# Complex Trauma Presentations in Eating Disorder Patients Across Scotland and Perceptions of Trauma-informed Care

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**Declaration** 

I declare that this thesis has been composed by myself, and that it embodies the results of my

own research. I acknowledge that to the best of my knowledge this thesis contains no material

written or published by another person, expect where due reference to such is made.

Signature: Laura Hulse

Date: 27<sup>th</sup> June 2022

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### **Abstract**

Understanding the role trauma and post-traumatic stress disorder have in the severity of eating disorders (ED) is important for achieving the best outcomes for those accessing ED treatment yet there is a lack of guidance for ED services across Scotland regarding best practice. Trauma-informed care sets out to make services more accessible to those with a trauma history, offering guidance on establishing a safe environment and adapting therapeutic approaches to accommodate the needs of service users who have experienced trauma. This study aimed to understand interpretations of trauma-informed care from the perspective of professional key informants, service users with a lived experience of complex trauma, and therapists delivering ED treatment in order to inform future ED service development. A convergent mixed methods design was used. Framework analysis was employed to manage and analyse the qualitative data. The study was split into four phases and included: semistructured telephone interviews with six key informants with expertise in psychological trauma; a focus group with two service users with a lived experience of complex trauma; a survey of 44 ED patients gathering data on prevalence rates of trauma and PTSD and their association with ED symptoms; and a focus group with four ED therapists. The survey results indicated a high prevalence of complex trauma in ED outpatients, with half also having active PTSD symptoms. Qualitative data highlighted the value of a thorough assessment, and the use of routine inquiry when asking about trauma history was of high importance, as was the role of the therapeutic relationship to foster trust and provide a validating experience for both patients and therapists. In addition, phase-based interventions were highlighted as a way of integrating trauma-specific interventions into ED therapy, requiring training and education for some therapists. The role of supervision and care of the wider team was flagged to protect against the risks of vicarious trauma.

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### **Abbreviations**

BPD borderline personality disorder CBT cognitive behavioural therapy CEA childhood emotional abuse CEN childhood emotional neglect CPA childhood physical abuse CPN childhood physical neglect CPTSD complex post-traumatic stress disorder CSA childhood sexual abuse DBT dialectical behavioural therapy ED eating disorder EMDR eye movement desensitisation and reprocessing EDNOS eating disorder not otherwise specified EUPD emotionally unstable personality disorder FBT family-based therapy OSFED other specified feeding and eating disorders PD personality disorder PE prolonged exposure PTSD post-traumatic stress disorder

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### **Chapter 1: Introduction**

#### 1.1 Introduction

This study aimed to understand interpretations of trauma-informed care from the perspective of professional key informants, service users with a lived experience of complex trauma, and therapists delivering ED treatment, in order to inform future ED service development. Trauma-informed care was a fledging subject at the onset of this study in 2016 and pre-dated much of the guidance that is now available for professionals, which is detailed in this study. There was a lack of direction for ED services in how to best treat patients presenting with a trauma history and the problems that often arise as a result of being exposed to trauma. The study comprised of four individual but interconnected phases which were designed to address each of the following research questions separately, whilst contributing knowledge to the other phases of the study.

- 1. How do experts in the field of psychological trauma define trauma-informed care and envision its implementation across mental health services?
- 2. How do patients with a history of complex trauma want to be treated within an ED outpatient service?
- 3. How prevalent is complex trauma in ED patients and does exposure to psychological trauma or symptoms of PTSD increase the severity of ED symptoms?
- 4. How do therapists working in an ED outpatient setting interpret trauma-informed care?

The overall goal of the study was to understand the gaps between the evidence base for trauma-informed care and clinical practice with the aspiration of informing future ED service development locally.

### 1.2 Positioning myself as a researcher

I have worked as a mental health nurse, both in in-patient and outpatient settings across England and Scotland, for the past 22 years. Within the early part of my career, I specialised in caring for people with opiate dependency problems in Greater Manchester and continued as a community psychiatric nurse in the addictions service (mixed drug and alcohol use) when moving to Scotland. The latter 13 years have been spent working in the field of eating

disorders and personality disorders (PD). I currently work as an advanced nurse specialist in an adult outpatient ED service. I am an accredited cognitive behavioural psychotherapist and have also trained in various other psychotherapies alongside this, including dialectical behaviour therapy (DBT). DBT is an evidence-based treatment for borderline personality disorder (BPD), or emotionally unstable personality disorder (EUPD)(Linehan, 2014), and DBT treatment is delivered through my role with the personality disorder (PD) service, which is separate to my ED role.

The PD service operates a phase-based approach to their treatment model which involves three main phases of therapy and an additional pre-treatment phase. Pre-treatment allows the patient to learn about the treatment model and get to know their therapist before deciding whether they wish to commit to therapy. Phase one addresses behavioural stabilisation, with a treatment hierarchy prioritising life-threatening behaviours, then therapy interfering behaviours and finally quality of life issues. Once stabilisation has been achieved, and the patient has adequate skills to regulate their emotions and tolerate distress, they can commence phase two of treatment. This phase addresses trauma-related symptoms and an assessment for PTSD will be undertaken to ascertain whether there is a need for trauma reprocessing. Prolonged exposure (Foa, 2011) is the trauma specific treatment on offer at this stage and this is an additional therapy I have trained in. Phase three of treatment brings the focus to the patient's personal life goals and finding meaning and a sense of self and planning for the future.

This is very different from the ED model of treatment which does not offer a phase-based approach. Both patient groups present with extreme levels of risk but the stabilisation process in ED therapy is significantly longer, possibly due to the nature of the illness and difficulty in finding shared goals for recovery. Many of the patients I have worked with in the ED service have described traumatic events from childhood and some of these patients have had additional diagnoses including, PTSD, CPTSD (complex PTSD), complex trauma, BPD and emotionally unstable personality disorder. There was no clear pathway within the ED service for treating PTSD, or formally assessing for a trauma history, when I began this research. Equally, many of the patients in the PD service presented with ED symptoms which were difficult to manage outside of the ED service. Both the ED service and PD service had a very different approach to assessing and treating the effects of trauma. There were frequent transitions between the two services as patients would need additional stabilisation work that the other service could not support. The PD service is very much a 'trauma-specific' service

whereas the ED service is not, and there was a lack of clarity as to where they position themselves in the tiered approach to trauma.

The service I work with is part of a larger managed clinical network (MCN) for the north of Scotland for ED. The MCN is a network of multidisciplinary professionals working within the same speciality, sharing expertise and driving a shared vision of service development. It aims to ensure an equitable experience for all ED patients, regardless of where they live across the region. Informal discussions with colleagues amongst the different services within the MCN revealed some variations in local policies and approaches to trauma. The level of training that staff have undertaken in trauma, whether this be assessing for traumatic histories or traumaspecific interventions, appears to vary from service to service and from profession to profession too. This would suggest there is inconsistency in the trauma-informed approach across ED services in Scotland. Each region also has variations in the peripheral services they are able to refer patients on to and for that reason, there are distinct entrance and exit points to the referral pathway which are unique to each service.

### 1.3 Rationale for the study

In response to the push for services to be adopting a trauma-informed approach, and given the lack of guidance that was available, this study aimed to understand interpretations of trauma-informed care from the perspective of professional key informants, service users with a lived experience of complex trauma, and therapists delivering ED treatment, in order to inform future ED service development. To achieve a rounded view from all perspectives, data was drawn from a variety of resources to investigate the various viewpoints and points of intersection. This included drawing on the expert opinions of key informants with expertise in psychological trauma and the wider literature. Secondly, the views of service users who have experienced complex trauma were sought to better understand their experience and perceptions of trauma-informed care. An observation of the clinical presentations of complex trauma in ED patients was then carried out to determine the occurrence rates of complex trauma and related PTSD and the impact it was having on these individuals ED symptoms. Lastly, the views of ED therapists were gathered to explore their understanding of trauma-informed care and how this fitted into ED treatment. The collective findings, including the expert opinions of key professional informants, along with the findings from the literature

review, acted as a point of triangulation when exploring the perceptions of trauma-informed care from the viewpoint of service users and therapists.

