz and Wiggins, 1987, p.76).

The ability to typify is acquired through direct observation and experience of objects so typified (Schwartz & Wiggins, 1987). Schwartz and Wiggins (1987) contend that typifications are not stereotypes. According to these authors, typifications become stereotypes only if their basic sense alone is used to define or characterize a patient. If used as an orienting guide to diagnosis, it can predelineate clinical investigations. As investigations and interactions with patients proceed, a typification is supplemented by a richer description and understanding of a patient as a unique human being. Hence, a clinician has a broader understanding of the patient as an individual and at the same time can view the patient as a member of a group with a certain class of disorder.

In this study, I place the clinicians as the social actors in the everyday world of their work with people who have experienced trauma. They experience and make sense of this specific world through their common-sense knowledge (or typification) of it. One typification that exists in their world is the concept of diagnostic categories. This study seeks to capture the common sense understandings (typifications) of actors (clinicians) of a typification (diagnostic category), defined and institutionalized through a classification system espoused and legitimized by the World Health Organization. By capturing the “constructs made by the actors on the social scene” (Schutz, 1973, p.59), the end view is to make the clinicians’ typification of a diagnostic category (EPCACE) explicit so that it can be rendered scientific (subject of scientific inquiry) and becomes more understandable to other actors who inhabit the everyday world of trauma work. This is built on the assumption articulated by

Schwartz and Wiggins (1987) that “because they remain crucial in diagnosis, acknowledgement and assessment of typifications is an essential factor in a psychiatry which is conscious and critical of its own methods” (p.76).

3.3 Research Approach

To adequately determine clinicians’ views and experiences about the ICD-10 category of EPCACE, I employed a qualitative research method using semi-structured, focussed in-depth interviews with clinicians working in the area of torture and refugee trauma, war trauma, and sexual assault trauma. Qualitative research methodology is advocated for use in clinical research (Miller & Crabtree, 1994), public health (Baum,1998), primary health care research (Harding & Gantley, 1998; Mardiros, 1994), health policy research (Short, 1997), and in applied policy research (Ritchie & Spencer, 1994). In applied policy research, qualitative research methods are used to achieve four broad objectives. These are:

1. contextual: identifying the form and nature of what exists;
 2. diagnostic: examining the reasons for or causes of what exists;
 3. evaluative: appraising the effectiveness of what exists; and
 4. strategic: identifying new theories, policies, plans, or actions
- (Ritchie & Spencer, 1994).

From the point of view of applied policy research, the policy referred to in this study is the ICD-10 criteria of EPCACE as defined by the WHO. The objectives of this study can be subsumed under the broad umbrella of contextual objectives. Specifically to be investigated is the form and nature of EPCACE from the perspective of clinicians whose clinical reasoning is influenced, one way or another, by diagnostic guidelines formulated in disease classification systems like DSM-IV and ICD-10. A qualitative approach to researching an applied policy (Ritchie & Spencer, 1994) was chosen in order to facilitate my understanding of how clinicians define and characterize the phenomenon of EPCACE as they observe it in their clients, and as guided by the WHO ICD-10 CDDG criteria.

3.4 Ethics Approval

This study was granted ethics approval by the Committee on Experimental Procedures Involving Human Subjects (CEPIHS) of the University of New South Wales, Kensington, Australia on 2 June 1995 (CEPIHS Project No. 95043) and the Research Ethics Committee of the South Western Sydney Area Health Service, Liverpool, Australia on 28 March 1996 (Project No. 96/12).

3.5 Participants

Clinicians working in the area of torture and refugee trauma, war trauma, and sexual assault trauma were recruited for this study to determine clinicians' views and experiences about the ICD-10 category of EPCACE. The decision to interview clinicians from these three practice groups was primarily influenced by the findings of my earlier study with my colleague Silove (Beltran & Silove, 1999), which showed that the types of trauma events that are likely to result in personality change are torture, combat and sexual assault. Based on this finding, I held the assumption that clinicians working with people who have experienced such events, are likely to encounter the phenomenon of EPCACE, as they are working with the most at-risk population.

I also assumed that the people most able to provide an expert and considered view about the EPCACE criteria would be the "front line" clinicians who see clients day to day. I recognized that the reflections of these clinicians are likely to be influenced by varying theoretical positions, due to their diverse professional backgrounds, potentially differing philosophical and theoretical positions of their workplaces, and because of their own set of beliefs and values. However, I understand based on Schutz's (1973) reasoning that their direct clinical experiences provide a practical demonstration of their positions within the applied context.

My decision to sample clinicians from diverse backgrounds was influenced by the practice of the World Health Organization (Sartorius, 1992) and the DSM Task Force (Frances & Egger, 1999). These practices involve representatives from other disciplines, and from various schools of thought in psychiatry, to review knowledge aimed to improve diagnosis and classification of mental disorders.

Sampling for this study was purposive (Dane, 1990). In this instance, purposively identifying clinicians who could provide understanding about personality change post-trauma, through their direct experiences with clients in three trauma contexts: torture and refugee trauma, combat trauma, and sexual abuse trauma.

3.5.1 Recruitment of Participants

Letters were sent explaining the research project to the executive director/head of two services within the South Western Sydney Area Health Service and to the executive director of one service located in the western metropolitan region of Sydney. These services dealt with survivors of torture and refugee trauma, Vietnam veterans, and sexual assault clients.

Subsequently, two services invited me to attend their staff meetings to explain the project. A third service asked me to discuss the research proposal in the Management Committee meeting and also to present it to their Research Committee. At the end of each presentation at these services, I gave staff

members a copy of the information sheet (Appendix E), consent form (Appendix F), and a copy of the ICD-10 EPCACE clinical descriptions and diagnostic guidelines (CDDG) (Appendix B) to peruse while making their decision whether to participate in the study. I left spare copies with the heads of the services for the staff members who were not present at the meetings.

A few days after the presentations, two heads of services contacted me to give me the names of staff who were interested in participating in the study. One executive director directed me to make contact with the staff of the service, having received their agreement after my presentation. These three services had a combined pool of 27 potential participants. An additional two potential participants from a non-government sexual assault service were referred by the head of the sexual assault team mentioned above. One clinician who worked with Vietnam Veterans in a private hospital was referred to me by one of the participants. I sent a formal letter to these three additional potential participants explaining the study including an information sheet, a consent form and a copy of the ICD-10 clinical guidelines for EPCACE. In total, I had a potential pool of thirty participants.

3.5.2 Contacting the Participants

The process by which I contacted the potential participants proceeded as follows: I contacted each clinician by phone to confirm their interest in the study. I then asked them if they had any questions, concerns or clarification about the study. My experience with this group of clinicians was very positive.

I found that the clinicians generally understood what was involved and no one raised any objections about the study. I then made an appointment for a mutually convenient time for an interview.

3.5.3 Characteristics of Participants

Of the potential thirty participants, twenty four trauma clinicians participated in the study. Of the six who did not participate, three felt they could not contribute to the study because most of their work in the services involved administration with little or no clinical work. Two were on leave during the period of data gathering and one was new in her position and felt she had very little experience to contribute. Table 1 describes the distribution of participants according to their professional background.

Table 1. Distribution of Clinicians According to Professional Background

Professional Background	Torture and Trauma Clinicians	Vietnam Veterans Clinicians	Sexual Assault Clinicians	Total
Bicultural Counsellors	6			6
Physiotherapist	1			1
Psychiatrists	3			3
Psychologists	2	3	2	7
Social Workers	2	2	3	7
TOTAL	14	5	5	24

Of the twenty four clinicians who participated there were seven psychologists, seven social workers, three psychiatrists, six bicultural counsellors and one physiotherapist. Fourteen of these clinicians worked in the torture and refugee trauma area, five clinicians worked with veterans of war and the remaining five worked with sexual assault survivors. Of the fourteen clinicians who worked with the torture and refugee trauma service, five were part time workers and nine were full time. Of the five part time workers, four had their own private practice. Of the clinicians who worked with the veterans of war, four were employed full time within a counselling service for Vietnam Veterans and one was employed full time in a private hospital with a specialized program for Vietnam Veterans. Of the sexual assault clinicians, two were employed full time with a non government sexual assault service, and three were employed full time in a sexual assault service within the public hospital system. In total there were eleven male and thirteen female clinicians. The average years of clinical experience in current trauma work for the clinicians in this study was seven years, ranging from three to fifteen years. These clinicians were working in various areas in their fields prior to engaging in trauma work. Table 2 describes the distribution of clinicians according to area of work, work mode and gender.

Table 2. Distribution of Clinicians According to Work Mode and Gender

	Number of Clinicians	Part Time Work	Full Time Work	Male	Female
Torture and Trauma Clinicians	14	5	9	8	6
Vietnam Veterans Clinicians	5		5	3	2
Sexual Assault Clinicians	5		5		5
TOTAL	24	5	19	11	13

Mean years of experience in trauma work = 7

Range = 3-15 years

The reader may ask why clinicians, other than psychiatrists, were interviewed about a diagnostic category when their roles do not officially cover diagnosis. I am often asked this question when I talk about my study to colleagues. It is accurate that giving a client an official psychiatric diagnosis according to ICD-10 or DSM-IV is not the purview of other health professionals aside from the psychiatrist. However in the everyday clinical situation, these mental health professionals are presented with the manifestations of the criteria included in diagnostic categories by the way clients behave, think and feel, and the way these manifestations affect clients' day-to-day lives. In addition, the DSM Task Force and the ICD-10 Task Force, both of which are responsible for making decisions about the inclusion of diagnostic categories are also composed of professional experts, not exclusively psychiatrists. The expertise of clinicians is grounded in their everyday experiences.

3.6 Data Collection Methods

3.6.1 The Interview

The focus of this study was the description and interpretation of clinicians of the EPCACE criteria as they see it manifested in their clients. In order to explore these descriptions and interpretations, my primary method of data collection was in-depth interviews. I read works on doing and using interviews in qualitative research, particularly that of ethnographic interviewing by Spradley (1979), and the recursive model of in-depth interviewing by Minichiello, Aroni, Timewell, and Alexander (1990). The concepts and principles embedded in these methods guided my process of interviewing, to the extent that I was able to create a structure for the interview to focus attention to the definitive phenomenon of interest, that of EPCACE. I listed questions relating to EPCACE and discussed these with a researcher-psychologist colleague. I then discussed these questions with a psychiatrist colleague. These discussions were to ensure that I covered the necessary ground which related to the ICD 10 criteria.

As a result of these discussions, I decided to use a focused interview format with pre-determined questions (Morse & Field, 1996). Focused interviewing is a semi-structured technique introduced initially by Merton and Kendall (1946) in sociology for media research. In their work, they presented interviewees with a uniform stimulus (a film, or a radio broadcast, or a newspaper release, etc) and subsequently interviewed them on the impact of

the stimulus. The original aim of their interview was to provide a basis for interpreting findings in a quantitative study. There are four criteria that need to be met in focused interviewing. These are non-direction, specificity, range, and the depth and personal context of the interviewer.

The unique feature of a focused interview is the use of a stimulus in advance (film, radio broadcast, etc). Recall (in “Recruitment of Participants” section of this chapter) that a copy of the ICD-10 EPCACE diagnostic criteria clinical guidelines was given to clinicians to assist in deciding whether to participate weeks prior to the interview. This served as the advance stimulus in this study. The criteria associated with focused interviewing have now become more general criteria for designing semi-structured interviews. As Merton and Kendall (1946) suggest, the main aim is to give the interviewee as much scope as possible to discuss his or her views.

Although my objective in using the focused interview process was not to use the findings to explain quantitative data, its structure and criteria suited the purposes of this study. The criterion of range ensures that all aspects and topics relevant to the research are covered in the interview. To meet this criterion, an interview guide was developed, based on the objectives of the study and the criteria specified in the ICD-10 EPCACE CDDG. The interview guide is attached as Appendix G.

The criterion of non-direction was achieved by using several forms of questions. Unstructured questions such as, “What do you think of the criteria included in ICD-10 EPCACE?” invited open responses from the participants. Semi-structured questions, where an issue is defined but the response is left open, were also used, for example, “One of the criterion states that maladaptive personality changes lead to impairment in interpersonal, social and occupational functioning. How would you describe the functioning of your client in these areas?”. The other form of question used was the structured question. For example, “Are the criteria included in the ICD-10 EPCACE sufficient or need modification?”.

To meet the criterion of specificity, the interview invited participants to recount clients that they had seen who exhibited manifestations of the criteria of/in EPCACE. The interview also invited participants to recount concrete examples of how their clients manifested a specific EPCACE criterion. For example, “How is estrangement manifested in your client?” or “What are the indications that your client mistrusts the world?”.

In the effort to be specific, non-direction was also integrated into the interview, allowing open opportunities for participants to decide what client/s story or situation he/she wanted to narrate or describe. In relation to specificity, Merton and Kendall (1946) suggest that questions should be explicit enough to help the participant relate his/her responses to the specific

aspect of what is being asked, and yet general enough to avoid the interviewer structuring the participants' responses.

The criterion of depth and personal context relates to the interviewer becoming aware of responses that need probing and further clarifications, and that these are pursued, re-stated and clarified as appropriate to the given case. At the same time, it is necessary to be non-directive and listen attentively to participant's responses or lack of response.

3.6.2 Conduct of the Interviews

All interviews except for two were conducted in the workplaces of the participants. For two participants, home was more convenient as they were both working part-time and one had a small child. Each interview lasted from 1 to 2 ½ hours. I did not spend much time on preliminaries prior to the interview because thirteen of the participants were known to me through previous employment roles. I had met and spoken with eight of the participants face to face during presentations of my proposal in staff meetings. I had spoken to all participants by telephone at least once, and sometimes twice, prior to the interview.

During the interview sessions, after the usual greetings and clarifications, I took the opportunity to remind participants of the confidentiality of the interview, and the option for them to withdraw from the study at any time should they decide to do so. I reminded them about taping and transcription

of the interview, and that they could stop the tape at any point should they wish to do so. I also collected their signed consent forms.

I started the interview proper with a “grand tour question” (Spradley, 1979). Depending on the context on how the study was introduced to the participant, I would proceed as follows: “As presented in your staff meeting or “As we discussed over the phone....) the ICD-10 has this new diagnostic category called EPCACE. I have given you (or “you have a copy of....) a copy of the clinical guidelines. Looking at the guidelines, could you describe a client of yours that may fit the criteria”?

I used the schedule of questions that I prepared as a guide, though the wording and ordering of the questions were not fixed. This allowed both me and the interviewee the flexibility to ask and respond to the relevant information being discussed. Hence, “probing” and additional questions were asked to elicit further information on, and clarification of, current narratives or descriptions. For example, “What traumatic events has this client of yours experienced?” “How did he/she show his/her hostility?”. The flow of questions resembled that of “funneling” (Minichiello et al, 1990). The questions that were asked at the beginning stages of the interview were broad, covering general and wider ideas about the topic. The interview then gradually flowed into more focussed questions regarding specific aspects of each symptom criteria of EPCACE (Spradley, 1979; Taylor & Bogdan, 1984). This technique is similar to what Merton and Kendall (1946) suggested, that is, that

unstructured questions are asked first, followed by semi-structured questions and then by structured questions.

I also used information and insight gained from reflection on and preliminary analysis of interviews to inform subsequent interviews in a recursive manner. For example, “Some clinicians have expressed difficulties and concerns about these criteria. Could you describe for me any experiences and views you have about this”? In the final part of the interview, I allotted time to evaluating whether I missed anything from the guidelines, or if I missed following up a point made by the interviewee. For example, “At this point I just want to go over my guidelines to see if there is anything I missed that we need to talk about before we wind up”; whether the interviewee had anything she/he wanted to say or ask for, which no opportunity was accorded in the interview, like “Is there anything you want to add to what you have described/narrated today?” or “Do you have any questions you want to ask me relating to this study?”.

Once the tape recorder was switched off, I usually ended with small talk about related topics outside the interview framework. I usually took this opportunity to ask the interviewee if I could give her/him a phone call about any questions that I may have had about the content and my interpretation of the interview. I also informed them that I would send a copy of their transcribed interview and that they were free to make any clarifications they may have about the transcriptions and about the interview in general. All the

participants agreed to be followed up after the interview with a phone call if necessary.

After each interview, I recorded the context of the interview as a diary entry including the name of the interviewee, his/her role, the setting of the interview, duration, my impressions of the interview and any relevant information that arose in the conversation after the tape was switched off. Although it was not by design or intention, I interviewed the torture and refugee trauma clinicians first, followed by the Vietnam Veterans clinicians, and lastly the sexual assault clinicians. This was on the basis of who responded first to my request for participation. Interviews with clinicians occurred and were completed within an 11 month period.

3.7 Data Management

As stated, all interviews were tape recorded and transcribed verbatim. I personally transcribed the first three interviews. Coding data began by using different coloured highlighting pens and writing the names of codes in the margin. Whilst doing this, I wrote tentative ideas, relationships between ideas, and questions I had about the data to follow up in the next interview. This is akin to the theoretical memos suggested by Glaser (1978), Strauss and Corbin (1990) and others.