### 1.4 Organisation of the thesis

Chapter two offers an overview of the literature relating to adverse childhood experiences and the interaction this has with eating disorders, which demonstrated a well-established link between complex trauma and eating disorder symptomology. Co-morbidities and the mediating factors in this link are also discussed. In chapter three the methodological underpinnings of the study and the rationale for adopting a convergent mixed methods approach are discussed, including an appraisal of the research design and the methods used to justify the data gathering techniques, as well as the ethical considerations. This is followed by chapter four which describes the methods. Chapter five begins the qualitative findings, presenting the results from phase one of the study, the interviews with key informants. This leads on to chapter six where the findings from the focus groups are presented in order. Phase two, the focus group with service users makes up the first half of the chapter, and phase four, the focus group with ED therapists is detailed in the latter half. Chapter seven reviews the results of phase three of the study, a quantitative observational approach gathering data from patients attending for outpatient ED treatment. Finally, chapter eight offers the discussion and conclusion, summarising and critiquing the overall research and findings.

### 1.5 Adverse Childhood Experiences

Adverse childhood experiences (ACEs) were originally studied over 20 years ago to explore the link between adversities in childhood and the long-term impact these had on health and risk-taking behaviours into adulthood (Felliti et al, 1998). The CDC study (Centers for Disease Control and Prevention, CDC Kaiser-Permanente, 2014) was conducted over a two-year period between 1995 and 1997, and recruited 17,000 adult participants in San Diego; a primarily white, middle-class area with low levels of poverty. Participants were asked to complete a postal survey indicating their early childhood experiences, as well as a standard medical evaluation. Adversity was measured across ten domains including: physical, sexual, and emotional abuse; physical and emotional neglect; exposure to adult incarceration, mental illness, substance abuse, violence in the household, and parental separation or divorce. These

adversities have been shown to have a significant impact on both the physical and mental health of an individual, as well as the health-related behaviours that a person engages in (CDC Kaiser-Permanente, 2014). Four or more ACEs are associated with high-risk alcohol use, unintended teenage pregnancy, substance misuse, perpetrating violence, being the victim of violence, and custodial sentences (Public Health Wales, 2015). Those with the highest number of adverse experiences had the lowest life expectancy, 20 years less than those with low numbers of ACEs (Felitti et al. 1998).

Over the years, ACE has become a common term when discussing childhood trauma, despite the ten domains missing other common traumas such as bullying, racial discrimination, poverty, exposure to community violence and separation from immigrant parents (Cronholm et al, 2015). This has sparked some debate regarding the breadth of the definition of ACEs (Portwood et al, 2021) and a suggestion that when capturing complex trauma, ACEs are referred to alongside childhood trauma as 'traumatic and adverse childhood experiences (TRACES+)' (Weems et al, 2021). Adverse childhood experiences are subjective and not all of these experiences would be identified as traumatic through the eyes of the individual experiencing them. ACEs are not intended to be diagnostic, merely an indication of increased risk for physical and mental health issues later in life. The scoring of ACEs is a simple summing procedure, adding up the total from the ten domains that an individual has been exposed to. This treats all the domains as equal, despite research demonstrating trauma is most damaging when it is severe and repeated over a longer duration (Hughes et al, 2017). Throughout this study, the terms complex trauma, ACE, and type two trauma (Terr, 1991) have been used to capture a broader sense of exposure to psychological trauma and adversity.

Many further studies have been conducted over the years which corroborate the original findings of the ACE study, with ACEs thought to contribute to approximately a third of all mental health and behavioural disorders (Green et al., 2010; McLaughlin, 2017). Finkelhor et al (2015) make specific criticisms of the ACE questionnaire as a tool, calling for revisions to be made. They suggest it omits to explore other important adverse childhood experiences, such as: rejection by peers, exposure to violence outside of the family, low socioeconomic status, and difficulties with academic performance. However, the ACE questionnaire still offers a structured tool to gather a relatively comprehensive variety of childhood traumas. The studies contributing to "ACEs Too High" (2017) have helped to shape the approach and interventions offered to those who have experienced complex trauma, including the introduction of trauma-informed care.

### 1.6 Complex trauma

A review of the literature demonstrates a strong link between complex trauma and the development of ED, most commonly bulimia nervosa (Brewerton, 2007). Complex trauma, or type two trauma, is a term which refers to traumatic experiences which happen repeatedly, as opposed to a single event; it is usually of an invasive, interpersonal nature and has a wideranging, long-term impact (Complex Trauma Treatment Network, 2016). Often these are events that are experienced during childhood, such as sexual abuse, physical or emotional abuse, physical or emotional neglect, or bullying. There are many other examples of exposure to complex trauma including natural disasters, intimate partner violence, traumatic grief, trafficking, medical trauma, and terrorism (Greeson et al, 2014). The term complex trauma can also be used to describe the long-term, wide-ranging effects of these traumatic events and the learned adaptations that survivors develop as a means of coping and functioning on a day-to-day basis (The National Child Traumatic Stress Network, 2017; Mantovani and Smith, 2021).

Psychological trauma generates stress hormones such as cortisol and catecholamines and these neuronal hormones have been shown to influence the developing brain which does not reach maturity until early adulthood (Teicher et al, 2002). These neurodevelopmental deficits negatively impact a child's social, emotional, cognitive, and affective functioning (Soloman and Heide, 2005) and are associated with a later diagnosis of personality disorders and PTSD for some (Scannapieco & Connell-Carrick, 2005). PTSD affects approximately one third of people who have been exposed to traumatic events (National Institute for Health and Care Excellence, NICE, 2018) and a much larger number of people will experience subthreshold PTSD. Subthreshold or subclinical PTSD can be defined as the presence of some PTSD symptoms (avoidance, intrusions, hyperarousal) but not meeting the full criteria for diagnosis (Cukor et al, 2010). Subthreshold PTSD can cause significant impairment in social and family functioning and is associated with depression, suicidal ideation, and psychiatric co-morbidities (Marshall et al, 2001).

Exposure to psychological trauma and PTSD are associated with a greater incidence and severity of an eating disorder (Mitchell et al, 2012; Brewerton and Brady, 2014). When PTSD is present in EDs this has also been associated with greater ED comorbidity (Lipschitz et al, 1996). The exact mechanisms for this link with PTSD and ED aetiology are not clear. Exposure to childhood sexual abuse may directly impact on perceptions of body image (Sacks et al, 2001) and early trauma is also associated with the development of a self-critical view (Dunkley et al, 2010) which could encourage engagement in ED behaviours to pursue an ideal sense of self or,

conversely, to become less attractive to perpetrators by minimising gender-specific physical characteristics. Emotional dysregulation has been shown to be a common factor in both ED and PTSD presentations (Corstorphine et al, 2007), as are alexithymia and dissociation (Mazzeo et al, 2002), and ED behaviours are thought to be a method of attempting to emotionally regulate.

Psychiatric co-morbidity in ED patients is associated with poor engagement in treatment and treatment resistance (Agras, 2000), and full recovery from an ED is dependent on the satisfactory treatment of all the comorbidity and this includes PTSD symptoms (Brewerton, 2007). Subthreshold PTSD would not be identified on standard screening tools and is linked with eating disorder symptoms which highlights the importance of a detailed assessment of trauma in ED patients, sensitive enough to pick up on subthreshold PTSD symptoms, (Cukor et al, 2010). Eating disorders present high levels of physical risk, with anorexia nervosa having the greatest mortality rate of all mental illnesses (Arcelus et al, 2011). Long term follow-up studies demonstrate a considerable number of former ED patients will continue to meet the full diagnostic criteria for an ED decades later (Fichter et al, 2017) so understanding the aetiology of the disease and exploring barriers for recovery is a crucial area for research. Whilst there is a wealth of evidence supporting the link between trauma and poor mental health, there is very little literature regarding trauma-specific treatment in ED patients. Trauma-informed care was a relatively new topic at the start of this research and there was no gold standard to look towards regarding the delivery of trauma interventions for ED patients.

### 1.7 Trauma-informed care

The concept of exposure to a traumatic event is now widely recognised as a contributing factor to the development of a variety of mental health conditions and several guidelines and recommendations have been published to encourage mental health services to adopt a trauma-informed approach to patients entering services (NICE, 2005; World Health Organization, 1992; NHS Education for Scotland, 2017). Trauma-informed care (TIC) is a values-based approach to service delivery which takes into account an individual's early traumatic experience to understand the physical, mental and behavioural symptoms they present with when entering healthcare settings (DeCandia and Guarino, 2015). The Substance Abuse and Mental Health Services Administration (SAMHSA, 2015) define trauma-informed care as having four broad aims:

- realising that trauma has a widespread impact on individuals, families, groups, organisations, and communities, and has an understanding of paths to recovery;
- 2. ability to recognise the signs and symptoms of trauma in clients, staff, and others in the system;
- 3. integration of trauma knowledge into policies, programs, and practices;
- 4. to avoid re-traumatisation.

Increasing awareness of psychological trauma can aid clinicians to respond to the individual's needs, possibly signposting them on to the appropriate services. Trauma-informed approaches are intended to have a positive influence on both staff and service users, yet there is limited evidence that exists on the implementation of trauma-informed approaches across ED outpatient services. There are two main benefits that a trauma-informed workforce offers an individual with a trauma history. Primarily it offers a new experience of relationships, building trust through safety, choice, and collaboration, as opposed to coercion, control and betrayal. These repeated positive exposures to healthy supportive relationships help to extinguish the link between trauma and abusive relationships which is an important part of recovery. Secondly it addresses the potential barriers to entering treatment, seeking to provide an environment which will not risk retraumatising the individual through the triggering of traumatic memories (NHS Education for Scotland, 2017).

The knowledge and skills framework "Transforming Psychological Trauma" (NHS Education for Scotland, 2017) highlights that a trauma-informed approach is not intended as a tool for treating trauma but, rather, a guide for the wider workforce to improve the accessibility of services and improve the experience of those effected by trauma and to support the staff who are dealing with these individuals. Within this framework, a tiered approach to trauma is outlined with the following four levels: (i) trauma-informed practice, (ii) trauma skilled practice, (iii) trauma enhanced practice, and (iv) trauma specialist practice. Delivering trauma-specific therapies carries the occupational hazard of exposing the therapist to developing vicarious trauma, changing the professional's cognitions, schemas, and world view; the risk of developing secondary trauma including PTSD symptoms in relation to another's experience; and the risk of burnout, including loss of motivation and compassion fatigue (Kapoulitsas and Corcoran, 2015; Zimmering et al, 2003). The knowledge and skills framework (NHS Education for Scotland, 2017) addresses these risks and promotes the importance of a robust support network, clinical supervision and good self-care to help minimise the impact of working with trauma.

# Chapter 2: Review of the literature exploring the link between adverse childhood experiences and the development of an eating disorder

#### 2.1 Introduction

The purpose of this review is to examine the literature regarding the interaction between adverse childhood experiences and the onset of eating disorder behaviours. A greater understanding of the role that psychological trauma plays in eating disorder patients will help to inform future service provision. This is of particular significance as the principles of trauma-informed care are starting to be adopted across more areas of service provision. A narrative approach was adopted for the literature search and reporting of the findings which offered a broad perspective on the research matter. This chapter outlines the search terms and methods used and gives an overview of the findings. The adverse childhood events are grouped into themes of psychological trauma, including physical abuse or neglect, emotional abuse or neglect, or sexual abuse. Eating disorders included anorexia nervosa, bulimia nervosa, binge eating disorder, and eating disorders not otherwise specified.

### 2.2 Method

The aim of the literature search was to identify articles related to adverse childhood experiences and the relationship this has with the development of an eating disorder to inform the conduct and focus of this study. The reason for keeping the search term to ACEs, rather than including broader search terms relating to psychological trauma, was to explore whether specific eating disorder diagnoses or behaviours had been included in the ACE studies using the original ACE categories. Four electronic databases were searched in September 2017: CINAHL, PsychInfo, PsychArticles and Medline as these were the most relevant to the subject area as they included articles from life science journals. Searches were made from the inception of the database, rather than limiting dates, in order to capture as wide a field of data as possible. An additional search of Google Scholar and the Cochrane Central Register of Controlled Trials was also undertaken. In order to identify relevant papers the following search terms were used: (i) eating AND disorder\*or dysregulate\*, (ii) bulimi\* or anorexi\*; (iii) adverse AND childhood AND experiences, and (iv) ace OR aces. Combining (i) and (ii) with (iii) and (iv)