Ideally in qualitative research, data collection and data analysis go hand in hand (Streubert & Carpenter, 1999). In reality, this was not always possible. In my case, transcription of interviews was becoming a laborious and time consuming task. Although initially advantageous (I could listen to the tapes several times over which helped me to think about the data) it was proving to be impractical. With an internal school grant (School of Occupation & Leisure Sciences, December 1995), from the fourth interview onwards, the transcriptions were completed by an experienced transcriber. This meant that two or three interviews were delivered at any one time; and several weeks elapsed before I could review data from these transcribed interviews.

The only computer program I used to help manage the data was MS Word. I was not as computer literate eight years ago as I am now. I explored Ethnograph, but I was too slow in absorbing the nuances of technology so I gave it up. I figured that I felt more competent and it was less complex for me to use the cut and paste features of word processing software (or cut and paste manually from a printed copy), and keep data as separate Word files (or keep data in separate labelled folders physically) than trying to learn another technical software. Later, with the sophistication of word processing software, I was able to use highlighting features and font colours in my Word files. This type of data management is referred to as the manual method (Morse & Field, 1996).

For each interview transcript, I kept a Word file on my computer drive, a back up file in a disc and a printed file in a folder. As suggested by Morse & Field (1996), when I analysed the data, I cut the significant passages from a printed copy of the interview, writing an identifier on the margin to note which interview transcript the passage came from. I then taped each piece of cut passage to a full-size sheet of paper and filed it in an appropriate folder for that category. As there were some segments of data that fitted in more than one category, I needed to have more than one printed copy of the page. I found this method manageable but I would not recommend it for larger studies. For my purposes, it suited my personal style (Morse & Field, 1996) and my level of computer skills.

3.8 Data Analysis

In analysing the data I followed the “framework” outlined by Ritchie and Spencer (1994). ‘Framework’ for these authors is an analytical process which involves a number of distinct though highly interconnected stages (p.177). They are careful to point out that it is not a strictly linear mechanical process. It is systematic and disciplined but it also relies heavily on the creative and conceptual ability of the analyst to determine meaning, salience and connections. This conceptual ability is akin to possessing what is referred to as theoretical sensitivity (Glaser, 1992; Strauss & Corbin, 1990). This is the ability to generate concepts from the data, identify meanings and salience, and

make connections between ideas, critically important to progressing from raw data to theorizing (Strauss & Corbin, 1990).

My conceptual ability or theoretical sensitivity for this study started to develop during my clinical work as an occupational therapist in psychiatry and community mental health services. In the trauma area this began when I had the chance to attend a workshop on torture and refugee trauma conducted by Danish experts who visited Sydney in the late 1980s prior to the establishment of a torture and refugee trauma program in Sydney. Since that time my interest in this area has continually developed. In my previous role as a fieldwork educator in mental health, I had the opportunity to work with occupational therapy students at the newly established torture and refugee trauma service in Sydney, developing and implementing programs with clients alongside counsellors and other clinical and community development staff. As a fieldwork educator and part-time clinician, I read the literature on refugee trauma, posttraumatic stress disorder, psychological trauma and related topics to keep myself abreast of current developments. It is through this work that I decided to pursue research in this area.

Whilst continuing to read the literature, and in my role as lecturer in occupational therapy, I supervised undergraduate honours research on school role performance of refugee children; coping with extreme stress; and parenting of Vietnam Veterans with PTSD. In addition I developed and taught an elective unit in the undergraduate occupational therapy course on

occupational therapy and posttraumatic stress syndromes. I attended and presented papers at international, national and state conferences and attended presentations by experts in this field including that of one of my supervisor.

Discussions with one of my supervisors, whose expertise is in the area of psychological trauma, helped to sensitize me to the issues related to psychological trauma in general and specific issues related to this study. Whilst conceptual ability or theoretical sensitivity in one's research and interest area is an important quality to develop to be able to make sense of qualitative data, I also believe in Strauss' (1987) notion of linking one's theoretical sensitivity with sensitivity toward social relationships.

Strauss (1987) suggested that a qualitative analyst who is able to combine and make use of these two abilities is in a more advantageous position over someone who possesses ability in one or the other skill. A combination of these two skills is particularly important for this study, as the topic is about a specific human suffering, caused by the infliction of that suffering by one human being to a fellow human being. As can be inferred from ICD-10 EPCACE diagnostic criteria, the problems of trauma survivors believed to suffer from enduring personality change have an impact on social relationships and human connections. I sincerely hope I also possess sensitivity towards human suffering and social relationships.

The 'Framework' approach involves a systematic process of sifting, charting and sorting data according to key issues and themes. The five key stages to qualitative data analysis in 'Framework' include familiarization, identifying a thematic framework, indexing, charting, and mapping and interpretation (Ritchie & Spencer, 1994, pp. 177-178). Each method is illustrated by the description of each stage as it took place in this study.

3.8.1 Familiarization

This stage requires the researcher to become familiar with the range and diversity of the data and requires gaining an overview of the body of material gathered. It involves immersion in the data. My familiarization started at the beginning of the first interview. I listened to the tape of the first interview listing key ideas, themes and questions which I followed up in the second interview. I listened and transcribed the first three interviews and re-read the transcripts of these interviews. Whilst doing these, I continued to list key ideas and themes, new and recurring. This process is similar to open coding as described by Strauss and Corbin (1990). Chunks of data which varied in length from one line to a few paragraphs were coded using colour coding (highlighter pens), and labelled by writing notes on the bracketed side of a printed transcript. This process of beginning abstraction and conceptualisation, or open coding, was applied to all the transcripts.

3.8.2 Identifying a Thematic Framework

A thematic framework for this study was drawn from

- i. the ICD-10 EPCACE criteria which were considered a priori themes and issues
- ii. the emergent issues raised by the respondents themselves, and
- iii. the themes arising from patterning and recurrence of particular views or experiences.

Refining this thematic framework was not an automatic process. It involved logical judgement and intuitive thinking. It involved making judgements about meaning, about relevance and the importance of issues, about making connections between ideas and at the same time, making sure that the research questions were being addressed (Ritchie & Spencer, 1994).

3.8.3 Indexing

The thematic framework was used to examine, sift, sort and reference the data in its textual form. This process is called indexing. All the data or interview transcripts were read and annotated according to the thematic framework. I wrote the indexes or annotations of the bracketed texts on the margins of the transcripts. Indexing is not an automatic process. It involves judging the meaning and significance of the data. As an analyst I also had to decide whether a chunk of data referred to one index only or to multiple indexes. This process of making judgment is subjective and open to differing

interpretation. However by adopting a system of indexing or annotating data, the process is made visible and accessible to others (Ritchie & Spencer, 1994).

3.8.4 Charting

After going through all the transcripts and applying the thematic framework, I ‘decontextualized’ or ‘lifted’ the data from their original context by putting together all data that pertained to one index, category or theme. I did a further analysis of the data under each category to identify their dimensions and characteristics. This process is akin to axial coding as practiced by Strauss & Corbin (1990). Charting was done firstly for each group of clinicians for each theme, and then for all three groups to identify the similarities and differences, and uniqueness for each group. This process involved abstraction and synthesis of data, and took into consideration possibilities for presenting and writing up the data (Ritchie & Spencer, 1994).

After charting the combined data from three groups of clinicians, I wrote a report of the preliminary results for my supervisor for review. Copies of this preliminary analysis, as well as the 1999 published article on the first study (Beltran & Silove, 1999) were sent to heads of services where most of the participants were recruited from. I also sent a copy of the same article and preliminary report to a nosologist prior to my meeting with her to validate whether the data made nosological sense. The nosologist suggested ways by which the data could be mapped (Michelle Bramley, personal communication, 2002).

3.8.5 Mapping and Interpretation

This final part of the analysis of data requires the analyst to synthesize the data by identifying key characteristics. This is where Ritchie and Spencer (1994) note the analyst returns to the key objective of qualitative research in the context of policy research (Ritchie & Spencer, 1994). In this study, the objective was contextual, in this instance, identifying the form and nature of EPCACE criteria.

In the process of mapping and interpretation, I reviewed the earlier analysis I had done on the data, reviewed the charts, identified similarities and differences, identified unique characteristics, searched for patterns and connections and sought explanations. Ritchie and Spencer (1994) emphasized that synthesizing data to present a holistic picture is not simply a matter of aggregating patterns. It involves discerning the salience and dynamics of the issues and “searching for a structure rather than multiplicity of evidence” (p. 186). The results presented in the next chapter are the outcome of this final stage of mapping and interpretation.

CHAPTER 4

RESULTS

I present the results of this study using the format of the DCR (Diagnostic Criteria for Research) for EPCACE. As discussed in the Literature Review chapter, DCR provides more specific and more elaborated criteria for the diagnoses contained in CDDG (Clinical Descriptions and Diagnostic Guidelines) (Sartorius, 1993; Sartorius, Bedirhan Üstün, Korten, Cooper, & van Drimmelen, 1995). In DCR the criteria for EPCACE category are lettered from A to F. The format appears more systematic and structured than the narrative description of CDDG which lends itself as a useful methodical tool. The main focus of this study is the symptom criteria, Criterion B of EPCACE. As indicated in the Methods chapter, clinicians used the CDDG to describe the manifestations of EPCACE symptoms that they saw in their clients. I now use the DCR as a framework to analyse and present the results. This framework is also used in the Discussion Chapter.

F62.0 Enduring Personality Change After Catastrophic Experience

4.1 Criterion A

- A. There must be evidence (from the personal history or from key informants) of a definite and persistent change in the individual's pattern of perceiving, relating to and thinking about the environment

and the self, following exposure to catastrophic stress (e.g. concentration camp experience; torture; disaster; prolonged exposure to life-threatening situations).

4.1.1 Evidence of Persistent Change

All the evidence of “persistent change in the individual’s pattern of perceiving, relating to, and thinking about the environment and the self,” which clinicians described relate to Criterion B and are therefore elaborated in that section.

4.1.2 Key informants who can corroborate the evidence with clinicians

Clinicians highlighted the roles of family members such as parents, spouse, siblings, children and close relatives in providing and corroborating evidence. One Vietnam Veteran clinician commented “when you speak to the wives of these Veterans, you often get that confirmation”. Relatives of torture and trauma survivors reported to clinicians that their family member had become a dysfunctional person from a competent one, or “from a quiet to irritable man”. Clinicians also commented on the role of the client as informant. For example, a torture and trauma clinician related the distress of his client at “...things I can do before, I can’t do now”. A sexual assault clinician talking about her clients noted, “They say they want to go back to how they were...they want to be how they used to be”.

4.1.3 Exposure to catastrophic stress

Sexual assault trauma experienced by clients as identified by clinicians included early childhood sexual abuse repeated in adolescence and later in an abusive marriage relationship; family generational abuse (physical, sexual, emotional abuse); ritual abuse; rape in adults; sexual assaults by fathers and male siblings and by strangers. In addition to their combat experiences, clinicians reported Vietnam Veterans who had joined the Police Force upon returning to Australia and continuing to experience repeated life threatening events. Some Veterans experienced one off sexual trauma, some experienced multiple sexual traumas. The experiences reported by clinicians of torture and trauma survivors were related to the following: Bosnian war, concentration camp (Croatia); torture in Chile, Turkey, Bangladesh, Iran, Afghanistan; war in Central America, South America; Vietnam War; Cambodian genocide; and civil war in East Timor.

An issue raised by some clinicians in relation to Criterion A is the nature and definition of catastrophic stress. The definition of what is "catastrophic" is at present limited to global traumatic events. Clinicians noted, "There can be other forms of trauma abuse which can be equally as catastrophic". They questioned: "What is catastrophic stress? Whose definition is important?"

Clinicians from all three groups agreed that the stressor is a salient factor in post traumatic personality change. There are two aspects of the stressor that clinicians identified. The first aspect is the **trauma event** itself. Some

clinicians expressed the view that trauma events are so terrible that personality change is the best way of facing them. One clinician commented, "The best way to protect yourself is to become very angry or very frightened". The trauma of war and torture gives the individual the feeling that the experience is ongoing because they had experienced something horrific. One clinician referred to this as "prolonged experiential effect". Severe trauma such as the "brainwashing" in concentration camps, and the Cambodian and Bosnian genocide, were such extraordinary experiences that they changed the individual's assumptions about the world, a change which is then reflected in their behaviour. For example, the individual's view that the world is unsafe may result in a hostile attitude and on-edge behaviours. As one clinician expressed, "trauma changes your assumptions about the world, therefore it changes your behaviour". Childhood trauma such as severe abuse was also identified as bringing about severe personality change in adults.

The other aspect of the stressor identified by clinicians is the **severity and extent of trauma**. From clinicians' comments "constant, continuous, multiple and successive onslaught" was seen as a salient factor to personality change. Sexual assault clinicians cited repeated sexual trauma. The refugee experience was a typical experience where some refugees suffered the trauma of their own torture, were fearful for the lives of relatives who were left in their country of origin, and suffered the consequences of forced migration and the adaptation process in the new country.

4.2 Criterion B

In this section, I begin by stating the criterion, as specified by ICD-10 DCR followed by the results for each of the five features.

B. The personality change should be significant and represent inflexible and maladaptive features, as indicated by the presence of at least two of the following:

- (1) a permanent hostile or distrustful attitude toward the world in a person who previously showed no such traits;
- (2) social withdrawal (avoidance of contact with people other than a few close relatives with whom the individual lives) which is not due to another current mental disorder (such as mood disorder);
- (3) a constant feeling of emptiness or hopelessness, not limited to a discreet episode of mood disorder, which was not present before the catastrophic stress experience; this may be associated with increased dependency on others, inability to express negative and aggressive feelings, and prolonged depressive mood without any evidence of depressive disorder before exposure to the catastrophic stress;
- (4) an enduring feeling of being 'on edge' or of being threatened without any external cause, as evidenced by an increased vigilance and irritability in a person who previously showed

no such traits or hyper alertness; this chronic state of inner tension and feeling threatened may be associated with a tendency to excessive drinking or use of drugs;

- (5) a permanent feeling of being changed or being different from others (estrangement); this feeling may be associated with an experience of emotional numbness.

4.2.1 B. (1) a permanent hostile or distrustful attitude toward the world in a person who previously showed no such traits

Clinicians' descriptions revealed different characteristic manifestations for hostile and distrustful attitudes. A hostile attitude was manifested variably by clients through aggression, rage, anger and/or hatred, whilst a distrustful attitude was evident in fear, sense of withholding and paranoia.

a) Hostile Attitude

Aggression was described by torture and trauma and Vietnam Veterans clinicians, but not by sexual assault clinicians. It was manifested in attacks, verbal and/or physical, towards people and in aggressive communication such as shouting. With Vietnam Veterans in particular, these attacks occurred in the context of abusive relationships with their respective spouses. Clients tended to be over-reactive and hypersensitive towards issues (related to trauma events) that served as a provocation to aggression.

Similar to aggression, **rage** was described by torture and trauma and Vietnam Veterans clinicians, but not by sexual assault clinicians. For some torture and trauma survivors, rage was manifested through attempted suicides which clinicians believed were an outcome of rage directed inwards. Some clinicians believed that rage was associated with the view “that the world has done an injustice to them (torture and trauma survivors) and the expectation that the world should compensate them for their suffering”. At some stage, this rage turned into anger because of the realisation that “in a way the world cannot compensate their suffering”. Vietnam Veterans clinicians described rage as an “explosive arousal symptom”. Some clinicians related rage to unassertive coping behaviour. Rage was also considered to be a conditioned response, noting that the "military has a culture that makes rage a normal occurrence".

Anger was another manifestation of a hostile attitude, which unlike aggression and rage, was identified across all three groups of clinicians. For torture and trauma survivors, anger may be accompanied by drive for revenge, such anger being directed towards the torturer and the regime which initiated and perpetuated the torture. Anger was also directed towards the self, for the self-blame of trusting others too much. Anger may also be due to abandonment of significant others, due to loss of status, income, and other losses associated with the traumatic experience. Anger may be suppressed, very intense and may also be an outcome of extreme irritability. Some level of passivity was also found as an expression of anger. Such level of passivity was accompanied with “the expectation that someone fixes their problem”. This

was also associated with thoughts like "people are stuffed. The world is stuffed. You can't make any sense of what's going on in the world". This feature was particularly common among those torture and trauma survivors who were not involved in the political struggle in their countries of origin.

Anger was also described as a "burst" which was related to impatience and rage. Four out of five Vietnam Veteran clinicians identified anger as a common manifestation of hostility. Both torture and trauma and Vietnam Veterans clinicians described anger in conjunction with rage. Like rage, these clinicians described anger as an "explosive arousal symptom".