resulted in 87 studies, 68 of which were original peer reviewed articles in English, see below for detailed steps taken and inclusion and exclusion criteria used:

```
S1 = eating AND disorder* (57,084)

S2 = bulimi* OR anorexi* (34,652)

S3 = S1 OR S2 (58,902)

S4 = adverse AND childhood AND experiences (4,016)

S5 = ace OR aces (8,601)

S6 = S4 OR S5 (11,980)

S7 = S3 AND S6 (87)

S8 = peer reviewed, English, original studies (duplicates removed) (62)

S9 = removed those with no focus on link with ACE and ED (including obesity studies with no reference to ED behaviours) (14)

Two further papers included (Total included studies: 16)

(S = search)
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<u>Inclusion criteria:</u> (i) studies which explore the link between psychological trauma and eating disorder symptoms (eating disorder recognised by ICD10 or DSMIV, to include anorexia nervosa, bulimia nervosa, binge eating disorder or EDNOS – eating disorder not otherwise specified), (ii) observational studies, case control, cohort studies and case series designs, systematic reviews, (iii) peer reviewed articles, (iv) published in English.

Exclusion criteria: (i) studies focusing on obesity with no clear eating disorder diagnosis or behaviours, (ii) not examining the link between trauma and ED, (iii) case study designs, (iv) non peer reviewed articles, (v) not published in English, (vi) duplicates.

A snowballing exercise was used to identify further relevant papers which is a process of gathering further literature through identifying citations in selected research papers. This complete process resulted in 16 papers for review in the initial search (September 2017). This original search has been illustrated (appendix 1) using the PRISMA guidance (Moher et al, 2009). The search was then re-run on the same databases with the same inclusion and exclusion criteria in October 2021, when the thesis was almost complete. This was to ensure that all relevant work was captured and a further six papers were retrieved. The narrative review presented below summarises all 22 papers retrieved via this process.

### 2.3 Search results

The majority of the research was cross-sectional in design and each paper was screened to ensure there was a clear statement of aims and that the methodology used was appropriate to the research. Further questions regarding the research design, recruitment strategy, data collection, role of the researcher, ethical issues, rigour, statement of findings and overall value of the research have then helped to appraise each article. A summary of the sample, main findings and limitations of each study was noted in a matrix to aid comparison (see Appendix 2). The literature search revealed there is a lack of research directly relating to ACE and the onset of eating disorders. There are many ACE studies citing links between ACEs and the development of obesity. Obesity is not an identified eating disorder, unless the cause for the high BMI is explicitly related to binge eating (Bentley et al, 2009; Rohde et al, 2008; Williamson et al, 2002). However, the search did identify additional papers, not within the realms of the original ACE study, which included some of the trauma components of ACE without the use of the ACE questionnaire, such as: childhood sexual, physical, and emotional abuse, as well as neglect, and their links to eating disorders.

### 2.4 Findings

All of the studies explored the relationship between complex trauma experiences during childhood and the future development of disordered eating behaviours, but only five of these studies included the ACE as a means of exploring childhood traumatic experiences (Afifi et al, 2017; Coffino et al, 2020; Fairburn et al, 1998; Forrest et al, 2021; Speranza et al, 2003). The other 17 studies explored various forms of childhood trauma and these could be grouped broadly into the following categories: childhood sexual abuse (CSA), childhood physical abuse (CPA), childhood emotional abuse (CEA), childhood physical neglect (CPN) and childhood emotional neglect (CEN). Within these categories, much of the literature in these remaining 13 papers focus on childhood sexual abuse. All of the studies relied on collecting data from adults regarding adverse childhood experiences, through the retrospective recording of the psychological trauma. This can give rise to recall bias and also fails to identify very early traumas which occurred in the first years of life, prior to language development.

Many of the studies recruited only women (Fairburn et al, 1998; Hodson et al, 2006; Lejonclou et al, 2014; Moulton et al, 2015; Romans et al, 2001; Speranza et al, 2003; Oppenheimer et al, 1985) and this may reflect that men make up a much smaller proportion of the eating disorder

population. It is estimated that men represent 25% of individuals with anorexia nervosa and bulimia nervosa, and 36% of those with binge eating disorder, with even smaller percentages of men presenting for treatment (Hudson, 2007). The proportion of men in clinical samples who present for treatment, quoted by NICE guidelines (2004) is 10%, and across the UK, it is estimated men represent 20% of the 1.6 million with an eating disorder (Sweeting et al, 2014). Within this review, of the thirteen studies that did recruit men (Afifi et al, 2017; Coffino et al, 2020; Forrest et al, 2021; Fuemmeler et al, 2009; Gupta et al, 1995; Hazzard et al, 2021; Isohookana et al, 2016; Kinzl et al, 1997; Minnich and Gordon, 2017; Mitchell et al, 2005; Pugh et al, 2018; Thornley et al, 2016; Palmisano et al, 2018), several published results that were not comparable with the other studies using only women, which highlights the importance of including men in eating disorder research.

Also, most of these studies only recruited adults in their sample, with only a couple of studies focussing on a child or adolescent ED population (Isohookana et al, 2016; Hodson et al, 2006). An understanding of the role that psychological trauma and PTSD play in childhood ED presentations and recovery would be helpful as it is recognised that early intervention in EDs is crucial to recovery rates and the longer-term prognosis (Treasure et al, 2011). However, gaining information on childhood trauma during childhood maybe more problematic, especially when using self-report measures which may rely on reading ability. There is likely to be a reluctance to share details of abuse whilst it is happening, or even an inability to describe it and there are specific guidelines in place for assessing for PTSD in children and adolescents (National Collaborating Centre for Mental Health (UK), 2005).

### 2.4.1 Gender and psychological trauma in eating disorders

The largest studies evaluated in this review utilised data extracted from the National Epidemiologic Survey on Alcohol and Related Conditions, wave 3 (NESARC-III) in the USA, with a sample size of 36,145, nationally representative, including both genders (Afifi et al, 2017; Coffino et al, 2020; Forrest et al, 2021). Within this data, the prevalence rates for the presence of ACEs in those who met the criteria for an ED diagnosis was 60.2%, as assessed through the use of the NIAAA Alcohol Use Disorder and Associated Disabilities Interview Schedule-5 (AUDADIS-5; Grant et al., 2015) (Forrest, 2020). Afifi et al (2017) used this data from the NESARC-III to explore the prevalence rates of EDs in this sample and how ED correlates with ACEs. They found a higher lifetime prevalence of EDs in women, at 2.7%, in comparison to

men, who had a 0.8% lifetime prevalence rate. The strongest links with ED were CSA and CPA among the male sample, and CSA and CEA among the female group. This link to ED in men who have experienced CPA was also found in the Mitchell et al (2005) paper. They recruited only men (non-clinical sample in USA) and found that CPA and CPN had significant correlations with ED symptomology. It also highlighted that the presence of PTSD was associated with this link between trauma and ED, rather than exposure to the trauma alone, which could indicate that certain individuals with lower levels of resilience, who develop PTSD, may also be more vulnerable to developing an ED. This was a cross-sectional study with a sample size of 168 and they acknowledge that causation of the ED cannot be inferred from this. CPA appears to feature in much of the reviewed literature researching trauma in men with ED. There is no evidence to suggest men experience greater incidence of CPA than women, with estimated rates for boys at 2.1 per 1000 and for girls at 2.2 per 1000 (Child Maltreatment, 2000). However, CSA has been found to be more prevalent in women, estimated to be around 2-3 times higher than in men (Finkelhor et al, 2014).

The link between CPA in men and ED symptoms was also identified in male university students in Austria (Kinzl et al, 1997). They found that severe CPA, in comparison to moderate or no CPA resulted in higher scoring on the EDI (eating disorder inventory, Garner et al, 1983), which is a measure of the severity of an eating disorder. CSA had no measurable impact on these EDI scores in men, which differs from the female samples in this review, which highlights the complexity of the ED aetiology and the need for further understanding in this area. The data was collected by self-completed, anonymous questionnaires and there was a return rate of 67%. There were also confounding factors that may need to be considered. An adverse family background, in comparison to a positive family atmosphere, also contributed to higher EDI scoring. A stable family environment and supportive relationships are both external factors associated with resilience building when faced with adverse experiences (Cairns et al, 1994).

Isohookana et al (2016) found that ACEs were not associated with BMI in adolescent men, whereas adolescent women who had experienced CSA or parental unemployment were often either obese or engaging in extreme weight-loss behaviours. These adolescent women were five times more likely to be engaging in compulsive exercise to drive down their weight, than those without any ACEs. This was a large study including 449 adolescent inpatients in Finland. This may not be representative of the ED population as a whole, as inpatient admissions are generally reserved for those presenting with the greatest clinical risks and often with comorbidities. One of the explanations offered for this gender difference is the prevalence and