Anger in sexual assault survivors stemmed from their lack of control as one clinician expressed, "they feel that they didn't have control and anyone even in a minor way tries to control them now it seems to set them off and they, you know, explode". Anger also stemmed from their feeling "that they put themselves in that position. That they let themselves be assaulted". Their anger was also directed to people who were supposed to have been able to protect them from the assault. The lack of protection from authorities and from family members and the sense of betrayal (for example, from a family member who did the abuse, as expressed by one clinician as "why did he do this to me?") fuel anger and hatred.

A hostile attitude towards the world was also seen to be accompanied with **feelings of hate. Hatred** was identified by clinicians across the three groups.

For example, one clinician cited a Bosnian woman who described hatred “as a major change in herself accompanied by thoughts of killing member (children) of the enemy side”. In Vietnam Veterans hatred was manifested in their “anti-authority in attitude and style”. This was expressed in the manner of dressing and doing things, pushing boundaries, and in their body language and positioning. The body language carried with it “a ‘don't mess with me’ message”. With positioning for example, “a veteran would choose to sit in a corner of a room to get a full view of what is going on and to make sure one has an unobstructed path to the exit”. For sexual assaults survivors, hatred is often directed towards the self. One clinician noted, “I think often it can be sort of self-hatred as well. The anger can be in the form of self-hatred. And I think that goes back to feelings of guilt and responsibility”.

b) Distrustful Attitude

The characteristics of a distrustful attitude were described by clinicians across the three groups. One of these is **fear**. Some torture and trauma clinicians believed that fear leads to a distrustful attitude for a reason, for example, torture and trauma survivors “fear for what might happen to their family back home, fear of harm that might happen to them”. Real and pervasive fear was also described as a consequence of being "rigidly shocked" by the torture experience. With Vietnam Veterans, fear involved “a feeling of not being safe in one's environment, e.g. in the street, therefore, one might carry a knife around as protection”. With sexual assault survivors, fear was fuelled by “the belief that they might be further attacked and violated”. Like torture and

trauma clinicians, sexual assault clinicians were also of the view that fear leads to a distrust, carried over by some clients to the therapy situation.

The second characteristic of distrustful attitude is **sense of withholding**.

For torture and trauma clinicians, distrust was also evident in clients' sense of withholding, which was characterised by "extreme cautiousness and guardedness". In Vietnam Veterans this was exemplified by "living a hidden identity as a Vietnam Veteran by not telling other people that they've been involved in the Vietnam War". The sense of withholding was also manifested in other ways, for example, "never talking to anyone". This difficulty had a temporal characteristic. For example, "taking a long time to tell anyone the full story of whatever it is; or taking a considerable time to seek help at all". When help was sought, distrust was very evident in the initial phase of treatment. One clinician commented that it was not uncommon to "not experience success in building trust with all patients". With sexual assault survivors, one saw the other side of sense of withholding, that is, "not being able to let people into one's real self". When in interaction with others, sexual assault survivors feel "as if they are playing a role (false self)", which impacts on their ability to form relationships.

It is interesting to note that underlying a distrustful attitude was what torture and trauma clinicians described as an increased and more acute level of **paranoia**, "...very tuned into what the other person is thinking". Sexual

assault clinicians described it similarly at an increased level in their clients. For Vietnam Veterans however, the paranoia is “low level but constant”.

A hostile or distrustful attitude was directed towards society and its structures, towards individuals, towards perpetrators, towards other groups and towards the self. This was more often extended towards the treatment situation, for example, being suspicious of medication. One clinician cited the case of a woman who was in an abusive relationship with a partner and was also tortured in her country of origin. Her hostility was directed towards men and not women.

Some clinicians acknowledged the validity of distrust in their clients. A torture and trauma clinician put forward the view that, for some clients, distrust happens for a reason, for example, “promise of a work, housing, etc. in (country of origin), then none of these came into fruition in Australia”. For Vietnam Veterans, the validity of a hostile and distrustful attitude stemmed from the initial lack of appreciation from the society as a whole of their involvement in the Vietnam War.

Hostile and distrustful attitudes varied in intensity summed up as, “Some days it is stronger than other days”. In some cases clinicians noted that “there may be mistrust but no hostility nor aggression”. This observation validates the assumption of this criterion that hostility OR distrust may be present. The question is can the two co-occur? For sexual assault clients in particular,

hostility and distrust varied in degree depending on number of episodes of trauma with “More incidences of trauma, the greater the mistrust and paranoia”.

There was also a question of differentiation of trait vs. disorder in understanding distrust and hostility. One clinician commented whether what one observes in patients is “distrust as a trait and not as a disorder”. The possibility that a patient can be distrustful but not necessarily hostile was also raised.

Table 3 summarises the characteristics of hostile or distrustful attitude as identified across the three groups of clinicians.

Table 3. Criterion B.1 Hostile or Distrustful Attitude toward the World

Hostile Attitude	Torture & Trauma	Vietnam Veterans	Sexual Assault
Aggression	✓	✓	
Rage	✓	✓	
Anger	✓	✓	✓
Hatred	✓	✓	✓
Distrustful Attitude			
Fear	✓	✓	✓
Sense of withholding	✓	✓	✓
Paranoia	✓	✓	✓

4.2.2 B. (2) social withdrawal (avoidance of contacts with people other than a few close relatives with whom the individual lives) which is not due to another current mental disorder (such as mood disorder)

There were two features of social withdrawal that stood out in clinicians' descriptions. These are 1) Tendency to isolate or social isolation, and 2) Apathy. The tendency to isolate was identified by the three groups of clinicians in their clients. Apathy was identified only by clinicians working with torture and trauma, and sexual assault survivors.

In torture and trauma survivors, a **tendency to isolate** was characterised as wandering away "in his thoughts", inward turning, not present most of the time (non-presence) and "just wanting to be by themselves". Clients were described as "not engaging", not participating in usual activities, for example, going out shopping and socialising.

In Vietnam Veterans, the tendency to isolate manifests in veterans who had chosen lifestyles that allowed them to withdraw from society, for example, living in rural areas (outback). For urban dwelling veterans, some tended to disappear for a period, "just take off on a motorbike". The only social contacts that they had would be with other veterans because "they are the only people that really understand me". Some veterans not only want isolation for themselves but also for their family members, for example, not allowing family members to maintain social contacts. This may stem from paranoia, or from the need to protect family members because of their experience of

seeing death at close hand, and from the belief that this is not a safe world. Underlying the tendency to isolate is an “inability to tolerate crowds and inability to tolerate an attitude or opinion they do not share”. This is summed up by one clinician “when they are with people they get too uptight. They cannot tolerate having visitors or family get-togethers”.

Social isolation was also evident in sexual assault survivors. Survivors usually “feel alone because they can't trust anyone” (related to Criterion B.1). They do not want to go out because of the fear of going out and the fear of rejection (related to B.1). Some beliefs underlying isolation which sexual assault survivors hold include: “. . . that people are sick of them”, “not worthy of being talked to”, “that they are dirty and shameful and not acceptable”, and, “this is not a safe world”.

The other feature of social withdrawal that clinicians described was **apathy**. This was only described in torture and trauma and sexual assault survivors. With torture and trauma survivors, apathy was manifested as “having loss of vitality, less vibrant” and some survivors “exude blackness, deadness, lacklustre, lifeless quality”. Patients lacked interest and responsiveness in what was going on around them like “unable to do practical things around the house”. Similar to torture and trauma survivors, apathy in sexual assault survivors related to vitality. Clinicians described it as “no joie de vivre, no life - just surviving”; “no energy, interest, libido or spark”. Why apathy was not manifested in Vietnam Veterans survivors was not evident in the data.

Table 4 summarises the characteristics of social withdrawal as identified across the three groups of clinicians.

Table 4. Criterion B.2 Social Withdrawal

	Torture Trauma	& Vietnam Veterans	Sexual Assault
Social isolation /tendency to isolate	✓	✓	✓
Apathy	✓		✓

Clinicians forwarded some hypotheses why social withdrawal manifested in their clients. Torture and trauma clinicians attributed social withdrawal to depression of energy, lack of trust and motivation. It was also viewed as a symptom of chronic PTSD in "ones who have never recovered". Some clinicians attributed social withdrawal to more of a manifestation of anger and displacement due to loss of social roles. "Social withdrawal is reported by wives of survivors of the Bosnian war as a big change that they see in their respective husbands".

Some clinicians were of the opinion that Vietnam Veterans manifested social withdrawal because of the "fear of exploding around people and the embarrassment that this entails" (Criterion B.1) and a sense of estrangement - "other people cannot understand me, I'm so different". (Criterion B.5). There is also the sense of isolation on a larger scale that is isolation from society due to an unshared cause (Vietnam War). In sexual assault survivors, clinicians hypothesized that social withdrawal may be due to "paranoia and not able to

trust therefore withdraw”, “fear of going out and fear of rejection” (B.1) which stem from the above beliefs and to “depersonalization which brings a sense of not belonging” (B.5).

Clinicians across the three groups also identified consequences of social withdrawal which impact on survivors’ ability to communicate, and to develop and maintain relationships. Patients thought of as having EPCACE and who exhibited social withdrawal were described as

- not having long lasting relationships,
- having a decreased capacity for intimacy,
- having none or few friends, and
- "being happier with his dog than with people".

In a therapy situation they were also described as having "no relationship in therapy". In the broader social network, there was lack of evidence for social participation and sense of community. Patients with EPCACE who exhibited social withdrawal “do not communicate to anybody and hold the view that there's nothing to talk about”. This reflects the characteristic feature of apathy in social withdrawal. All these identified consequences constitute some of the features of Criterion C discussed in a later section in this chapter.

A question that was raised in relation to social withdrawal in torture and trauma clients is “how much of this is part of migration, and how much of it is part of personality”.

4.2.3 B. (3) a constant feeling of emptiness or hopelessness, not limited to a discreet episode of mood disorder, which was not present before the catastrophic stress experience; this may be associated with increased dependency on others, inability to express negative and aggressive feelings, and prolonged depressive mood without any evidence of depressive disorder before exposure to the catastrophic stress

As in Criterion B.1, there were specific features that distinguish emptiness and hopelessness. Emptiness was characterized by lack of self worth, a sense of nothingness and anhedonia. These were consistent across the three groups of clinicians. Hopelessness was characterized by a sense of powerlessness and passivity; sense of futility and despair; and a sense of foreshortened future. These were also consistent across the three groups. Loss of the will to live, was identified only by torture and trauma clinicians.

a) Constant Feeling of Emptiness

In torture and trauma survivors, a **lack of self worth** was fuelled by the belief “that they do not have anything to offer to anyone”, not trusting oneself, inability to recognise one's abilities, and no sense of achievement, even if there was evidence to the contrary. The beliefs and reasoning attached to these feelings were inflexible and very rigid. For Vietnam Veterans, a lack of self worth included the feeling of not being appreciated and accepted by peers, which one clinician believed led to the feeling of hopelessness. For sexual assault survivors, a lack of self worth stemmed from not being believed

that they were assaulted, and even blamed for it. As one clinician noted, "Because you have yourself to blame, then you can't be trusted in the future to protect yourself".

It is interesting to note that across the three groups, the cognitive quality of a **sense of nothingness** appeared to characterize emptiness. In some torture and trauma survivors, their cognition was described by clinicians as "almost incapacity to generate language and thought, no imaginal qualities left". The "long silences in therapy" was evident of this sense of nothingness. For Vietnam Veterans and sexual assault survivors, sense of nothingness was reflected in the "loss of capacity to see options and unable to problem solve" and "inability to see other options and other points of view, being stuck". For sexual assault survivors, this extended to "not knowing how they feel" and "not connected to feelings at all" (B.5).

Anhedonia is another feature of emptiness that was identified across the three groups. It was described by clinicians as "lack of capacity for pleasure" and "no feeling of enjoyment". This is manifested by some clients as the "inability to do and enjoy things which they were able to do before", "crying a lot", "lethargy and tiredness".

b) Constant Feeling of Hopelessness

The **sense of powerlessness and passivity** was a feature of hopelessness identified by clinicians across the three groups. For torture and trauma survivors, this feeling was accompanied by a belief in the control of external forces, for example “waiting for death”. For Vietnam Veterans, such powerlessness and passivity was held with the view that "I am altered; I can't change from the way I am and I don't even know if I want to". With sexual assault survivors, the thought that "I should have fought back... I should have been able to stop it" reinforced the sense of powerlessness and the feeling of victimization. This feeling of victimization was described by one clinician as follows:

Yes, being a victim. You know. What is it about me that means that this keeps happening to me over and over again? What do I keep doing wrong? What do I have written on my forehead? That's what a lot of people say. You know, come and abuse me. Is this, why do people keep doing this to me? It's, I mean you can't say it's worse and then it's much harder I think in counselling to deal with that because for people who are multiply abused those feelings of being responsible or being to blame because of something particular about you - it's harder then to counter them I think in a therapeutic situation because it keeps happening to them. So it must be something about them. It's a lot harder to think, oh it's about the abuser rather than that it's something about me. So I think there are differences. But yes I certainly see all of these with people who have been raped in adulthood.

Another feature of hopelessness described by clinicians across the three groups was the **sense of futility and despair**. Some torture and trauma clinicians described the “sense of never ending suffering as if in a ‘dark bottomless pit’” that they see in their clients. Vietnam Veterans clinicians described the “sense of futility with anything they try” that their clients feel. “Vietnam Veterans do not feel that they can change their lives”. This feeling was reinforced by a seeming lack of change in clients despite treatment. Some sexual assault survivors maintained “no hope that things could get better”, or “No belief that she will ever get through this”.

A **sense of foreshortened future** was another feature of hopelessness that was common across the three groups. Survivors “don’t see any future or anything for themselves”. Torture and trauma clinicians described this as “not having a sense of life that is important and have a future” and “not having a personal destiny that is interesting and important to the person”. Similar to lack of self worth, this view was rigid and inflexible. The “lack of concept of future” was evident in the “day to day survival mode mentality”.

The **loss of will to live** as a feature of hopelessness was described only by torture and trauma clinicians. Clients are perceived to have a certain death wish - “I’d rather die than go mad”. One clinician described a client whose family members had been killed thus “he was bringing death with him”.

Table 5 summarises the characteristics of constant feelings of emptiness or hopelessness as identified across the three groups of clinicians.

Table 5. Criterion B.3 Feelings of Emptiness or Hopelessness*

Emptiness	Torture & Trauma	Vietnam Veterans	Sexual Assault
Feeling of lack of self worth	✓	✓	✓
Sense of nothingness (cognitive quality)	✓	✓	✓
Anhedonia	✓	✓	✓
Hopelessness			
Sense of powerlessness and passivity	✓	✓	✓
Sense of futility and despair	✓	✓	✓
Sense of foreshortened future	✓	✓	✓
Loss of will to live	✓		

*This criterion is associated with prolonged depressive mood

Criterion B.3 states that “a constant feeling of emptiness or hopelessness.... may be associated with increased dependency on others, inability to express negative and aggressive feelings, and prolonged depressive mood without any evidence of depressive disorder before exposure to the catastrophic stress”.

There was nothing directly apparent in the data to indicate that emptiness or hopelessness may be associated with increased dependency on others.

Similarly in relation to “inability to express negative and aggressive feelings”,

there was nothing in the data to support its association with emptiness or hopelessness. Note that aggression as a feature of hostility (Criterion B.1) is expressed through verbal attacks and that communication difficulty was identified as a consequence of social withdrawal (Criterion B.2). The majority of clinicians identified that emptiness and hopelessness may be associated with prolonged depressive mood. Clinicians described it as “extremely depressed”, "deep depression near the surface" with clients being at a “point or nucleus of sadness” and attributed it to the profound losses that survivors had experienced, that is “loss of everything - youth, skill, status, significant others, etc” and the “constant mourning” brought about by these losses.

Other behavioural consequences identified by clinicians that were associated with emptiness and hopelessness were attempted suicide and self-mutilation. Lifestyle consequences were described as “unproductive.... lifestyle of someone who can't work, who doesn't work and on TPI” (Total Permanent Incapacity pension). These consequences are described further under the section on Criterion C which presents the impact and distressing consequences of enduring personality change.

Some clinicians also commented that emptiness and hopelessness were reinforced by repeated trauma. One Vietnam Veteran’s clinician observed that hopelessness becomes more pronounced when there is an acute exacerbation of PTSD symptoms. In some cases with Vietnam Veterans, hopelessness was associated with sexual dysfunction. One torture and trauma clinician

commented that in some cases, hopelessness is present but not emptiness and vice versa. Similar to Criterion B.1, the way B.3 is stated (a constant feeling of emptiness OR hopelessness) implies that one may be present without the other. Similar to Criterion B.1 (permanent hostile OR distrustful attitude), the case that one equates to the other was not raised.

4.2.4 B. (4) an enduring feeling of being ‘on edge’ or of being threatened without any external cause, as evidenced by an increased vigilance and irritability in a person who previously showed no such traits or hyper alertness; this chronic state of inner tension and feeling threatened may be associated with a tendency to excessive drinking or use of drugs;

Clinicians’ descriptions of their clients’ behaviour in relation to this criterion validated the presence of **increased vigilance** but not irritability. Note that clinicians linked irritability with anger when they discussed criterion B.1. Other features of this criterion include restlessness and hypersensitivity. Clinicians also talked about the fear underlying this behaviour. What is striking with this criterion was the associated anxious mood reported by the majority of clinicians. There was no evidence in clinicians’ description that they associated this criterion with the tendency to excessive drinking or use of drugs, although abuse of drugs and alcohol was suggested as an additional criterion for EPCACE as presented in a later section in this chapter.

Hypervigilance was described by clinicians across the three groups. For torture and trauma survivors, hypervigilance was related to a “feeling that something bad is going to happen to oneself and one's family. This therefore placed the patient in a survival mode”. Some patients went to the extent to “secure one’s house – locks, traps and all, and plans on how to escape from one’s house” in the event of an intrusion. “Hypervigilant like a radar” was another expression to describe this. Hypervigilance was described in Vietnam Veterans as “being on red alert, all the time” and attributed to an “outcome of not being demilitarised, not debriefed” after the war. Some sexual assault survivors exhibited this in behaviours such as “constantly checking and locking doors”.

Associated with increased vigilance was **restlessness or agitation**. Clinicians described this as “jumpy” and manifest in physical agitations such as rocking behaviour, constant leg shaking and frequent change of positioning, not being able to sit still, moving all the time, walking around and the inability to settle.

Hypersensitivity also featured in this criterion. This was described as “distracted by slight noise or slight movement”, “prickliness”, “jumpiness”, “exaggerated startle reaction”.

Clinicians described the **fear** that accompanied feeling “on edge”. Some clinicians described this as “chronic fear, due to fear of losing control”, “fear of madness, for thinking the horrible things that happen to him and his friends”, “fear that something bad is going to happen”, “fear of losing control

of one's anger", "fear of intruders" and "fear of open spaces, closed spaces and crowds". One torture and trauma clinician alluded to the sense of withholding, carefulness and guardedness that accompanied feeling "on edge". Recall that in discussing criterion B.1 – hostile or distrustful attitude, fear and sense of withholding were identified as a feature of distrust. This suggests the possibility of co-presence of B.1 – distrust and B.4 - on edge.

As previously stated, associated with feeling on edge is an **anxious mood**. Clinicians described it as "enduring anxiety", "feeling anxious", "overwhelmed with feelings because she doesn't know who to trust and does not even know if she can trust herself". Some torture and trauma clinicians posited that enduring anxiety is "due to flashbacks, ongoing nightmares, and arising from feeling of constant threat". The fears described above tended to fuel the anxious mood as one clinician noted, "Worries all the time especially when they don't know who the assailant is". The anxious mood spilled over into other areas of life, for example at work one clinician described their client as "Anxious about authority at work, how they will respond if work is not done properly".

Other consequent behaviours associated with feeling on edge included

- crying, for example, "He feels constantly threatened that he can burst to tears anytime". "In fact", according to one torture and trauma clinician, "crying is a major change in this man who does not usually cry". One sexual assault clinician described a client who "easily bursts

into tears at seemingly nothing.which brings anxiety due to not being able to control it”.

- cognitive problems such as difficulty concentrating, remembering, and thinking clearly,
- sleep disturbance caused by insomnia and nightmares and tiredness.

Clients had difficulty concentrating “because of distraction in the environment for which they are hypervigilant”. Their sleep pattern was described as “sleep, wake up, not being able to sleep again” which contributed to tiredness. One clinician described her client’s sleep problems, *“He's got very severe sleep disturbances to the point where if he can get 4/5 hours sleep a night he thinks he is doing really well, because often till recently he was getting a lot less. And even with medication he can't actually get beyond about that 4/5 hour patch and he still gets nightmares. And also, I mean the interesting thing is that his wife also gets nightmares, although she hasn't been tortured. She, it's kind of like in the dream state they are both going through the trauma.”*

Some clinicians hypothesised on the reasons for the presence of feeling on edge as an aspect of characterological change in people who experienced catastrophic stress. Clinicians explained this criterion as an outcome of over stimulation of the sympathetic nervous system, the fight or flight mechanism being on constantly or as a conditioned response, for example, a continuation of concentration camp behaviour. This criterion may be an outcome of thought intrusions. As stated previously, for Vietnam Veterans it may be an

outcome of not being demilitarised (not debriefed) upon return to Australia after their military service in Vietnam.

Clinicians did not identify irritability and tendency to excessive drinking or use of drugs associated with this criterion. I can only hypothesize that this was the case because they used the clinical guidelines which did not state the full research criteria. Neither I nor the clinical guidelines prompted them to think about these other behaviours.

Table 6 summarises the characteristics of enduring feeling of being on edge as identified across the three groups of clinicians.

Table 6. Criterion B.4 Chronic Feeling of Being “On Edge”, As If Constantly Threatened*

	Torture & Trauma	Vietnam Veterans	Sexual Assault
Hypervigilance	✓	✓	✓
Restlessness	✓	✓	✓
Hypersensitivity	✓	✓	✓
Fear	✓	✓	✓

*Clinicians associated this with anxious mood.

4.2.5 B. (5) a permanent feeling of being changed or being different from others (estrangement); this feeling may be associated with an experience of emotional numbness.

Clinicians' descriptions of clients across the three groups validated the presence of this criterion; however its association with emotional numbness was not explicitly described. A permanent feeling of being changed or being different from others is marked by a feeling of alienation from others and from oneself. What is also striking about this criterion is its association with criterion B.2 social withdrawal.

Torture and trauma clinicians' descriptions of estrangement was characterised by **feelings of alienation from oneself and from others. Alienation from oneself** was described as "alienation from someone that they were before, that they are not now". One clinician described it metaphorically as "something is broken and can no longer be repaired, something is lost and cannot be found". Some clinicians described patients with estrangement as "living dead", with a diminished life force. Patients were described as not having "presence" as exemplified by a description of one clinician referring to an Afghan man - "he was so split apart you could hardly feel him sometimes". Some clinicians described the phenomenon of **physical estrangement**. This was related to the description of "living dead". Patients who manifest this physical estrangement have no affect, have blank facial expressions, have resilient stares; they do not blink, have cold skin and look like a corpse "like he's dead". For these patients, the proof of their existence was the knowledge

and feel of their body. For example, "I exist because I can touch myself. I have a body". However, they express the knowledge "that there is a world out there [that] does not have meaning". Estrangement was also expressed in behaviour such as "keeping oneself away", which stemmed from an "inability to see the world around her". Emotional numbing is implied in the descriptions of "living dead" and non presence.

Some Vietnam Veterans manifested estrangement as "feeling different but not look[ing] different", "feeling detached almost in limbo". It is possible that feeling detached may be an indication of emotional numbness. Estrangement in Vietnam Veterans was tied with the following beliefs: "I'm so different from everyone that no one will understand no one will be able to relate to me"; "I am different. I am unworthy. I am some way bad and evil". Some Vietnam Veterans held the view "that most people in their world don't have any understanding of how they are, what they are like, who they are". They held the view that "they have nothing in common with other people", "...that they are not appreciated and understood by society". These beliefs were perceived by clinicians as part of the collective consciousness of Vietnam Veterans.

For Vietnam Veterans, estrangement from the broader community stemmed from the belief that they were treated unfairly by the wider society when they came back from Vietnam. The feeling of detachment spilt over to one's

relationships, resulting in estrangement from family and from the Veterans' community.

Estrangement from oneself was reflected in the descriptions of Vietnam Veterans. "Most Vietnam Veterans went to Vietnam as young men. On self-reflection, these men see themselves as who they were as young men prior to Vietnam, and how they had become at the present time. Issues such as loss of youth, grief over lost self and lost opportunities contribute to self estrangement". This description was similar to the descriptions of estrangement from oneself in torture and trauma survivors.

Sexual assault clinicians commented that estrangement was a common feature in sexual assault survivors. For sexual assault survivors, the sense of alienation came from the feeling that "no one understands" their experience. The loss of connectedness to the self stemmed from changed self-perception dominated by a "sense of shame, guilt and self-blame"; a view of oneself as "not able to self protect, as not being able to recognise their emotions and express them due to not having been able to see oneself as separate with rights and needs". One client "does not feel she belongs at all to the world", "...does not feel like she belongs within herself".

Table 7 summarizes the characteristics of estrangement across three groups.

Table 7. Criterion B.5 Estrangement

	Torture & Trauma	Vietnam Veterans	Sexual Assault
Feeling of alienation from self and/or others	✓	✓	✓

Some clinicians suggested that estrangement is related to criterion B.2 - social withdrawal. Torture and trauma survivors lived with a sense of not having a place in a community. This stemmed from not knowing one's final destination, as in the case of refugees and asylum seekers, which may lead to a constricted and reduced interest in the wider world.

Some Vietnam Veterans' clinicians also posited a link not only between estrangement and social withdrawal but also with hopelessness B.3. One clinician expressed the link this way from her experience: *"I'm so different that I isolate myself and can't connect with society. I don't belong and there's no hope, there's no future. There's no way that I can see that I'm going to change. I'm different. I'm altered"*.

Some Vietnam Veterans identify only a few people who understand them, namely: doctor, therapist or fellow veterans.

For sexual assault survivors, clinicians suggested that estrangement arises out of shame, embarrassment and stigma that come with being different. For example, the thought of oneself as the one assaulted amongst a circle of friends can result in social withdrawal.

Clinicians offered some hypotheses about why estrangement developed in people who experienced catastrophic stress. One clinician suggested that

estrangement is associated with the experience of solitary confinement. Another clinician explained estrangement as being “due to disruption of identity and disruption of continuity of the history in the minds of the patients. Their personal history becomes fragmented in their minds and in their recollection, like a puzzle which they don't know how to put together”. Estrangement may also be due to the experience of flashbacks which brings confusion about the present. It is also linked with how other people around the survivor react/respond to the event. Estrangement was increased if the victim was stigmatised, rejected or branded.

It is evident from the above descriptions how estrangement can have an impact on the survivors and their relationships to the wider social environment (Criterion C). One clinician described how the sense of alienation that one of her clients experienced led to “ending intimate social relationships” and how this client was “unable to trust even the closest person”.

The difficulty of assessing estrangement was raised by two clinicians, who said that it was “...difficult to assess estrangement particularly if they are in a strange situation”. These clinicians were referring to the situations of refugees who had been dislocated and relocated several times in their search for refuge and/or asylum and were unfamiliar with their current environment.

4.2.6 Hypothesized Relationship between Symptom Criteria Based on Clinician Responses

Some clinicians described their observations and hypotheses about the relationship between the symptom criteria. One torture and trauma clinician suggested that it is likely that when patients are hostile and distrustful (criterion B.1), they will also feel estranged (B.5) *“It’s not just that they will have this part (a) [referring to B.1} they also have part (e) – this estrangement”* (criterion B.5). This same clinician elaborated on this and stated *“Yeah. It’s like (a) (referring to B.1) when you have (a) you also have this (d) (referring to B.4) and you may in fact have the (e) meaning, the estrangement”*. This clinician was suggesting the co-presence of criteria B.1, B.4, and B.5. Another torture and trauma clinician suggested a slightly different relationship. *“There seems to be issues that make a person hostile and aggressive [criterion B.1] that triggers the survival mode [criterion B.4]....gives one the feeling that something is wrong, something is not going well... makes one suspicious, vigilant and distrustful”* [criterion B.1]. This statement suggests the co-presence or the bi-directional relationship of these two criteria as discussed above.

One torture and trauma clinician recalled a patient possessing all criteria except criterion B.3 feelings of emptiness and hopelessness. *“The feeling of emptiness and hopelessness may not be there but their life situation is incredibly sterile and empty”*. Another clinician suggested that a combination of criteria B.1, B.3, and B.4 (hostile and distrustful attitude, emptiness or hopelessness, and feeling of

being on edge) may bring about criteria B.2 and B.5 (social withdrawal and estrangement).

A Vietnam Veteran clinician hypothesised a relationship between Criteria B.5 estrangement, B.2 social withdrawal and B.3 feeling of emptiness or hopelessness which suggests that a sense of estrangement can bring about social withdrawal which then leads to feelings of hopelessness or emptiness.

This relationship could be shown as:

B.5 → B.2 → B.3

One sexual assault clinician suggests that estrangement is related to social withdrawal as shown above.

4.2.7 Relationship between Symptom Criteria: Criteria B.1 to B.5

In the analysis of results under Criterion B in the previous section, I raised the possibility of influencing relationships between some criteria. Under criterion B.1 hostile or distrustful attitude, the possibility was raised that it may influence B.2 social withdrawal and B.4 feeling of being on edge. These relationships could be shown as:

B.1 → B.2 and B.1 → B.4.

Under Criterion B.2 social withdrawal, the influence of this criterion on B.1 hostile or distrustful attitude was also a possibility. It is possible that these two criteria are co-present or there may be a bi-directional relationship between these two as illustrated:

B.2 ↔ B.1 (see B.1 above in the preceding paragraph)

Hostile and distrustful attitude may bring about social withdrawal; social withdrawal reflects distrust and hostility.

Under Criterion B.3 emptiness or hopelessness, there is a potential relationship between this criterion and B.1 hostile and mistrustful attitude and B.2 social withdrawal as follows:

B. 3 \longrightarrow ? B.1 and B.3 \longrightarrow ? B.2

From the analysis under criterion B.4 feeling of being on edge, this criterion may be co-present with B.1 hostile and distrustful attitude and influence each other as illustrated.

B.4 \longleftrightarrow B.1 (see B.1 above in this section)

Hostile and distrustful attitude may bring about feeling of being on edge and feeling on edge may be fuelled by a hostile and distrustful attitude. As shown in the analysis of criterion B.1, fear is identified as a feature of distrust. As shown in the results under B.4 criterion, the feeling of being on edge is similar to a feeling of being threatened which may be associated with fear.

Under B.5 estrangement, this criterion may influence B.2 social withdrawal and B.3 feeling of emptiness or hopelessness as shown:

B.5 \longrightarrow B. 2 and B.5 \longrightarrow B.3

Estrangement may lead to social withdrawal and it may also fuel the feelings of emptiness and hopelessness.

4.2.8 Outstanding EPCACE Symptom Criterion

Of the fourteen torture and trauma clinicians, thirteen were able to identify at least one patient/client whose symptomatology resembled that of EPCACE. These thirteen clinicians were able to describe from one to four patients citing a total of twenty six cases. One clinician who did not identify an individual client described the changes in the client population (one ethnic group) as a whole. This clinician talked about a whole traumatized population that he was dealing with and was convinced that most of the members of this population exhibited most of the symptoms of EPCACE two decades post trauma. This is similar to the view of some Vietnam Veterans clinicians who commented that most clients who attended their services fit the criteria for EPCACE. In essence all symptoms of EPCACE are seen in their clients. "Vietnam Veterans live the EPCACE symptoms all the way". Only two out of the five Vietnam Veterans clinicians cited individual cases. All the sexual assault clinicians were able to cite individual cases.

I asked the clinicians to identify which two of the five symptom criteria of EPCACE were outstanding features in the cases that they discussed. Only fourteen of the twenty six cases cited by torture and trauma clinicians had outstanding features. The individual cases cited by Vietnam Veterans and sexual assault clinicians had outstanding features.

Table 8 indicates the number of clinicians interviewed, the number of clinicians who identified individual cases, the number of cases cited and the number of cases with one or two core features.

Table 8: Clinicians, Cases and EPCACE Core Features

Cases	N1	N2	N3	N4	B.1	B.2	B.3	B.4	B.5
Torture and trauma cases	14	13	26	14	11	6	4	6	1
Sexual assault cases	5	5	5	5	5	2	1	1	1
Vietnam Veteran cases	5	2	2	2	2	0	1	1	0
TOTAL	24	20	33	21	18	8	6	8	2

N1 = Total number of clinicians

N2 = Number of clinicians who identified individual cases

N3 = Total number of cases identified

N4 = Number of cases with core features

B.1 to B.5 = EPCACE symptom criteria

It appears from the total in Table 8, that Criterion B.1 hostile or distrustful attitude was identified as an outstanding feature in 18 cases, followed by B.2 social withdrawal and Criterion B.4 feeling on edge - 8 cases each, B. 3 emptiness or hopelessness (6 cases), and B.5 estrangement (2 cases).

As shown in Table 8, Criterion B.1 appears as a core feature in more than half of the torture and trauma cases. This is also true with sexual assault and

Vietnam Veteran cases. Some clinicians also observed that with one off sexual assault in adulthood, other symptoms get better but Criterion B.1 stays. One clinician suggested that for people such as this, their experience had a profound change in their worldviews - "that the world is not safe". However a torture and trauma clinician commented that "it is difficult to identify a single criterion...criteria come in combination". This is echoed by some Vietnam Veterans clinicians who observed that for most of their clients there are no core symptoms that stand out as this varies for each individual. Despite this observation, some clinicians commented that B.2, B.3, and B.4 are commonly observed features.