type of co-morbid psychiatric diagnosis present, and the tendency for boys to develop more disruptive psychiatric disorders during adolescence (Herpertz-Dahlmann et al, 2013), affording an outlet for expressing or regulating their emotion. Eaton et al (2012) also suggest that boys are more likely to develop externalising disorders, whereas girls are more likely to develop internalising disorders (with ED being an example of an internalising disorder). This corresponds with Cavanaugh et al's (2015) findings that multiple ACEs were associated with fewer mental and substance misuse disorders in men, apart from alcohol misuse.

Fuemmeler et al (2009) also explored the gender differences in those with a history of CSA, drawing data from a large-scale longitudinal study on adolescent health in the USA. They found that there were higher rates of obesity in males then females in this adolescent group and a significantly higher proportion of ED behaviours in the females. They presume this is due to greater societal pressures on women and girls regarding body image, which drives restricting and purging behaviours, which are seen less in men (Abebe et al, 2012; Streigel-Moore et al, 2009). However, all of the data was collected via self-report measures, which may not capture information accurately due to feelings of shame in acknowledging some of these dysfunctional behaviours. It's also possible that men cope with having experienced trauma or PTSD in a different way to women, developing other means to manage these unwanted emotions, such as sensation seeking behaviours, which may be reflected in the higher rates of delinquency in adolescent men (Zuckerman, 2007). A further example of this would be the higher levels of dissociation. Dissociation can be described as a disruption to the functions of consciousness, memory, identity or perception of the environment, which are normally integrated (Holmes et al, 2005). Thornley et al (2016) found dissociation was linked to EDs in the men in their study.

Body image across the genders was also explored in a small non-clinical sample by Gupta et al (1995). They surveyed 173 shoppers and found a direct correlation between a perceived deprivation of physical contact and tactile nurturing during childhood and a drive for thinness, but only in the women surveyed. They suggest this may indicate that the female development of body image is related to a perceived deprivation of tactile nurturing. This was a small sample which again relied on self-report measures, increasing the risk of bias. Body image in men has been explored in other studies and there has been a shift in opinion over time, with an initial belief that women were more susceptible to socio-cultural norms regarding physical appearance (Fredrickson and Roberts, 1997). More recent studies have found high levels of body dissatisfaction in men (Mellor et al, 2010). The drive for muscularity was present in both

men and women who had experienced CPN and CEN and was mediated by alexithymia, but binge eating was only present in the women in the study (Minnich and Gordon, 2017). Despite this being a large study, this was a non-clinical sample including subclinical symptomology.

Thornley et al (2016) also found gender differences within their study, with both ED and PTSD symptoms less prevalent in the male group. This was a large online study which recruited 519 North Americans. They found a difference in the reporting of the trauma histories across the genders, with women experiencing more sexual traumas and men reporting greater violent trauma. The specific type of life events which have been experienced may well then impact on the development of the individual's personality and the associated emotional and behavioural responses. Despite ED behaviours and PTSD symptoms being higher in the female group, complex trauma and PTSD were still identified as risk factors for the development of EDs in both sexes. Individuals when asked, also believed the ED and trauma to be causally linked. However, financial incentives were offered for participating in the study which may have had an impact on the diversity of the sample.

### 2.4.2 Trauma history, ED diagnosis and co-morbidity

A variety of ED diagnoses were explored within the studies, but bulimia nervosa was the most frequently cited, possibly due to the overlap between bulimia nervosa and borderline personality disorder (BPD) which is closely associated with adverse childhood experiences, so much so that BPD and the term 'complex trauma' are often used interchangeably (Kulkami, 2017). Fairburn (2005) has suggested that all eating disorder psychopathology can be linked to one of three personality subtypes: under-controlled, over-controlled, and low psychopathology. Tight inhibitory control is associated with a variety of psychiatric disorders (e.g., obsessive compulsive personality disorder, avoidant personality disorder and anorexia nervosa) and is notoriously difficult to treat, given the rigidity of these individuals personalities and their risk-averse nature (Lynch, 2008). Bulimia nervosa and binge eating disorder can be considered features of under-control and are typically a characteristic of emotionally unstable personality disorder (Johnson et al, 1990). Lack of impulse control can manifest itself in many behaviours and is evident in bulimia nervosa as binge eating and purging behaviours.

The link between trauma, ED and BPD was also discussed in the Speranza et al (2003) study. They found participants had higher ACEs in bulimia nervosa than anorexia nervosa patients and also higher levels across both ED diagnoses for self-criticism and dependency traits,

compared to controls. Both the anorexia nervosa and bulimia nervosa group scored higher on the BDI (Beck Depression Inventory; McDowell, 2002), compared to the control group, although self-critical depression was only a feature of the bulimia nervosa group. They suggest this is related to difficulties regulating self-esteem and disturbance in identity, often seen in BPD (Zanarini, 1998). Although this was a relatively large study with 150 ED patients and 236 matched controls, the study excluded those with major depressive symptoms. This potentially overlooked a cluster of individuals who are likely to have experienced higher than average levels of trauma, as childhood trauma is also a widely accepted determinant of major depression (Hill, 2009).

This observation of ACEs being linked to under-control or greater levels of impulsivity was also evident in a meta-analysis exploring childhood maltreatment and ED pathology (Molendijk, 2017). The strongest association between ED and childhood trauma was found in the bulimia nervosa, binge eating disorder, and anorexia nervosa (binge-purge sub-type) patient groups, and less so in anorexia nervosa (restrictive subtype) group. Binge eating disorder is now recognised as a diagnosis in its own right under DSM-V (2013) but would previously have been classed as either an atypical form of bulimia nervosa, or EDNOS (eating disorder not otherwise specified) (World Health Organisation, 2003). Binge eating disorder was studied by Fairburn (1998) who found two separate determinants for the onset of binge eating disorder: (i) those factors that are associated with a general risk of developing a psychiatric disorder (including: negative self-evaluation; parental depression) and (ii) those factors that increase the risk of obesity. Vulnerability to obesity and being overweight as a child distinguished this binge eating disorder group from the bulimia nervosa group.

Despite the overlap in pathology between bulimia nervosa and BPD, the two disorders are not universally linked. BPD co-morbidity was found to be irrelevant in the severity of ED symptoms in bulimia nervosa patients attending a specialist ED outpatient service in the USA (Steiger et al, 1996). CSA and CPA were commonly seen in those with co-morbid BPD and other PDs and there was a weak correlation between CPA and the frequency of binge eating. Trauma was rarely seen in those without co-morbid PDs, which may suggest that bulimia nervosa can be divided into two sub-categories of co-morbid BPD being present, or not. However, this was a small study including only 61 participants, and there was a narrow trauma focus of CSA, CPA, and parental bonding. Although there is an established link with complex trauma and bulimia nervosa, and bulimia nervosa being the dominant ED diagnosis in the literature regarding trauma, many studies have failed to distinguish any pattern between

traumatic histories and the specific ED diagnosis. Anorexia nervosa and bulimia nervosa have both been associated with invalidation and childhood trauma (Mountford et al, 2007), and Oppenheimer (1985) found there was no correlation between CSA and the type of ED that later developed in their study. This was a small UK study of only 78 women. It also extended the criteria of CSA to include sexual abuse that happened outside of childhood, which dilutes the focus on childhood trauma.

CSA and CPA were not found to be associated with binge eating disorder in the case control study by Palmisano (2018). Binge eating disorder was found to be associated with emotional abuse and neglect, compared to both the control groups of obese and healthy individuals, but this was a small study with only 34 binge eating disorder cases. Romans et al (2000) also found trauma histories prevalent across both anorexia nervosa and bulimia nervosa diagnoses. They examined CSA in a non-clinical community sample in New Zealand and found significant incidence of this amongst individuals who had an ED diagnosis. They also explored comorbidities across the anorexia nervosa and bulimia nervosa groups, with and without a CSA history. They found higher rates of major depression and suicide attempts in the bulimia nervosa group with a CSA history and high levels of anxiety disorders and obsessional traits in anorexia nervosa. Substance misuse figures did not differ between the anorexia nervosa / bulimia nervosa / no ED group amongst those who had experienced CSA. Paternal overcontrol was related to the onset of EDs in those who had experienced CSA, and low maternal care was found to increase the risk of bulimia nervosa. A further risk factor for bulimia nervosa was an early age of menarche. However, some argue that the age of onset of menarche is related to BMI (body mass index) (Mumby et al, 2011). Therefore, girls who are engaging in binge eating behaviours during childhood, may be of a higher weight which could prompt the onset of puberty. This has been acknowledged by Heatherton and Polivy (1990) who suggested early puberty which is linked to an increase in body fat and changes in body shape may provoke dieting behaviours, which is a known risk factor in the development of eating disorders.