4.3 Criterion C. The change should cause significant interference with personal functioning in daily living, personal distress or adverse impact on the social environment

It is obvious from the results presented on the five symptoms within Criterion B that these symptoms pose significant consequences in the daily lives of survivors. Not only do these symptoms cause personal distress among survivors but also they impact on their social environment. As shown in Criterion B, hostility and distrust (B.1) impacts on survivors' relationships with family and the outside world including relationship within the context of therapy. Social withdrawal (B.2) has adverse consequences on the survivors' ability to communicate and in developing and maintaining intimate relationships, relationships within the family, friendship and community

contexts. Attempted suicide, self-mutilation and unproductive lifestyle were identified as behavioural consequences related to emptiness or hopelessness (B.3). Personal distress was associated with constant feelings of being on the edge (B.4) included crying, difficulty concentrating, sleep disturbances and tiredness. Similar to hostility and distrust (B.1) and social withdrawal (B.2), estrangement (B.5) also affected survivors' intimate relationships and their sense of belonging.

In addition to the above consequences associated with each of the B criteria, clinicians also described the effects of these symptoms on the occupational functioning of some of their clients, the effect on their social environment, particularly their relationships, and the negative and positive changes in their worldviews.

With torture and trauma survivors, eight out of the 26 cases cited by clinicians were able to sustain a job while others only worked occasionally and part-time. Two of the cases cited were on a job placement scheme. One was learning English; another was taking TAFE (Technical And Further Education) courses. One survivor who "spent a lot of time on work, lead a constrained, restricted lifestyle". For most of the cases, there was a "long undetermined period of unemployment".

Some Vietnam Veterans were able to hold down jobs with TPI (total permanent incapacity pension) and some “end up living on the edge”. A Vietnam Veteran clinician explained:

... there's also another characterological change I think. These guys end up living on the edge. And I think that if you, for a long of period of time, engage in behaviour that has your body pumping adrenalin out at very high levels, then you start to operate at that and (you've,) that's the level of arousal you need to be operating. And you see a lot of Vietnam Veterans that come back and they join State Emergency Services, they become Police Officers, they become Fire Fighters. All of that. That they take up jobs where again the level of arousal is higher than usual and I think that some of the behaviours that they engage in - the motor bike riders, the sky divers, the, that kind of stuff - it's getting the adrenalin hit and so I think that there are other elements like that that these guys are changed and maybe it is neuro- physiological or psycho-physiological and they need to maintain that level of arousal and that level of adrenalin rush to be able to, as their base line level.

Sexual assault clinicians indicated that some of their clients were “not able to work and on sickness benefits”, “able to function on a day to day routine but have difficulty holding down a job”. For those who were abused as children, some of them had lost the opportunity to go to school and therefore had literacy problems.

The effects of these symptoms on the survivors' social environment are centred on their interpersonal relationships. Torture and trauma clinicians talked about relationship problems that survivors experienced within the family context. These problems included difficult relationships with partners and parenting difficulties due to irritability towards children. One clinician hypothesised about the likely cause of family breakdowns post trauma as "everything that happens around their environment evokes memories of trauma" hence this intrudes into their ability to relate. Some survivors engaged in friendships but not on a deep level due to hostility and distrust (B.1) whilst others did not socialise at all. Impulse control problems that impact on social functioning of torture and trauma survivors included gambling and substance abuse which included alcohol, drugs, coffee and cigarette. One clinician described the gambling behaviour of one client as a "psychopathic tendency" that was mixed with no sense of trustworthiness.

Some Vietnam Veterans due to their experiences "develop a strong belief in their ability to handle pressure to the point where they can build an attitude of belittling others who can't handle it". Their experiences also become a focal point or cause of everything as expressed by one clinician as, "This is what happened to me. This is what I am".

Similar to torture and trauma survivors and Vietnam Veterans, sexual assault survivors' relationships with their partners were also affected due to the level of sexual dysfunction. Some were still living in a domestic violence situation.

Some sexual assault survivors developed a “heightened sense of responsibility towards younger siblings”. For those who were parents, similar to torture and trauma survivors and Vietnam Veterans, they experienced parenting difficulties, for example, in setting limits and providing physical and emotional care.

Clinicians also described the effects of personality change on the worldviews and existential concerns of survivors. This area had effects that were both positive and negative. For some torture and trauma survivors, clinicians described that it was in their worldviews that trauma seems to bring about a positive change – “a change for the better” as one clinician put it. One client was able to adopt a more open lifestyle, had become less worried about personal belongings and less concerned about material trappings. On the other hand, some survivors “forget their goals or lose them and hence see no future for them”. Trauma also “erodes people's sense of trust and naivety believing that the world is not a safe place”. A high level of pessimism existed in some clients, whilst in others the experience of trauma strengthened their commitment to social justice and hence they adopted a more compassionate view of the world. Others became more resourceful in their problem solving and emerged out of the trauma with stronger coping ability. In some cases, the will to live was even stronger due to family commitments, which were viewed as their link to life.

Such changes in worldviews also impacted on the emotional responses of survivors. One survivor had “become short tempered but also quickly realised his behaviour and its consequences and made amends”. One clinician observed that some survivors became less aggressive and less hostile towards people and became more tolerant. On the other hand, one clinician talked about a client's wife's observation of her husband who had become irritable and impatient, unable to maintain concentration, had lost the will to live and to fight, and experienced changes in self perception, for example, his perception of his sexual function.

One Vietnam Veteran clinician also noted “change in attitude towards work, life and society which is not necessarily negative” while sexual assault clinicians observed that survivors of sexual trauma underwent a radical change in perspective. The experience challenged some of peoples' assumptions such as: i) “safety in the world - that the world is not a safe place which leads to overprotection of the self and others who are close to them, their siblings, children” ii) belief in God and subsequent questioning and loss of religious convictions as one clinician expressed "why didn't God look after me?" iii) sense of justice – as in "the world is not a just place". Some sexual assault survivors also developed a deterministic, fatalistic attitude expressed as "This has happened to my mother and it happened to me and it's going to happen to my children. There's nothing I can do to stop it".

Clinicians also described how survivors seemed to “adapt” to the changes in themselves. One clinician described the post trauma adaptation of torture and trauma survivors as a phenomenon that can be viewed on two planes.

Externally, a survivor can present as a functional individual, productive and seem to have adapted. Internally, there is a sense of sadness and hollowness with a conviction that things could have been different. This arises from the fact that they've arrived at this state of being not by choice. There was a sense of powerlessness that leads them to this current state of life”.

Another clinician summed up by stating that for some survivors, the “initial rehabilitation was OK” and “they managed to get some semblance of life. Those who are not ostracised, alienated or are dealing with other problems like jobs, etc. do find a modicum of adaptation”, that is, “they get by” but this adaptation “is shaky and eventually breaks down” given other life stresses. This is also true for those who had experienced childhood trauma where in the course of their development they reached a certain level of adaptation. The torture experience in adulthood eroded this level and evoked early traumatic experiences that contributed to psychopathology in adulthood.

For Vietnam Veterans, as a post trauma outcome, other personality problems may develop, for example, paranoid personality, obsessive-compulsive disorder, borderline personality disorder, passive-aggressive personality. One clinician stated, "My feeling is they were not like that before they went to Vietnam". One Vietnam Veteran clinician who also worked with sexual

assault survivors also noted similar personality problems with sexual assault clients.

4.4 Criterion D. The personality change should have developed after the catastrophic experience, and there should be no history of a pre-existing adult personality disorder or trait accentuation or of personality or developmental disorders during childhood or adolescence that could explain the current personality traits.

Clinicians raised some difficulties and issues in ascertaining whether the changes were really caused by catastrophic experience and not by pre-existing conditions or childhood disorders. Clinicians across the three groups found it difficult to ascertain whether an individual's personality had changed because they did not know what the person was like prior to the torture experience, for example before Vietnam. One clinician noted, "The issue of measuring personality changes post trauma is problematic without considering the history of the person". To this end, clinicians were of the strong view that to ascertain personality change there was a need to involve partners, parents and relatives in the diagnostic process. This view supports Criterion A.

The importance of a family member who can corroborate a survivor's history was underscored in cases where there might be history of pre-existing disorders or early abuse as in the case of some sexual survivors. A sexual assault clinician expressed, "Personality change is very hard to establish because it's from the time these people have been preverbal, quite often

they've been abused.....Overtime these people are actually trained to be the way they are". Another sexual assault clinician posed the question, "Is it personality formation or personality change?"

One criticism levelled by some clinicians at this point was that granted the personality changes developed due to catastrophic experience and not due to other conditions, this diagnostic category did not take into account confounding variables that influence symptom expression. Examples of these variables include migration/resettlement experiences. Some clinicians pointed out that "the asylum seeking process confounds criterion B.3 - feelings of hopelessness or emptiness. The person feels pessimistic about the future". Clinicians also expressed that childhood trauma and other psychiatric illness, that for some reason or another may not be known, can be exacerbated by trauma in adulthood. Symptoms can be confounded by cultural traditions and religious beliefs.

4.5 Criterion E. The personality change must have been present for at least 2 years. It is not related to episodes of any other mental disorder (except Post-traumatic Stress Disorder) and cannot be explained by brain damage or disease.

Clinicians were asked whether personality changes specified by EPCACE criteria may be attributable to other disorders aside from post-traumatic stress disorder. The answer to this was "yes". One of the issues raised was that

symptoms specified in Criterion B are not exclusive to EPCACE. Clinicians identified some criteria that were present in people who had not experienced trauma or may have had childhood trauma experience which are difficult to ascertain. Criterion B.1 hostility and distrust and B.4 feeling of being on edge, for example, are present in people with paranoid schizophrenia. Chronic schizophrenia and organic causes such as brain injury can bring about personality changes. One torture and trauma clinician cited an example of a wife of a torture survivor. She was not directly traumatised but “she lived the traumatic experiences of her husband and exhibited symptoms like mistrust towards the world, emptiness and hopelessness”. This raises the possibility of a secondary trauma or vicarious traumatisation causing personality changes. On the other hand one Vietnam Veteran clinician thought that “EPCACE symptoms are not seen in non-trauma patients”.

Similar to the above concern, clinicians identified some diagnostic categories, the symptomatology of which would be similar to EPCACE. These are anxiety disorders, manic-depression, psychotic paranoia, borderline personality disorder, dissociative disorder, multiple personality disorder, psychosis, endogenous depression and central nervous system neurological impairments.

4.6 Criterion F. The personality change meeting the above criteria is often preceded by a post-traumatic stress disorder (F43.1). The symptoms of the two conditions can overlap and the personality change may be a chronic outcome of a post-traumatic stress disorder.

However, an enduring personality change should not be assumed in such cases unless, in addition to at least 2 years of post-traumatic stress disorder, there has been a further period of no less than 2 years during which the above criteria have been met.

Clinicians recognized the overlap and similarity of the symptoms of personality change with that of PTSD and also recognized that “EPCACE may be a form of chronic PTSD”. This recognition is consistent with that of the participants in the first study by Beltran and Silove (1999) discussed earlier. Recall that intrusion symptoms such as nightmares, flashbacks, and intrusive thoughts, which are symptoms of PTSD, were associated by clinicians with feeling of being on edge and that chronic PTSD had been associated with social withdrawal. However, clinicians questioned the utility of labelling the chronicity of “this disorder” or that of PTSD as a personality change. The example of people with schizophrenia usually having quite a dramatic change in personality but not usually labelled as personality change was cited by clinicians in this current study. (Note that ICD-10 includes a category called F62.1 Enduring personality change after psychiatric illness. Clinicians who made similar comments were probably not aware of the existence of this category). Clinicians suggested that “perhaps the approach is

not to view it as a psychopathology but trauma symptoms and syndromes”. This suggestion implies the “medicalization and pathologizing of a social-relational phenomenon”. Clinicians also expressed that “differentiation between chronic PTSD and chronic personality change is difficult to specify”. One of the reasons cited was the non- exclusivity of symptoms to EPCACE.

4.7 Other Issues Raised by Clinicians

In addition to issues already discussed under each criteria of EPCACE (A, B, C, D, E, F) clinicians held other concerns related to the use of this diagnostic category. These concerns have an impact on therapy and their confidence in using the diagnosis. EPCACE implies that personality changes are permanent and fixed, therefore not amenable to therapy and change. Some clinicians were of the view that “personality changes are not fixed”. The questions: What features are amenable to treatment and how amenable? need to be asked. One Vietnam Veteran clinician raised the concern that the symptoms of EPCACE are difficult to change in therapy. This is complicated by the difficulty of establishing trust with Vietnam Veterans. Some clinicians also felt that the symptom criteria are too general and “do not capture the depths of people’s experiences” and suggest that there are other symptoms that need to be included.

4.8 Suggested Additional Criteria for EPCACE

Clinicians suggested additional criteria that their clients with EPCACE manifest that are not captured by the current EPCACE criteria. There are three symptoms or dysfunctions that are common across the three groups of clinicians. These are: i.) Somatization ii.) Self injurious/self damaging behaviours, and iii.) Sexual dysfunction. One symptom suggested only by torture and trauma, and sexual assault clinicians is enduring guilt.

Somatization is a common observation noted by most clinicians and exemplified by this suggestion, “I’ll also add into that kind of diagnostic framework chronic somatization”. One clinician commented about these symptoms as “symbolic representation of pain”. Another clinician exemplified this by saying, *“The kind of physical, I think perhaps what happens is that the physical reminisce kind of...take on a kind of meaning, the physical pain, takes on a kind of a meaning which gets reenacted through feeling the pain again on different parts of the body”*. Another clinician thought that somatic symptoms may be related with the trauma of having family members slaughtered by friends [in Bosnia] saying, “They also present with somatizations especially when they have...uhm...slaughtering in their family members by former friends”.

Among the somatic symptoms, skin problems were noted across the three groups. These problems include eczema, boils, lumps, tinea and rashes. One clinician attributed this to torture using chemicals. Another clinician noted the

flare-ups of eczema in times of stress and explained eczema and rashes as “level of rage/outrage that is projected”. Another clinician likened the skin problems “as a defence against the world”. Other commonly observed somatic symptoms include body tension, aches and pains, palpitations, chest pains, blood pressure problems, overweight, irritable bowel, decreased sensitivity of olfactory and gustatory senses, headaches, migraine, nausea and menstrual problems.

Self injurious or self damaging behaviours included abuse of drug and alcohol and self mutilation. Thinking about what is missing in the EPCACE criteria, one clinician suggested, *“When looking at this, that....what my thoughts about this diagnosis.. I would think that drug and alcohol problems could be given a high profile ... in that particular group”*. Substance abuse was described by one torture and trauma clinician as follows, *“Oh, I think it would have to be in an addictive way, numbing. You know, often because they can't sleep, there's this sort of incredible cycle of smoking and drinking and then in the morning they feel so terrible that they drink coffee throughout the whole day and then it just sort of all fits into each other. But I think that within, you know, it's definitely a substance abuse”*.

The self injurious characteristic of substance abuse was described by one clinician,

Yes..I think there will be some kind of self.. abh.. destructive..that's my interpretation. I don't know how you can put it into a category ...that its really that living on edge that has something to do with defiance and fear..that takes

people into drinking beyond what they can drink and using drugs beyond what they can use and getting into situation where ..umm.

The dialogue below indicates the suggestion of self injurious behaviour as an added criterion of EPCACE. This clinician also thought that estrangement was a core symptom of EPCACE.

R:(respondent) *Sure. I would think that the sense of estrangement, the fact that I am different, is very significant. I think that it's interesting that there's not a symptom in there about self injury.*

I(interviewer) *Yes, yes.*

R: *And I think that there should be, because of lots of people that have been through this kind of experience self injure in a variety of ways.*

I: *Yes. What sort of ways do they do that?*

R: *I think that part of their drug and alcohol use is self injury. They also self injure in that they get into fights. They're often highly sexualised and they don't have safe sex. They also injure themselves by self mutilation - burning themselves, cutting themselves, stabbing themselves and so forth - and like the borderline disorder like the self injurious of people that have had, you know, chronic sexual abuse and so forth. And I think that is a very significant endure....*

Another clinician noted a different kind of addiction,

but I've seen a couple of people who have been through traumatic experiences who sort of become addicted to violent...violent movies, and things like that.

The absence of a criterion related to **problems in sexual functioning** and issues related to sexuality in the current EPCACE criteria was exemplified by this comment, “One of the other things, I just sort of jot down some things. I think issues around people’s body image or sexuality isn't, you know, that isn't sort of down there at all”. Sexual dysfunction described by clinicians included “loss of sexual capacity or interest’ which is related to “decreased capacity for intimacy” and alteration of perception about sexuality. One torture and trauma clinician explained sexual problems as,

Yeah. That seems to sort of fall into different sorts of groups. There seems to be like for example, men who've had experienced torture where there's actually been some physical damage and then there's the (unclear). There's also I think more men who have been physically injured by the rape, the violations that have gone on and then there's the, I think, the sort of suppression or depression of interest in interacting sexually that happens which I think is very common. The low energy, the feelings of mistrust, all that kind of thing. It's actually quite hard to move into relaxing sort of sexually. And then I think there has been other cases where men have been - I've had a couple of guys who are South American chaps who have been raped while in prison and there's a whole cultural thing about that if you have actually penetrated them that means you

are going to become sexual and then there's this whole kind of confusion, sort of struggle around their sexuality.

One clinician who worked with Vietnam Veterans and sexual assault clients described the pervasive lack of libido,

Yes, all the time. There's no sense of joy. Enjoyment is gone. So, libido's gone out so they don't get any pleasure that way,

Note that in an earlier section in this chapter, apathy in social withdrawal (criterion B.2) was related to the lack of libido and estrangement (B.5) was related to decreased intimacy.

One sexual assault clinician described how her client's relationship was affected,

The most remarkable, resilient young woman I've ever met however I would say her relationships, her relationship with partners was very much affected. In fact her choice of partner has probably been affected by her experience. There are particular things that she can't do sexually because that triggers flashbacks.

Enduring guilt was one symptom suggested by torture and trauma and sexual assault clinicians. This particular symptom was not suggested by Vietnam Veteran clinicians. Enduring guilt was described as “feeling bad about oneself and feeling responsible for what happened”, “feeling that you are such a bad person to deserve it” as explained by one clinician,

Well, you sort of feel very bad about yourself, like you sort of responsible somehow for what happened to you, that somehow you deserved it or that you are such a bad person to deserve it ... I'm sure this is what you get told during and ... you sort of feel ... I understand it a way of taking control, feeling like that somehow if it was your fault then you have got some way of preventing it in the future, that's why in one way, people make themselves feel guilty perhaps....But I think too that maybe you feel that you have compromised yourself and that makes you feel guilty and bad or something.

For some refugee survivors of torture, the enduring guilt stemmed from the view “that they should be out there fighting [in Bosnia] and should not have gone to Australia”. Survival guilt was described by one clinician as related to anger,

I think in one sense I can say that because I work with him in the field, guilt to survive, because he witnessed the whole thing and he still survived, that's.. the feeling of surviving from guilt, it's sort of like deep down and for me, it's attached to the anger that he see that he lost, he feels guilty and the anger is part of, the big part of that one.

4.9 Summary

In this chapter, I presented a composite picture of the characteristics and features of EPCACE based on the understanding of clinicians of the criteria of EPCACE as specified in the ICD-10 and how they observe and

understand these features in their patients. Clinicians used the description of ICD-10 criteria of EPCACE as specified in the CDDG when describing observed symptoms. I used the structure of the criteria as described in the DCR to present my findings, as these are clearly defined and specified in more detail than the narrative statements in CDDG. Clinicians described and raised issues in relation to the stressor criterion, the symptom criteria which is the main focus of this study and in relation to the impact of enduring personality changes on daily living. In their discussion of the symptom criteria, clinicians identified core features of EPCACE and also suggested additional symptom criteria and offered hypotheses on the relationships of various symptoms. Clinicians expressed the difficulty of ascertaining whether a trauma survivor's personality has changed without knowing what the person was like prior to trauma. Although I did not specifically seek comments about the duration criterion and the precedence of PTSD, clinicians raised some issues and spontaneous comments about these aspects of EPCACE criteria. In the following chapter, I discuss the results in the context of current understanding of EPCACE.

CHAPTER 5

DISCUSSION

In this chapter, I discuss the findings of the study in the context of the ICD-10 DCR criteria for EPCACE juxtaposed with CDDG. As discussed in the Literature Review chapter, the use of DCR (Diagnostic Criteria for Research) and CDDG (Clinical Descriptions and Diagnostic Guidelines) for some disorders has posed some issues related to lack of compatibility and agreement between these two versions (Andrews, 1999; Bertelsen, 1999; Peters, et al., 1999; Rosenman, 2002). It is useful therefore to examine these issues further by using the DCR as a comparative framework to discuss the findings in relation to the use of the CDDG criteria.

5.1. Criterion A - Stressor Criterion in DCR and CDDG

Table 9. Comparison of EPCACE Criterion A in DCR and CDDG

DCR	CDDG
<p>CRITERION A There must be evidence (from the personal history or from key informants) of a definite and persistent change in the individual's pattern of perceiving, relating to and thinking about the environment and the self, following exposure to catastrophic stress (e.g. concentration camp experience; torture; disaster; prolonged exposure to life-threatening situations).</p>	<p>Enduring personality change may follow the experience of catastrophic stress..... Examples include concentration camp experiences, torture, disasters, prolonged exposure to life-threatening circumstances (e.g. hostage situations-prolonged captivity with an imminent possibility of being killed)..... Excludes short term exposure to life threatening experience – e.g. car accident</p>

The characteristics of EPCACE criteria described by clinicians as presented in the Results chapter indicate that clinicians recognize the phenomenon of EPCACE in their clients. The evidence for this phenomenon was embedded in their descriptions of the symptoms that they observed and the effects of these symptoms on the functioning of their clients.

The first issue raised by clinicians in this study, was the nature and definition of catastrophic stress likely to lead to enduring personality change. What kind of stress is catastrophic? As can be seen from the comparison table above, both the CDDG and DCR versions of the EPCACE criteria provide examples of catastrophic experience that may lead to personality change.

However, CDDG excludes short term exposures to life threatening experience such as car accidents as a factor, whereas DCR criteria do not explicitly state such exclusion. The reason stated in the CDDG for this exclusion is that “recent research indicates that such a development depends on a pre-existing psychological vulnerability” (WHO, 1992a, p.209). Clinicians in this study using the CDDG, did not question the exclusion of short term exposures, nor specifically supported the view that short term exposures to life threatening experience may lead to personality change.

In Beltran and Silove’s 1999 international survey, it was found that just on a quarter of the respondents agreed that natural disasters or short term exposures such as motor vehicle accidents could lead to personality change. Although the percentage is small, absolute exclusion of other traumatic events such as motor vehicle accidents as a factor may be excessively rigid. At that time my colleague and I (Beltran & Silove, 1999) suggested that it may be more appropriate to propose a probabilistic model in regard to different categories of trauma, that is, certain types of trauma (e.g. torture) are more likely to lead to personality change than others (e.g. natural disasters).

The second concern was the non-inclusion of domestic violence and sexual assault such as rape as examples of catastrophic stress in both the CDDG and DCR. This is surprising given that the initial formulation of complex PTSD was based on studies on the experiences of survivors of trauma of domestic and sexual abuse (Herman, 1992a, 1992b, 1993) and the recognizable

similarity between complex PTSD and EPCACE (Roth et al, 1997). Is the exclusion of domestic violence and rape from EPCACE an oversight or should their inclusion be obvious? The differentiation of complex PTSD and EPCACE is at issue here. Are these two syndromes mutually exclusive, overlapping or are they one and the same? Several researchers (Weine et al,1995; Roth et al, 1997) have raised the possibility that complex PTSD may be more applicable to survivors of early life prolonged trauma such as child rape and sexual abuse as originally formulated by Herman (1992a, 1992b, 1993). It could be that sexual abuse in adulthood, despite severity and duration, may not be sufficient to be considered as an extreme stressor in EPCACE.

Despite these omissions, clinicians in this study concurred with the ICD-10 criteria that the major focus was on the prolonged, repeated trauma of whatever origin as a factor in personality change. They held no reservations about the role of trauma in bringing about maladaptive personality change. Their view is consistent with the earlier assertions of Eitinger (1964), Chodoff (1966), Krystal and Niederland (1968) and the later findings of Bower (1994) and Shea (1996) that profound changes in personality can be explained as an outcome of extreme trauma, independent of factors such as premorbid personality or pre-existing vulnerability.

Clinicians recognized the importance of information gained from key informants corroborating the evidence of personality change. In addition,

they highlighted the role of clients in articulating changes through their ability to narrate their own personal history. As Westen (1997) found, when assessing and diagnosing personality disorders, clinicians primarily relied on listening to and observing clients' behaviours and their descriptions of their interactions rather than direct questioning using instruments developed from DSM-IV criteria. [Examples of these direct questions are: "Do you think that it's not necessary to follow certain rules or conventions when they get in your way?" Or "Do you feel that your situation is so special that you require preferential treatment?" (Westen, 1997, p. 898).] Gabbard (1997) commented that at the core of these questions is the question "What kind of a person are you?". Such inquiries heighten defensiveness in individuals (Gabbard, 1997). Similarly in this study, clinicians avoided direct questioning; rather they relied on their observations and clients' descriptions.

5.2 Criterion B - Symptoms Criteria

Table 10. Comparison of EPCACE Criterion B in DCR and CDDG

DCR	CDDG
B. The personality change should be significant and represent inflexible and maladaptive features, as indicated by the presence of at least two of the following:	The personality change should be enduring and manifest as inflexible and maladaptive features.... In order to make the diagnosis, it is essential establish the presence of features not previously seen, such as:
(1) a permanent hostile or distrustful attitude towards the world in a person who previously showed no such traits;	(a) a hostile or mistrustful attitude towards the world;
(2) social withdrawal (avoidance of contacts with people other than a few close relatives with whom the individual lives) which is not due to another current mental disorder (such as a mood disorder);	(b) social withdrawal;
(3) a constant feeling of emptiness or hopelessness, not limited to a discrete episode of mood disorder, which was not present before the catastrophic experience; this may be associated with increased dependency on others, inability to express negative or aggressive feelings, and prolonged depressive mood without any evidence of depressive disorder before exposure to the catastrophic stress;	(c) feelings of emptiness or hopelessness
(4) an enduring feeling of being “on edge” or being threatened without any external cause, as evidenced by an increased vigilance and irritability in a person who previously showed no such traits or hyper-alertness; this chronic state of inner tension and feeling threatened may be associated with a tendency to excessive drinking or use of drugs;	(d) a chronic feeling of being “on edge”, as if constantly threatened;
(5) a permanent feeling of being changed or of being different from others (estrangement); this feeling may be associated with an experience of emotional numbness.	(e) estrangement

Clinicians in this study described behaviours, feelings and thoughts by which symptoms of EPCACE are expressed and manifested. Following Schutz's (1973, p.7) assertion, clinicians through their professional training and experience, possess common sense knowledge or "stock of knowledge at hand" to make sense of EPCACE criteria, a typification which exists in their clinical world. Their prior ability to typify enabled them to "render explicit what one already knows through typifications (Schwartz & Wiggins, 1987, p.76).

As mentioned in the literature review and as seen from the comparison in Table 10 above, DCR has a more elaborate description of the symptom criteria than the one line listing in CDDG. Clinicians in this study were given a copy of the CDDG to refer to during the interview. Despite the lack of further explanation in CDDG, clinicians elaborated on these criteria through rich descriptions of how these symptoms manifest in their clients. In essence, the findings of this study demonstrate that the symptoms as phenomena are not as simple and straightforward as listed in the CDDG. A symptom can be manifested in many ways and may be characterized by many other symptoms. For example, from this study, a hostile attitude may include features such as aggression, rage, anger, and hatred.

That clinicians describe personality changes by citing multiple heterogeneous symptoms is not that surprising. As discussed in Chapter 2 - Literature Review, earlier studies of concentration camp survivors (Bower, 1994;

Bychowski, 1968; Chodoff 1966; Eitinger, 1969; Krystal, 1968; Krystal & Niderland, 1968; Niderland, 1968a;), survivors of combat (Horowitz et al., 1987; Kardiner, 1959; Marmar, 1991; Parson, 1988), and refugee survivors of torture and trauma (Doerr-Zegers et al., 1992; Eitinger, 1959; Turner & Gorst-Unsworth, 1990) and the findings of Herman (1992a, 1992b, 1993) and other studies on complex PTSD (Adshead, 1994; Allen, Coyne & Huntoon, 1998; Allen & Huntoon, 1999; Dickinson et al., 1998; Ford & Kidd, 1998; Jongedijk et al., 1996; Josephs, 1996; Newman et al., 1995; Newman, et al., 1997; Roth et al., 1997; Rorty & Yager, 1996; Zlotnick et al., 1996; van der Kolk, 1996; Weine et al., 1995; Weine et al., 1998;) consistently describe a multiplicity of symptoms as features. Herman's (1992a, 1992b, 1993), and van der Kolk's (1996) reviews on complex PTSD and Shea's (1996) review on EPCACE also discussed how symptoms occur not alone but in the context of other symptoms.

Despite concerns about symptom complexity and multiplicity, poorly substantiated connections between symptoms, and lack of core symptoms identified, particularly in previous studies on DESNOS (Jongedijk et al., 1996; Newman et al., 1995; van der Kolk, 1996), the current study presents contrasting findings. Clinicians were able to articulate specific characteristics for each symptom criterion, to identify core symptoms, to hypothesize relationships between criteria, to identify other symptoms indicative of personality change and to comment on the clinical utility of the diagnostic criteria.

When examining individual symptoms within the symptom criteria of EPCACE, clinicians clearly differentiated between hostile or distrustful attitude (B.1) and between emptiness or hopelessness (B.3) by describing each differently. Note the use of the word “OR” in the criteria. The way these criteria are stated in both DCR and CDDG suggests that either one of the pair is sufficient for a diagnosis to be made. The difficulty for clinicians was the linking of these symptoms as pairs, given for example that they noted hostile attitude could exist without distrust and emptiness without hopelessness.

In the DCR criteria, depressive mood is associated with Criterion B.3 - feeling of emptiness or hopelessness. Although not stated in CDDG, clinicians recognized that depression is linked with feeling of emptiness or hopelessness. Critically, clinicians identified a relationship not mentioned in either DCR or CDDG, that anxious mood is associated with criterion B.4 - enduring feeling of being “on edge”. In DCR, B.4- enduring feeling of being “on edge” is explicitly stated as “may be associated with a tendency to excessive drinking or use of drugs” (WHO, 1993, p.130). This was not recognized by clinicians. Rather, tendency to excessive drinking or use of drugs was put forward as one of the additional criteria for EPCACE.

In DCR, B.5 estrangement is stated as associated with emotional numbness. In this study, clinicians did not associate emotional numbing with estrangement, possibly because this part of the criteria is not stated in CDDG.

However, this explanation is doubtful given that in other instances when some parts of the criteria were not stated in the CDDG, clinicians identified other concerns. For example, clinicians associated estrangement with B.2 social withdrawal which is not recognized in either DCR or CDDG. Another possible explanation is an acknowledged difficulty in describing and understanding the phenomenon of estrangement (Beltran & Silove, 1999). This could also explain the sparse characterization of this criterion as shown in Table 7. Either the clinicians had difficulty describing this phenomenon and thus it was not reflected in the data and/or with a potentially limited understanding of this phenomenon, the researcher may have missed this in the data.

In discussing symptom criteria, clinicians did not draw particular attention to the effects of culture and ethnicity on symptoms although some of their clients came from culturally and linguistically diverse backgrounds. There are several possible reasons for this. The first is the method used in this study. The focus of the interview was on symptom manifestation. Clinicians were not specifically asked to explain the effects of culture and ethnicity on symptom expression. The second could be because, as Schutz (1973) argued, clinicians are influenced by their own personal biographies and their own beliefs and theoretical perspectives which may override their concern about the influence of culture and ethnicity on symptom expression. The third possible reason is the nature of common-sense knowledge or typifications. According to Schutz (1973) human beings use typifications purposively. For

example, when we enter a house, we typify a room as a living room, bedroom, kitchen, etc. in order to orient ourselves to the space we are in. Schwartz and Wiggins (1987) extended this notion by asserting that typifications are tied to situations and are one-sided. One set of typifications gives access only to certain characteristics of things, events or people. In the case of EPCACE criteria, clinicians were focused on describing how these symptoms were manifested by their clients and not how culture and ethnicity affect symptom expression. It is possible that clinicians had in mind the impact of these factors on the symptoms they were describing. However, these were not articulated by clinicians nor were these probed by me.

It is significant to note that over and above clinicians' possible variability, DCR clearly states the requirement of presence of at least two of the symptom criteria for a diagnosis of EPCACE while the CDDG does not specify a number of criteria to be present for a diagnosis. Such lack of clarity in definition and lack of consistency in the criteria between the two systems can impact on the reliability in the use of the criteria and in the future development and use of standardized instruments that can guide research and epidemiological studies on EPCACE.

5.2.1 Hypothesized Relationship between Symptoms Criteria

Clinicians suggested possible relationships between criteria, and based on analysis of results of this study, other relationships emerged between symptom criteria. As previously discussed, despite the already recognized

complexity and multiplicity of somatic, cognitive, affective and behavioural effects of psychological trauma, this study illustrates that symptom criteria can be understood by specifying characteristics and relationships with other symptoms. The clinicians' view that some symptoms do not appear in isolation and that certain symptoms co-occur fits with previous findings in relation to complex PTSD (Herman, 1992a, 1992b, 1993; van der Kolk, 1996; van der Kolk et al., 1996), and Shea's findings (1996) on EPCACE.