Adverse childhood events were also studied alongside other potentially traumatising life events, grouped into three categories: (i) interpersonal events, (ii) non-interpersonal events, and (iii) adverse childhood circumstances (Lejonclou et al, 2014). This study compared a clinical sample (including 50 women in an outpatient eating disorder service diagnosed with anorexia nervosa, bulimia nervosa or EDNOS) against a non-clinical group of 245 girls, recruited from two high schools in Sweden with different socioeconomic profiles. There was

higher reporting of multiple childhood traumas in the clinical group, but it should be noted that the mean age of the clinical group was 19.9, compared to 16.7 in the non-clinical group, which could indicate that the older group had had more opportunity for exposure to the traumatic life events. They also found greater numbers of interpersonal traumas (such as rape, violence, assault) in the clinical group than in the non-clinical group, as well as significantly more sexual traumas in the ED group. This was found in the bulimia nervosa, EDNOS and anorexia nervosa (purging subtype) EDs groups, with no significant differences across the diagnoses. They were surprised to find that the EDE-Q (eating disorder evaluation questionnaire) which measures ED symptoms was not scoring higher for greater traumas, indicating that the greater number of traumas did not have an impact on the severity of the ED, just on whether the ED was present or not. This may be due to the small sample size in the clinical group and a lack of statistical power.

The issue of childhood food neglect, as a specific aspect of CPN, was explored in the large survey conducted by Coffino et al (2020). They found lifetime prevalence rates for anorexia nervosa, bulimia nervosa and binge eating disorder were 2.8%, 0.6% and 3.5% in those with a history of childhood food neglect. By comparison, in those who denied food neglect, the respective prevalence rates were 0.8%, 0.3% and 0.8%. Adjustments were made to remove other confounding variables, including a history of other ACEs, and sociodemographic and financial difficulties, and the results suggested a threefold increase in the risk of developing anorexia nervosa or binge eating disorder following food neglect. They speculate that a lack of control over food intake during childhood may increase overcontrol of eating behaviours and lead to anorexia nervosa, or the impact of starvation may lead to binge episodes when food becomes more available. Starvation whether voluntary or involuntary is taxing both physiologically and psychologically and these effects are the same across genders (Tucker, 2007). The role of the GP, health visitor, social worker or school nurse is therefore important in helping to identify cases of failure to thrive (whether this be due to a lack of awareness of the child's needs, poverty, or chronic health problems affecting calorie absorption). Addressing these issues early may help to minimise associated issues, such as behavioural problems, developmental delays and an increased risk of developing an ED over time.

### 2.4.3 Dissociation, emotional dysregulation and resilience

Impulsive behaviours were noted earlier, and these are often seen as an attempt to regulate emotions, and emotional dysregulation is a prominent diagnostic category for borderline personality disorder (Zanarini, 2003). Affect dysregulation is strongly associated with early psychological trauma and attachment disorder (Schechter, 2009). However, whilst it can be assumed that affect dysregulation can cause ED behaviours in an attempt to regulate emotions, it should also be noted that ED behaviours themselves (such as dietary restraint or binge eating) could result in cognitive impairment, leading to emotional dysregulation, making it difficult to make causal inference. Cognitive impairments can be present across all eating disorders, due to the issues with selective attention bias, caused by pre-occupation with food, shape and weight (Von Wietersheim et al, 2012), but is most severe in anorexia nervosa as a result of inadequate nutrition and the resulting 'starvation syndrome' associated with this (Garner, 1997).

Hodson (2003) compared a group of 361 Latina women, exploring ED and substance misuse as outcomes of childhood trauma and family problems. They found bulimia nervosa was associated with dysphoria in those who had felt disconnected from their family and questioned whether bulimia nervosa behaviours had been used as a means to numb depressive and suicidal feelings. The sample was initially recruited to study teenage pregnancy and is limited as it only includes young Mexican women who were not pregnant but supports the literature suggesting bulimia nervosa behaviours are an attempt to emotionally regulate. As previously noted, the Thornley (2016) study suggests the men were using dissociation as a tool to deal with unwanted emotion. Dissociation is not a coping skill specific to men though. Moulton et al (2015) recruited 142 female undergraduate psychology students, exploring a variety of childhood traumas (with CSA being the most widely reported trauma with an incidence of 37.1%). They found CEA, CPA, CEN and CPN all to be significantly correlated with ED psychopathology, but no significant correlation in CSA. They found emotional dysregulation and dissociation both to be mediating factors between childhood trauma and ED.

Palmisano et al (2018) compared dissociative (including psychoform and somatoform) symptoms in binge eating disorder patients compared with two control groups of obese participants and healthy controls. The binge eating disorder group had significantly higher total scores for both psychoform and somatoform dissociation compared with both control groups, and there was an association with their binge eating disorder diagnosis and both CPN and CEN. This supports Moulton et al's (2015) study demonstrating the mediating effect of

dissociation in ED diagnoses and traumatic childhood experiences. The distinction between the binge eating disorder group and obese control group is an interesting finding and potentially reinforces the emotional dysregulation hypothesis mentioned above that suggests ED symptoms are a means to regulating emotions. However, this was a small study of 34 clinical cases and therefore does not allow for generalisation of the results, and traumatic events and symptoms were assessed through self-report measures. Dissociation was also found to be a potential mediating factor in the association between a strong internal eating disorder voice and a history of CEA (Pugh et al, 2018). The strength of the ED voice had direct correlation with ED pathology but did not have any correlation with BMI. This possibly reflects that the sample was made up of a mixed group of ED patients with various ED diagnoses, including, anorexia nervosa, bulimia nervosa, binge eating disorder and OSFED (Other Specified Feeding and Eating Disorders).

Difficulty regulating emotions increases psychological pain, which is one of the known drivers for suicidal ideation (Turton et al, 2021). The incidence of suicide attempts is particularly elevated within the ED population (Mandelli et al, 2019) and further breakdown of prevalence amongst ED diagnoses found rates of: 24.9% for anorexia nervosa, 15.7% for anorexia restrictive subtype, 44.1% for anorexia binge-purge subtype, 31.4% for bulimia nervosa, and 22.9% for binge eating disorder (Udo et al, 2019). Suicide attempts amongst those with a history of ACEs are also elevated, relative to those without ACEs (Dube et al, 2001). Forrest et al (2020) explored the link between ACEs and EDs in suicide attempts, using data from the NESARC-III survey. They found that suicide attempts amongst those with self-reported ACEs were higher in those with any ED diagnosis and all of the participants with bulimia nervosa who had a history of suicide attempts had also experienced at least one ACE. Despite this positive and significant association between self-reported ACEs and suicide attempts among people with EDs, they found self-reported ACEs did not appear to interact with EDs to predict even greater risk for suicide attempts. One theory they had for this unexpected finding was that some ACEs and not others interact with ED diagnoses to augment the risk of suicide.

Resilience is seen as a protective factor which helps an individual to adapt and continue to thrive after having experienced psychological trauma (Luther et al, 2000). Hazzard et al (2021) explored the role of self-compassion as a means to promote resilience and found self-compassion played a protective role in the relationship between ACEs and BMIs and disordered eating, with higher levels of self-compassion attenuating the link. This was a large study and also explored the link between ACEs and depressive symptoms and found self-

compassion also acted as a buffer against adverse mood, but less so than the role it played with BMIs and disordered eating. These findings support the work of Turk and Waller (2020) who conducted a meta-analysis and found that higher rates of self-compassion were associated with lower eating pathology and reduced body image concerns. This study omitted to measure emotional neglect, physical neglect, parental separation/divorce, and witnessing domestic violence amongst the ACES and therefore, it is possible that lower self-compassion may have been correlated with higher ACES which were not captured in this study.

### 2.5 Areas for development

The links demonstrated between trauma and ED suggest that ED therapists need to understand how to respond in the presence of trauma. Services need to be adopting trauma-informed approaches to accommodate these individuals in a way that seeks to avoid further traumatisation and helps to build resilience. A greater understanding of how trauma is routinely assessed for and treated within specialist ED services is also necessary. Formal screening for trauma would ensure it is not missed out of the formulation process and would help tailor the therapy accordingly. Specific models of care may have to be implemented to address these needs, such as the phase-based interventions model used in other specialist services (Herman, 1992), or the SAMHSA model for substance misuse (Substance Abuse and Mental Health Services Administration, 2011).