5.2.2 Core Criterion

The finding that Criterion B.1 is a possible core feature of EPCACE is consistent with the views of trauma experts surveyed earlier by Beltran and Silove (1999). The listing below compares the ranking of the criteria from the 1999 survey study with this study.

Survey Study (Beltran & Silove, 1999)		This Study
1 st	B.1	B.1
2 nd	B.3	B.2 and B.4
3 rd	B.4	B.3
4 th	B.5	B.5
5 th	B.2	

The findings of both studies with B.1 as the core criterion are in contrast to the core symptoms of anxiety, depression and survival guilt identified by Chodoff (1966). The findings from this study and the earlier study also contrast with the suggestion that dissociation, revictimization and somatization may form the core symptoms of DESNOS (or complex PTSD)

for survivors of sexual abuse (Zlotnick et al., 1996). This again raises the issue of the need for differentiation between EPCACE and DESNOS.

B.1, a permanent hostile or distrustful attitude toward the world, is not currently identified in the literature as a core feature of enduring personality change, yet it remains a consistent feature of the syndromes identified in the literature. As noted in the literature review, this symptom was identified in concentration camp survivors (Bower, 1994; Bychowski, 1968; de Wind, 1972; Krystal, 1968); refugees subjected to prolonged and repeated trauma (Doerr-Zegers et al., 1992; Eitinger, 1959; Silove, 1999); and war veterans (Horowitz et al., 1987; Jongedijk et al., 1996; Kardiner, 1958; Marmar, 1991; Newman et al., 1995). It was also observed in “victim” families (Danieli, 1985) and victims of violent crime and abuse (Ochberg, 1993; van der Kolk, 1996). The issue of trust is at the core of the treatment model developed by Shay & Munroe (1996) for Vietnam Veterans to address complex PTSD. Although not identified as a core feature, hostility and distrust are common features of EPCACE identified in Shea’s review (1996).

As mentioned previously, one of the issues raised about the validity of DESNOS is the lack of an identifiable core symptom (Jongedijk et al., 1996). The results of this study raise the possibility of an identifiable core criterion that may have the potential to differentiate EPCACE from other disorders.

5.3 Criterion C – Interference with Personal Functioning

Table 11. Comparison of EPCACE Criterion C in DCR and CDDG

DCR	CDDG
The change should cause significant interference with personal functioning in daily living, personal distress, or adverse impact on the social environment	The personality change should be enduring and manifest as inflexible and maladaptive features leading to an impairment in interpersonal, social, and occupational functioning.

Although DCR and CDDG separate symptom features (B Criterion) from effects on everyday life (C criterion) clinicians correlate the two when describing their clients. That is, in describing the manifestations of the symptoms in criterion B, clinicians also described consequences of these symptoms in daily living and the positive or negative impact of these on their social milieu. The CDDG description focuses more directly on adverse impact of this disorder. This reflects Williams’ findings (1999) that much of the research literature examining the influence of PTSD on personality focuses on negative changes. Despite this, Williams (1999) has highlighted empirical evidence of positive changes related to coping and resilience, echoing the earlier findings of Kahana et al. (1988). For some concentration camp survivors for example, their trauma experience produced positive growth as a delayed post trauma effect (Chodoff, 1966; Niederland, 1968b). In discussing the functional consequences of EPCACE, clinicians presented a balanced view between positive and negative impacts, despite the skewness of the criteria towards negative changes.

In considering the utility of the C impairment criterion, it is useful to remember the criticism of Wakefield (1997). That is, that an impairment criterion in DSM diagnoses, does not offer guidance in deciding whether the level of impairment or dysfunction is sufficient to make a diagnosis. In other words, he is of the view that impairment criteria are redundant when symptom criteria exist. In contrast to Wakefield’s view, Pfohl (1996) promotes the utility of an impairment criterion in understanding cultural variation and in determining when clinical intervention is indicated. My view based on the findings of this study, is that impairment criterion forces clinicians to consider how symptoms impact on daily functioning which is the context where symptoms are manifested and experienced.

5.4 Criterion D

Table 12. Comparison of EPCACE Criterion D in DCR and CDDG

DCR	CDDG
The personality change should have developed after the catastrophic experience, and there should be no history of a pre-existing adult personality disorder or trait accentuation, or of personality or developmental disorders during childhood or adolescence, that could explain the current personality traits	Enduring personality change may follow the experience of catastrophic stress. The stress must be so extreme that it is unnecessary to consider personal vulnerability in order to explain its profound effect on the personality. and should not be attributable to a pre-existing personality disorder.....

Both DCR and CDDG explicitly state that the enduring personality changes are independent of personal vulnerability. The difficulty for clinicians however is determining and quantifying personality changes when there is no knowledge of a survivor's pre-morbid personality. This difficulty poses a serious threat to the utility of this criterion because of the near impossibility of assessing pre-morbid personality and pre-existing vulnerabilities with a considerable degree of reliability. This was previously highlighted in Beltran and Silove's (1999) survey. Similarly, retrospective assessment of pre-trauma personality was identified as a major methodological limitation in the studies reviewed by Shea (1996) on EPCACE. This is a critical and fundamental limitation of EPCACE.

One way to try to overcome this limitation is for clinicians to involve partners, parents, family members and people close to the client who can provide information about the personality of the client prior to trauma. In spite of this, the concern about reliability of retrospective assessment of personality is long standing. There is an additional concern related to using information from two sources - client and relatives - particularly if these are discrepant (Bertelsen, 1999; Dahl & Andreoli, 1997).

A possible helpful development is the availability of instruments for the assessment of personality disorders such as the SWAP-200 (Westen & Shedler, 1999a). Outcomes of instruments such as the SWAP-200 depend on clinician's judgements and may be criticized as subjective. However, these

judgements depend on careful observation and interaction with clients which involve talking with and listening to clients, methods that have been shown as preferred and relied on by clinicians (Westen, 1997). The utility of assessment instruments such as the SWAP-200, suggest there is the possibility for a similar development in instruments suited to the assessment of EPCACE in ICD-10.

The DCR D criterion further states that there should not be a history of personality or developmental disorders during childhood or adolescence which could explain current personality change after catastrophic experience. This idea is not clear in CDDG. Clinicians in this study raised the possibility that childhood trauma and psychiatric illness can be exacerbated by trauma in adulthood. They also discussed how some confounding issues such as stresses related to adaptation to a strange environment, can influence symptom expression. Despite the lack of a clear statement in CDDG raising the awareness of clinicians that there should not be a childhood history of personality disorder or developmental disorders which could explain current EPCACE, clinicians know that such disorders can influence the development of later disorders. This indicates that these experienced clinicians are particularly knowledgeable about the phenomenon with which they are dealing with, even if, as yet, it is not adequately described or operationalized in CDDG.

5.5 Criterion E

Table 13. Comparison of EPCACE Criterion E in the DCR and CDDG

DCR	CDDG
The personality change must be present for at least two years. It is not related to episodes of any other mental disorder (except post-traumatic stress disorder) and cannot be explained by brain damage or disease.	The personality change must have been present for at least two years, and should not be attributable to a pre-existing personality disorder or to a mental disorder other than post-traumatic stress disorder (F43.1). The presence of brain damage or disease which may cause similar clinical features should be ruled out.

This DCR criterion, that the personality change must have been present for at least two years and not related to any mental disorder (except PTSD) or not explainable by brain damage or disease, is explicitly stated in CDDG.

Clinicians cited examples of how some of the EPCACE symptoms can be manifested by people who have not experienced trauma yet, have other mental disorders such as paranoid schizophrenia or disease or injury in the brain. This indicates that clinicians are aware that EPCACE, in this instance, is no different from other mental disorders, in that some symptoms are not exclusive to each disorder. For example, as previously mentioned, hostility and distrust and feeling of being on edge may be present in people with paranoid schizophrenia. Beltran and Silove (1999) cited the work of Gabbard (1997) and Westen (1997) who noted that blurring of boundaries between categories are no different from the difficulties faced in attempts to derive a typology of the conventional personality disorders in general. Criterion E

underscores the importance of understanding carefully the aetiology of enduring personality change after a catastrophic event before a diagnosis of EPCACE is made.

5.6 Criterion F

Table 14. Comparison of EPCACE Criterion F in the DCR and CDDG

DCR	CDDG
The personality change meeting the above criteria is often preceded by post-traumatic stress disorder (F43.1).	...Post-traumatic stress disorder (F43.1) may precede this type of personality change,
The symptoms of the two conditions can overlap and the personality change may be a chronic outcome of a post-traumatic stress disorder.	which may then be seen as a chronic, irreversible sequel of stress disorder.
However, an enduring personality change should not be assumed in such cases unless, in addition to at least two years of PTSD, there has been a further period of no less than 2 years during which the above criteria have been met	In other instances, however, enduring personality change meeting the description given below (<i>referring to symptom criteria</i>) may develop without an interim phase of a manifest post-traumatic stress disorder.

Clinicians were not specifically asked about this criterion however they talked about the overlap and similarity of the symptoms of personality change with that of PTSD despite the fact that the CDDG criteria do not specify that the symptoms of EPCACE and PTSD may overlap. Some went further to suggest that EPCACE may be a form of chronic PTSD. These comments from clinicians are not unusual as most of these are explicitly stated in CDDG as can be seen in Table 14. These clinicians' observations add weight to the

findings from earlier studies that there is overlap between PTSD and EPCACE criteria as noted in Shea's EPCACE review (Shea, 1966) and the exploratory study conducted by Beltran and Silove (1999).

Overlap between PTSD and complex PTSD, was identified in DSM-IV field trials. Ninety-seven percent of those diagnosed with complex PTSD were also diagnosed with PTSD (van der Kolk et al, 1996). Other findings (Jongedijk et al, 1996; Newman et al, 1995) support the view that complex PTSD is associated with PTSD and does not exist as a separate category. As previously mentioned DSM-IV-TR (APA, 2000) does not make a separate distinction between personality changes after exposure to trauma and PTSD. These personality changes are subsumed under PTSD criteria. Yet in ICD-10, EPCACE is classified as a separate diagnosis under the personality disorder class (WHO, 1992).

As discussed in Chapter 2, there are problematic issues in classifying EPCACE as a personality disorder. This includes the distinction between personality disorder and personality change (Cooper/WHO 1994) and the view that personality disorder is a pejorative label; this also explains the reluctance of clinicians to use this for trauma survivors (Allen et al., 1998; Beltran & Silove, 1999; Herman, 1992a; Shay, 1996).

Clinicians using the CDDG guidelines could operate on the assumption that EPCACE develops without PTSD as an interim phase. However, DCR warns

against this by including PTSD as a possible precursor. Moreover DCR does not allow diagnosis of EPCACE unless it has been preceded by two years of PTSD and at least another two years of symptom manifestations of EPCACE. Inconsistency in criteria between the two versions of ICD poses confusion in clinical and research work in this area.

Within the EPCACE publications, there is additional inconsistency. In CDDG and not in DCR, personality change is viewed as an “irreversible sequel of stress disorder” (see Table 14). Some clinicians in this study were of the view that “personality changes are not fixed”. For them the question was: What features are amenable to treatment and how amenable? The statement that personality change is irreversible seems premature given the findings that question the stability of personality disorders (Grilo & McGlashan, 1999).

5.7 Additional Criteria of EPCACE as Suggested by Clinicians

Clinicians suggested additional criteria that their clients with EPCACE manifest which are not captured by the current EPCACE criteria. Clinicians across the three groups identified three symptoms or dysfunctions in common. These are somatization, self injurious/self damaging behaviours, and sexual dysfunction. Torture and trauma, and sexual assault clinicians also added enduring guilt. These additional criteria highlight the inadequacy of EPCACE criteria as currently defined in ICD-10.

5.7.1 Somatization

Somatization has been consistently identified as a feature of enduring personality change in concentration camp survivors (Bower, 1994; Bychowski, 1968; Chodoff, 1966; Eitinger, 1964; Krystal, 1968; Krystal & Niederland, 1968; Niederland, 1968a) and appeared to characterize some behavioural patterns of families of survivors described by Danieli (1985) as “victim families” and “families who made it”. It has also been noted as manifested by Vietnam Veterans (Horowitz, 1986; Horowitz et al, 1987, Marmar, 1991) and survivors of torture (Turner & Gorst-Unsworth, 1990) and was one of the features of complex PTSD when this was first recognized (Herman, 1992a, 1992b, 1993; van der Kolk, 1996). Somatization is a consistent finding in studies of survivors with early history of sexual abuse (Allen et al, 1998; Van der Kolk et al, 1996; Zlotnick et al, 1996). It has also been posited as one of the symptoms that differentiates simple from complex PTSD in war veterans (Jongedijk, 1996). Shea’s review (1996) on EPCACE also identified somatization as a feature as did the international experts in Beltran and Silove’s (1999) exploratory study. Yet despite these findings, somatization does not feature as one of the symptom criteria of EPCACE in ICD-10. Given the evidence in the literature, its current exclusion from the list of EPCACE criteria appears to be an important omission.

5.7.2 Self Injurious Behaviour

Clinicians in this study included self mutilation and the use of drug and alcohol as self injurious behaviours. Remember that excessive drinking and

use of drugs is explicitly stated as associated with “enduring feeling of being on edge” in DCR but not in CDDG. Self injurious behaviour had been noted in concentration camp survivors (De Wind, 1973; Krystal, 1968; Niederland, 1968). Krystal (1968) suggested it may be associated with masochistic trait and self hatred. Abuse of drug and alcohol has been noted with Vietnam Veterans (Horowitz, 1986; Horowitz et al., 1987, Marmar, 1991). Herman (1992a, 1992b, 1993) in recognizing self injurious behaviour as one of the characteristics of complex PTSD noted it could be associated with repeated victimization, commonly observed in survivors of prolonged and repeated trauma where survivors may be at risk of repeated harm which may be self inflicted or perpetrated by others. Herman (1992a, 1992b, 1993) identified this as one of the characteristic features of complex PTSD. Vulnerability to repeated harm either from oneself or from others is also a feature of what Ochberg (1993) described as “victimization sequelae disorder”.

Van der Kolk (1996) hypothesized that self-mutilation is an effort by survivors to gain control of problems related to affect regulation. This includes bingeing, purging, drug and alcohol abuse, and unusual sexual practices (van der Kolk, 1996). In keeping with the findings of the international experts in Beltran and Silove’s (1999) study, clinicians noted self-destruction as being trapped in a role of victim, that is, unable to be anything else, dangerous risk-taking behaviours and, propensity for alcohol and drug abuse and dependency. Aside from excessive drinking and use of drugs, explicitly stated as associated with “enduring feeling of being on edge” in

DCR none of the other features describing self injurious behaviour are present in EPCACE criteria (Beltran & Silove, 1999).

5.7.3 Sexual Dysfunction

Sexual dysfunction has been noted in concentration camp survivors (Bower, 1994; Krystal, 1968), in victims of cruelty and violent crimes including physical violence, psychological abuse and sexual abuse (Ochberg, 1993), and survivors of torture (Turner & Gorst-Unsworth, 1990). Bower (1994) however subsumed sexual difficulties under somatization. The mechanisms of sexual dysfunction are not clear (Turner & Gorst-Unsworth, 1990). In a study of men subjected to torture by Lunde et al., (1981) of the 17 participants 29% had sexual dysfunction in the form of reduced libido and erectile dysfunction which was not related to previous brain or genital traumas, severity of torture or duration of imprisonment. This study however, was unable to determine the causation of sexual dysfunction. Over a decade later, Ochberg (1993) suggested that sexual dysfunction may be related to the inability to trust and be intimate with others and that this could be an outcome of having been victimized through internment in concentration camps, torture, physical violence, psychological abuse and sexual abuse. Shea (1996) noted that reduced libido was one of the many features of prolonged torture/victimization. Again, impairment of intimacy was one of the personality changes suggested by international experts in the EPCACE survey (Beltran& Silove, 1999). Currently, sexual dysfunction and its associated features are not included in the EPCACE criteria.

5.7.4 Enduring Guilt

Enduring guilt was the final symptom suggested, however this came only from torture and trauma clinicians and sexual assault clinicians. Various studies have identified survival guilt in concentration camp survivors (Bychowski, 1968; Chodoff, 1996; Krystal, 1968; Krystal & Niederland, 1968; Niederland, 1968a). Shea's (1996) review on EPCACE identified survivor guilt as a feature of prolonged torture/victimization in survivors of Nazi persecution and Hiroshima and in Korean prisoners of war. There was no evidence in the current study that Vietnam Veterans clinicians identified guilt as a symptom. It is possible that they may not have observed this feature in Vietnam Veterans as engagement in warfare is a legitimized event and undertaken by veterans as a sense of duty to one's country. This seems unlikely however when, as noted earlier, Vietnam Veterans were reported by clinicians to have difficulties stemming from the public perception of the futility of the war. An alternative explanation is that enduring guilt may not be as stark in survivors of warfare in comparison to guilt induced by other traumas.