### 2.6 Conclusions

The literature summarised in this chapter indicates a well-established link between childhood trauma and ED symptomology, with much of the research focusing on CSA or CPA. There are few studies using the ACE questionnaire as a basis for evaluating trauma, which limits comprehension of the risk factors associated with particular trauma categories. Greater knowledge in this area would deepen our understanding of the aetiology of ED and how trauma interacts with personality and biological factors, contributing to the onset of the disorder. The strongest links with trauma were seen in the 'under-controlled' personality groups, which included bulimia nervosa, binge eating disorder, and anorexia nervosa (purging subtype), with co-morbidity a common feature. BPD was frequently co-morbidly diagnosed but was not present in all those with ED who had a trauma history. Mediating factors were

discussed which may have an impact on the trajectory of early psychological trauma and whether an ED later develops. The mediating factors included: emotional dysregulation, the presence of PTSD, major depression, and dissociative disorders.

Most of the literature found focuses on women with EDs: the little research that is available regarding men suggests that their ED pathology and trauma histories are different to those of women. More research is therefore required concerned with men with EDs, to explore why men are under-represented in ED treatment settings and their reluctance to seek help for their ED. There is also a dearth of literature regarding the development of EDs in children and adolescents with psychological trauma. The importance of early intervention when treating ED is widely acknowledged (Loeb et al, 2011), and this patient group may hold the key to understanding the rationale for early intervention and how complex trauma fits into this picture.

# Chapter 3: Methodological approaches to study design and study methods

### 3.1 Introduction

This chapter describes the methodological underpinnings of the study and the rationale for adopting a convergent mixed methods approach, including an appraisal of the research design and the methods used to justify the data gathering techniques, as well as the ethical considerations. The study comprised of four individual but interconnected phases which were designed to address each of the following research questions separately, whilst contributing knowledge to the other phases of the study.

- 1. How do experts in the field of psychological trauma define trauma-informed care and envision its implementation across mental health services?
- 2. How do patients with a history of complex trauma want to be treated within an ED outpatient service?
- 3. How prevalent is complex trauma in ED patients and does exposure to psychological trauma or symptoms of PTSD increase the severity of ED symptoms?
- 4. How do therapists working in an ED outpatient setting interpret trauma-informed care?

### 3.2 Methodological approach

A mixed method design was chosen to answer the research questions, this was a pragmatic approach to address the multifaceted subject being addressed. Mixed methods research provides a framework for combining quantitative and qualitative research methods and has become increasingly popular in social and behavioural science over the past couple of decades (Timans et al, 2019). Mixed methods research capitalises on the strengths of both quantitative and qualitative research methods, offsetting the major drawbacks that single method designs present (Teddlie and Tashakkori, 2009; Onwuegbuzie and Johnson, 2006). Some of the disadvantages of quantitative research include difficulty in understanding the complexity of the phenomenon being studied and the inaccessibility of potentially related secondary data (Carr, 1994). Qualitative research also presents its own shortcomings, with problems arising

through the generalising of results to other subjects and the risks of introducing bias due the researcher's personal beliefs when analysing the data (Johnson and Onwuegbuzie, 2004). Qualitative research is often complex, presenting challenges to how studies are planned and conducted, and furthermore, there can be insufficient rigour in the analysis and reporting of qualitative research (Berg and Lune 2017).

As there were multiple research questions within this study, all requiring different methodological approaches yet pertaining to the same overall research problem, a mixed methods approach was deemed to be the best fit to address the aims and objectives of this study. A phased approach was utilised: a qualitative approach was applied to phases one, two and four of the study, to answer the respective research questions which were exploratory in nature. Phase one of the study was a scoping exercise aiming to understand how experts in the field of psychological trauma perceive trauma-informed care and how they envisioned its implementation across mental health services. The second phase explored the subjective views of patients with a lived experience of complex trauma and the treatment pathways they had been offered and had engaged in the forming of therapeutic relationships and the ending of therapy. This was an opportunity to compare and contrast the experiences of patients with the ideals and visions of trauma-informed care as described by the experts in phase one.

The fourth phase of the study gathered the views of eating disorder therapists, exploring their opinions of how the concept of trauma-informed care should be adopted within eating disorder services in Scotland. Therapists were encouraged to reflect on their own interpretation of trauma-informed care and to outline the way the service they work within responds to patients presenting with complex psychological trauma. They were encouraged to highlight any adaptations within their individual service that had been made to accommodate a trauma-informed approach, and any potential barriers to this. These views aimed to provide a benchmark for the gap between the theory of trauma-informed care, as described by the experts in phase one, alongside the experiences of service users, and the actual practice being delivered by professionals in eating disorder services within Scotland. This was not intended to be an empirical measure that could be generalised across all eating disorder services in Scotland, but rather an exploration of any common themes which could become potential areas for service development when planning a trauma-informed service.

A quantitative approach was adopted for phase three of the study which involved surveying the patient group accessing specialist outpatient ED treatment, examining the prevalence of complex trauma histories and, within this group, the prevalence of PTSD symptoms. This allowed the recruitment of a larger sample size and collection of quantifiable data. The quantitative phase of this study was designed to offer contextual understanding of the impact of complex trauma on individuals who have been diagnosed with an eating disorder, highlighting the relevance of the qualitative results. The quantitative phase alone would not have provided data about how best to address the problem of complex trauma: it was designed to be an illustration of trauma and PTSD presentations in this population.

Other methodologies were considered, including interpretative phenomenological analysis (IPA)(Smith, 1996) and grounded theory (Glaser and Strauss, 1967). IPA may have offered an opportunity to explore in greater detail the lived experience of patients with a complex trauma history and the overlap with eating disorders. Equally, grounded theory may have allowed for a deeper exploration into perceptions of trauma-informed care. However, this study set out to understand the fuller picture of both the presentation of complex trauma in eating disorder patients and the perceptions of trauma-informed care from different perspectives. Neither IPA nor grounded theory would have been suitable to address the research questions. Mixed methods allowed for the inclusion of four phases to the study, combining both quantitative and qualitative methods, aiming to give a greater comprehension of the research problem and therefore a completeness to the view of trauma-informed care from many perspectives. IPA and grounded theory are both very time-consuming methodologies that would not have been compatible with a mixed methods approach because they would have taken too long to do alongside the quantitative phase, so this was also a pragmatic decision based on the fact that this was a study undertaken by a sole researcher not a wider team.

The four phases allow for triangulation of the findings and corroboration across the results, increasing the validity of the study. It was anticipated that recruitment may be an issue for the quantitative phase of the study (based on personal experience of previous attempts to recruit from this patient group for other researchers and the poor response rate to patient satisfaction questionnaires within this same patient group) so including the additional three qualitative phases to the study was an attempt to offset any problems encountered in this phase. Given the overarching aim of the study was to guide service development, the usefulness of the findings was a crucial consideration in the design phase and why all four phases were deemed necessary to achieve a rounded view of the problem and why a mixed method approach was selected.