5.8 EPCACE Criteria: Typification as Validation

The ICD-10 is an institutionalized typification in the social world of clinicians and this is legitimized by the WHO. It contains criteria for disorders like the EPCACE which typically define what a disorder is about. Clinicians and researchers, as actors in their every day world of trauma work, (Schutz, 1973)

in this instance will experience components typical of EPCACE and at the same time come across features which conflict with, or throw doubt on, the institutionalized typifications of EPCACE. This has been well demonstrated by clinicians in this study who interpret the EPCACE criteria and describe features and relationships not encompassed and recognized by current criteria.

Following Schwartz's and Wiggins' (1987) arguments about typification, EPCACE as a diagnostic category is a typification which predelineates other not yet observed components of EPCACE. These authors further argued that typification in one sense takes on a "hypothetical status of a scientific prediction" (Schwartz & Wiggins, 1987, p.73). According to Schwartz and Wiggins (1987) the status of typifications is hypothetical, until proven to be true. In this study, clinicians using the CDDG criteria recognized that there is a typification such as enduring personality change. Their common sense knowledge (or typification) recognized the phenomenon of EPCACE (a typification) and expanded the clinical description of this phenomenon.

As previously stated, typification is a preconceptual skill that renders a list of diagnostic criteria meaningful (Schwartz & Wiggins, 1987). According to Schwartz and Wiggins (1987) this ability to typify is acquired through directly observing and dealing with objects, things, events and phenomenon so typified. Through their day-to-day trauma work and experience, clinicians in this study demonstrated this ability. In typifying the symptom criteria,

clinicians applied the criteria in their own work and client context. Clinicians were able to characterize EPCACE by describing how EPCACE symptoms, for example hostility or distrust, were manifested by particular clients. They were also able to exemplify EPCACE by citing examples of cases that, according to their common-sense knowledge, were typical of someone experiencing personality changes post catastrophic trauma. They were also able to illustrate their points about EPCACE by citing instances from their clinical work with clients. In addition, they understood relationships between criteria and suggested additional criteria which challenged the existing institutionalized typification of EPCACE. As argued by Schutz (1973) our common sense understandings remain until something occurs which leads us to doubt or question it.

Schwartz and Wiggins, 1987), argued for the “scientific objectivity of typifications in psychiatry” further arguing that “typifications are scientific only to the extent that they are based upon and tested by evidence” (p.73). In the clinical world this evidence comes from observations of clinicians on their patients’ behaviours and through communicating with clients about their experiences. There was no evidence in this study that clinicians mechanically applied the EPCACE criteria. Rather, their common sense knowledge and understanding of personality changes post catastrophic experience enabled them to name, describe and categorize their observations. Using their knowledge and experience, they were able to scrutinize and challenge given

typifications exemplified in EPCACE criteria. They were not reifying the criteria.

Although Schutz (1973) recognized that clinicians are influenced by their professional perspectives and the cultural and social settings in which they work, a list of EPCACE criteria which is a typification, predelineates for the clinicians what to look for (Schwartz & Wiggins, 1987). EPCACE as an institutionalized typification provides a broad framework within which clinicians' observations and experiences of clients' behaviours make sense. The perspectives of clinicians in this study indicates that, in applying and interpreting the EPCACE criteria, their central concern is to consider the idiosyncratic manifestations of symptoms in each individual patient's context. Foremost in this study was the clinicians' recognition that the way human beings experience pain and suffering, and body and emotional awareness is multifaceted and contingent on many factors. EPCACE criteria serve as a backdrop from which the unique manifestations of symptoms that emerge in individual clients can be understood.

5.9 Summary

The findings of this study focus on aspects of EPCACE criteria which include stressor criterion, symptom criteria, impairment criterion, criterion related to exclusion of personal vulnerability and early psychiatric history, symptom duration and relationship of PTSD with EPCACE. Clinicians

confirmed the possibility of B.1 hostility or distrust as a core criterion of EPCACE. Clinicians also suggested somatization, self injurious/self damaging behaviours, sexual dysfunction, and enduring guilt as additional criteria not encompassed by current EPCACE criteria. This study also identified some hypothesized relationships between symptom criteria. In using the comparison of DCR and CDDG criteria as a framework for discussion, similarities and differences between these two sets of EPCACE criteria were highlighted. I discuss the conclusion and implications of this thesis in the next and last chapter.

CHAPTER 6

CONCLUSION

Several issues challenge the validity and clinical utility of diagnostic categories like EPCACE. These issues relate to various and often confusing interpretations of clinical description and diagnostic guidelines, lack of agreement between criteria for the same disorder as specified in the CDDG and DCR in ICD-10, too specific or too broad and general criteria sets, and the varied ways in which symptoms are expressed and described.

6.1. Contributions of the Study

Studies focussing on ICD-10 EPCACE are just beginning. To the best of my knowledge this current study is one of only three in the literature which has EPCACE as its focal point. This study marks the beginning phase of validation by operationalizing EPCACE criteria. It contributes to the descriptive validity of EPCACE by making explicit the typifications of three groups of trauma clinicians about the criteria that define this diagnostic category. It provides a composite picture of how clinicians describe the manifestations of the symptom criteria of EPCACE that they see in their patients who manifest personality changes as an outcome of experiencing extreme trauma. This composite picture includes an enriched characterization of each of the symptom criterion; identification of a core symptom, identification of some additional features not included in the

current criteria for EPCACE and hypothesized relationships between several criteria. It also highlighted some comparative features of ICD-10 DCR and CDDG for EPCACE that impact on the current definitions of the criteria.

Another significant contribution of this study is the utility of a qualitative approach to the descriptive validation of diagnostic criteria. This study demonstrates the potential of a qualitative research approach to field testing of classification criteria. This approach involving clinicians is critical because what may seem very clear to the authors of the criteria may be incomprehensible to those, the clinicians, who apply the criteria. Confusion in the interpretation of criteria, compromises the reliability in the use of a diagnostic category for classification purposes (Spitzer and Williams, 1980).

6.2. Limitations of the Study

The research method used in this thesis has several limitations. One unavoidable limitation of this study is sampling as all participants were clinicians. Their description of the criteria is limited to those seeking treatment and therefore not representative of the traumatized population as a whole.

A second methodological limitation is lack of triangulation. Although the participants were drawn from three trauma contexts and were able to

provide data on EPCACE from these three areas of trauma, there are other relevant trauma contexts/areas that were excluded from this study such as domestic violence and trauma arising from institutionalization and removal from families (Richard Madden, personal communication, 2006).

Triangulation would also have been strengthened by using other sources of information. These sources include interviews with EPCACE patients and their relatives and review of EPCACE client notes (Aleksandar Janca, personal communication, 2006). Alternatively clinicians could be provided with a set of pre-selected EPCACE case histories or vignettes and ask them to comment using the ICD -10 CDDG (Aleksandar Janca, personal communication, 2006).

This thesis made use of various procedures to ensure credibility of data. In addition to detailed descriptions supplied by clinicians and use of field notes, my working hypothesis or theoretical memos were revised as more data became available. In succeeding interviews I was also able to clarify tentative findings with participants. The preliminary analysis of data was reviewed by one of my supervisors, the participants, and by a nosologist thus confirming or negating my interpretation. Notwithstanding these procedures, the representation of psychiatrists only within the torture and trauma group and not in the Vietnam Veterans and sexual assault clinicians group may be a significant source of response bias in the results (Richard Madden, personal communication, 2006) particularly so when the task of diagnosing and using diagnostic criteria are embedded in their roles much more so than with

other practitioners who participated in this study. In a future study, employing more than one person to code a set of data may enhance reliability (Aleksandar Janca, personal communication, 2006). Conducting a focus group with an expert reference group to examine the analysis and interpretation of data could also assist in minimizing potential bias by one person.

A second group of limitations relate to validation of diagnostic criteria. This study, while operationalizing the criteria for EPCACE, did not extend to differentiating those with the disorder from those without the disorder and did not investigate co-morbidity issues with PTSD, depression and other mental illness. The scope of this study did not include these foci for descriptive validation. Rather, the aim was to identify features of EPCACE as a first step to the development of measures to facilitate quantitative validity studies.

There was no opportunity in this study for clinicians to identify whether they found the CDDG more advantageous than DCR because they were only given the CDDG and not the DCR. This study did not seek to examine whether EPCACE as a diagnostic category, is categorical or dimensional. This issue is worthy of attention in a future study. This is discussed further in this chapter in the Implications section. Nor did this study seek to ascertain whether EPCACE is a separate category from complex PTSD or

DESNOS. The literature is not unanimous in this area. Some equate the two, others differentiate them. This issue is also worthy of future attention.

This study did not focus on cultural factors related to EPCACE and on mechanisms of developing EPCACE or the complex ways by which symptoms and other manifestations are interrelated. It also did not focus on causation of EPCACE, in particular the underpinning biological basis of this disorder, if any, which leads to an important question that baffles clinicians and researchers alike: how could enduring trauma change the personality? The aim and the research methods used specifically excluded attention to these issues. Focus on treatment efficacy was also beyond the scope of this thesis. All are worthy of future research and will assist in working towards confirming the validity of EPCACE (Berdihan Üstün, personal communication, 2006).

6.3. Implications of the Study

The findings of this study have several implications for research, policy and clinical practice. Each is discussed in turn.

One area of research is instrument development and evaluation of psychometric properties. The rich descriptors of various EPCACE symptoms generated from the results of this study could be used to develop an assessment instrument to objectively measure EPCACE to further

examine the empirical validity and reliability of this diagnostic category. Given the existence of the International Personality Disorder Examination (IPDE) developed within ICD-10, a new instrument could be developed with this format. Alternatively, the symptom descriptors generated from this study could be used as items to develop an instrument similar to the SWAP-200 using a Q sort method, overcoming the criticism levelled at self report measures such as the IPDE. An area ripe for investigation is whether EPCACE can indeed incorporate short term exposures such as motor vehicle accidents. Further, examining the hypothesised relationships between symptom criteria that arise from this study could be fruitful. Correlation research using the new instrument could serve as a starting point in testing the relationships between these symptoms. Understanding the relationships between these symptoms will help explain the multiplicity and complexity of symptom manifestations of EPCACE.

A second area of research is determining the dimensional nature of EPCACE as a diagnosis. Whilst criterion B.1, a permanent hostile or distrustful attitude towards the world in a person who previously showed no such traits, appears to be a feature that potentially may differentiate EPCACE from other mental disorders, there is a variety of features identified by clinicians which characterize this diagnostic category. Given the recognition that the personality disorders class includes a mixture of latent categories and dimensions, it is worth examining the dimensional properties of EPCACE.

As reviewed by Haslam (2003) and Trull (2000), there are reliable statistical procedures, albeit not perfect, that can identify whether a mental disorder is categorical or dimensional. Haslam's review focused on outcomes of taxometric procedures in identifying dimensional and categorical classifications. For example such procedures can examine the covariation among symptoms of EPCACE to see patterns indicative of latent categories (taxa) or dimensions. One suggested procedure is taxometrics which involves the use of multiple independent procedures to assess whether categories exist and if so, their prevalence. Consistency of findings across these procedures is paramount to consider a conclusion whether a disorder is categorical or dimensional (Haslam, 2003).

Similarly, Trull (2000) reviewed the research on various approaches to dimensional models of personality disorders. These approaches focus on identifying personality traits that underpin a personality disorder construct. The operationalization of EPCACE criteria as an outcome of this study is a starting point in further examination of its dimensions. It would be fruitful to test the relationship of EPCACE criteria with the trait, temperament, and character components of existing dimensional models of personality to find out whether specific traits, temperaments, and character dimensions underlie EPCACE.

A third area of research relates to the role and validity of Criterion C. Currently, there are no systematic studies examining the extent of functional impairment related to EPCACE. Although problematic consequences on social relationships, daily activities, work, school and other productivity areas may not be the main complaint when trauma survivors attend a health service, the social costs of these consequences are enormous. A starting point is to conduct qualitative research to understand, from the clients' perspective and their families how they experience the "changed person" as an outcome of extreme trauma experience and how these changes impact on various areas of their daily lives. Another potential method to examine Criterion C would be to use the International Classification of Functioning, Disability and Health (WHO, 2001) to ask the question "What type of impairments, activity and participation restrictions do people with EPCACE show?" (Berdihan Üstün, personal communication, 2006). Understanding these consequences would provide a functional validity rationale for inclusion of impairment criterion within this particular diagnostic category of ICD-10.

The findings of this study have implications in relation to the development of diagnostic criteria within the ICD system. I acknowledge that classification is a rigorous process backed by a combination of empirical research and expert consensus. The qualitative approach employed here offers a significant complement to the more usually employed quantitative studies. Systematic phenomenological descriptive studies which involve

clinicians who are in direct contact with clients are a critical component of validation of criteria. Phenomenological understanding is particularly important with traumatized groups. As discussed in this study, phenomena like estrangement and emotional numbing are not easy to operationalize and are difficult to assess. Likewise hostility or mistrust reflects disturbances in meaning systems which can only be understood in depth from a phenomenological perspective. Although not all clinicians are involved in making an 'official' diagnosis, they employ diagnostic criteria in understanding their client's disorder and in making treatment decisions. A firm recommendation from this study is that the ICD working party should include their participation as co-researchers on phenomenological studies on diagnostic criteria. Membership and representation of clinicians in diagnostic work groups or task forces must be increased. On-the-ground clinicians are not typically academics or researchers. However they are the consumers of research knowledge and apply this in everyday practice. Thus, they have the ideal vantage point to critique the clinical utility of diagnostic criteria. Their ability to do so has been demonstrated in this study.

The above suggestions complement other contemporary approaches identified in the literature in determining the clinical utility of psychiatric diagnosis (First, Pincus, Levine, Williams, Üstün, and Peele, 2004). In their review First et al. (2004) proposed that future changes in DSM classification should empirically demonstrate clinical utility to ensure that positive consequences of such changes outweigh negative ones. These authors define

clinical utility as the extent to which DSM assists clinical decision makers in conceptualizing diagnostic entities, communicating clinical information, applying diagnostic categories and criteria in practice, choosing appropriate and effective treatment and in predicting future treatment/management need (First et al., 2004). These authors suggested some empirical methods such as survey, field trial methods, randomized controlled trials, and naturalistic methods to measure clinical utility of proposed changes in DSM. These methods would focus on examining user acceptability, that is whether the diagnostic system is used at all by its intended audience; whether it is used correctly, that is how accurately the diagnostic criteria are applied; whether it enhances clinical decision making, for example selecting a particular setting or mode of treatment; and whether it improves clinical outcomes (First et al., 2004). Although the definition of clinical utility and methods to measure it are made in the context of DSM diagnoses, these are equally applicable to ICD and are worth implementing in future studies relating to the clinical utility of ICD diagnoses. The expert opinion survey conducted by Beltran and Silove (1999) and reviewed in this thesis fits the example of a survey suggested by these authors which examines aspects of user acceptability of EPCACE.

The results of this study also have implications for clinical practice. The findings of the comparative analysis of DCR and CDDG present a challenge to the way diagnostic criteria are conceptualized and stated. The practice of having two somewhat disparate sets of criteria can create confusion among

users. Having separate criteria for research and clinical use further dichotomizes the roles of clinicians and researchers. In the current climate of evidence based practice and accountability, it is critical to encourage development of clinician and researcher attributes in both clinical practitioners and researchers. Increased concordance between CDDG and DCR EPCACE criteria, it is hypothesized, would significantly add in achieving this outcome. Appendices H and I contain preliminary draft of a revised text for EPCACE CDDG and DCR derived from the findings of this study. To address concordance these drafts also incorporate features that were in DCR and not in CDDG and vice versa.

Secondly, the symptom descriptors generated from this study could be used to enhance the descriptions and guidelines contained in the CDDG. It is well recognized in health care contexts, that diagnosis is restricted to the medical profession. Other health professionals however are expected to be knowledgeable about symptoms and criteria of mental disorder. The ICD is acknowledged worldwide as the standard reference that clinicians use as a guide in their diagnostic understanding. In order to enhance confidence in their understanding of a disorder encountered in clinical practice, clinicians need contextual guidelines with ICD-10. Access to this information is crucial. On line access, in addition to print media, facilitates this process.

Given the preference of clinicians for observing their clients' behaviours and listening to their narratives when working with clients with personality

disorders, a simple observational tool could be devised for clinical use. This tool would include each symptom criterion and their characteristics listed with provisions for clinicians to check whether the symptom is present or not with space provided for qualitative description as observed and narrated. This data gathering and documentation procedure would need to include other criteria or conditions in order to arrive at a diagnosis of EPCACE.

This study has contributed original knowledge by identifying the salient features of the EPCACE criteria. As with all other studies, more questions requiring answers have been raised. The features of EPCACE need further research and refinement to increase the validity of this diagnostic category as a construct. The ongoing conceptualization and validation of useful constructs that afford justice to the experiences of survivors of catastrophic trauma is a worthwhile research endeavour.

“Apart from the inner qualities of the survivors, a primary condition for their rehabilitation is to live in a world free from fear, injustice and authoritative coercion” (de Wind, 1972, p.176).

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