#### 3.2.2 Mixed methods research

Many authors in the field of health and social research now view mixed methods research as a third methodology; a distinct, coherent approach in its own right, rather than merely a tool to triangulate results (Greene 2008, Tashakorri and Teddlie 2011, Johnson et al, 2007, Creswell, 2013, Taylor and Francis, 2013). Creswell and Clark (2011) identify five historical stages in the development of the mixed methods approach that has led it to be recognised as a credible research method which has become embedded in health and social sciences. According to these authors, the formative period began with researchers using a combination of quantitative methods in an attempt to triangulate or improve the validity of psychological scales. This was followed by a paradigm shift in the 1980s with researchers testing the feasibility of combining both quantitative and qualitative methods and analysing data from different philosophical stand points. This second stage involved researchers using both quantitative and qualitative data within a single research study. From here, focus was brought to the procedures for developing specific methods of data collection and data analysis for mixed methods research, this third stage they labelled as the "procedural development period". The fourth stage involved the emergence of a conference exclusively pertaining to mixed methods research, the launch of a dedicated journal, and the first publication of Tashakkori and Teddlie's (2003) mixed methods handbook. This symbolised the watershed of mixed methods research being placed firmly on the map. The final fifth stage has been described as the reflective period; a stage of learning, reflection and discussions debating the scientific positioning of mixed methods research.

This evolutionary process suggests that mixed methods research began only a few decades ago, whereas Maxwell (2016) argues that the history of mixed methods in the texts largely ignores studies which have been using a combination of methods without using the label "mixed methods". He argues that mixed methods research could pre-date the use of quantitative and qualitative terminology and this may distort the origins of mixed methods research. Platt (1996) suggests these "origin myths" have been created by self-identified mixed methods researchers for their own advantage. Coining the term "mixed methods research" positions these researchers as pioneers in their field, whereas Platt (1996) argues they were merely labelling an already established method. Regardless of this lack of clarity over where mixed methods research derives, it is now a firmly established research methodology. Mixed methods research has a robust scientific backing which is well placed for

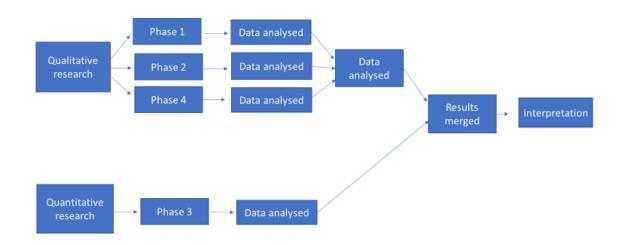
research in the field of health and social care and there is now a wealth of literature to support researchers designing studies in these areas.

## 3.2.3 Convergent parallel design

When designing a mixed methods study, the primary consideration should be whether the approach will be fixed or emergent. Fixed mixed methods designs are predetermined at the start of the study, whereas an emergent approach would allow the methodology to change in response to conducting the research (Creswell and Plano Clark, 2017). This was a fixed mixed methods approach and various typologies within this were considered at the design stage. Equal priority was given to the quantitative and qualitative phases and there was no importance of timing or order given to data collection as no phase of the study was dependent on the completion of another phase, therefore making this a concurrent design. The point of interface of the quantitative and qualitative phases is a further important consideration. The integration occurred at the point of interpretation of the results, allowing for comparison and inference of the findings across the different phases of the study. This type of design is referred to as a convergent parallel design and is a well-established, commonly used approach in mixed methods research (Creswell and Creswell, 2018).

Morse and Niehaus (2009) define the purpose of a convergent mixed methods design as being "to obtain different but complementary data on the same topic". The convergent mixed methods design is tendered as a simple and time efficient method of undertaking research as it allows for concurrent data collection (Creswell and Plano Clark, 2017). However, differing sampling strategies, sample sizes and capturing different perspectives can complicate its application (Cresswell, 2009). The research questions need to be designed to complement each other and to offer matching concepts so that when the data is analysed, comparisons can be made. One of the major risks of a convergent design is dealing with unexpected contradictions in the findings, making further data collection and new areas for analysis necessary (Creswell and Plato, 2017). The diagram below illustrates the process of data collection, data analysis and the point of integration before interpretation of the results.

Figure 3.1. Convergent parallel mixed methods design diagram.



#### 3.2.4 Service user involvement

There is an increasing expectation in the UK that healthcare researchers will involve patients and the public in the design of research studies, expanding the relevance of the research and addressing the potential moral or ethical arguments (Denegri, 2015). Funding bodies often now make this an obligatory step in the research design and a condition of the funding (Crocker et al, 2017). In the early stages of the research design, the researcher consulted with a service-user group. This group had experience in co-producing an established part of the personality disorder service so were used to being able to articulate their views well. All of these service users had a lived experience of complex trauma. The researcher was keen to gather their views regarding the study design and to hear their opinions as to whether the study would be of potential value. They were invited to discuss any potential concerns regarding the researcher approaching the sensitive topic of trauma with the service users in the target population. The overarching research problem and specific research questions were presented, and the service user group suggested that a focus group be considered rather than interviews when exploring the experience and opinions of those with a trauma history and suggested the wording for the patient information and consent forms. They felt focus groups would be less intimidating than interviews for the participants and may help others in the group to share information.

NIHR (National Institute for Health Research, 2019) have created a handbook called "UK Standards for Public Involvement" to guide researchers when involving the public in research and a national advisory group was created to offer expertise and support to encourage the active involvement of service users and members of the public in NHS research. Six key standards are highlighted within the handbook: communication, governance, impact, working together, support and learning, and inclusive opportunities. These standards have evolved from the previous framework: "Public involvement in research: values and principles framework" (NIHR, 2015) which identified the following values and principles for public user involvement: respect, support, transparency, responsiveness, fairness of opportunity, and accountability. NIHR (2015) classified three approaches to service user involvement which can include either: consultation, collaboration and user controlled; or any combination of these three. This study adopted a consultation approach to service user involvement and the NIHR (2015) guidelines were used to plan for this meeting.

The service users were given a briefing of the presentation in advance and voted whether to invite the researcher along. The service users invited the researcher to attend at the end of one of their regular meetings at their venue which was at the service user's convenience. When discussing the relevance of the research topic, the service user group expressed strong support for the study and specifically their support of recruiting patients to phases two and three of the study. There was overwhelming agreement from the service user group that asking questions about trauma histories and clinical features of post-traumatic stress is a crucial part of the assessment process. Service users suggested some patients may find it hard to find the right time in their life or the right words to express these issues. They also suggested that gathering this information about trauma histories should help tailor the treatment package appropriately or to signpost those wanting to engage in trauma-focused therapy to the right service. This focus on individual experiences of being asked about trauma histories was therefore incorporated into the interview schedule for phase two of the study.

## 3.3 Study design: qualitative phases

Qualitative research is employed when a research question demands exploration through a manner of enquiry that develops knowledge through the lived experience of participants and the meanings they attach to their experiences (Gray, 2018). A qualitative approach was therefore taken to phase one, two and four of the study to hear the opinions of experts in

complex trauma, patients who have a lived experience of complex trauma, and therapists delivering treatment to outpatient eating disorder patients. A combination of individual interviews and focus groups were selected to collect the data, based on the specific phase of the study and the research question and population being targeted. Typically, qualitative data is collected by a means of interview, focus group or observation (Barrett and Twycross, 2018). The rationale for the methods of collecting the data in each phase is detailed below.

#### 3.3.1 Phase one

Phase one utilised individual semi-structured telephone interviews to gather the data. This method was chosen as it was an efficient manner of gathering the information, saving time and costs by avoiding travel for face-to-face interviews. A systematic review by Novick (2008) compared telephone interviews to face-to-face interviews and found that the quality of telephones interviews was comparable to face-to-face interviews, with the additional benefits of savings in costs and travel. It also enables the researcher to reach geographically dispersed participants. Semi-structured interviews offer the opportunity to follow up answers to uncover further descriptive data and allow the researcher the chance to "listen to what people have to say" (Krueger and Casey, 2000). Interviews were selected over other methods of collecting the data, such as focus groups, as the emphasis in this phase of the study was to gather the individual, in-depth specific viewpoints of the experts recruited to the study and a focus group environment may have influenced the content of the discussion and response to the questions due to any pressures to conform or fear of expressing an opinion that differs from that of the others. It would also have limited the depth of the questioning.

#### 3.3.2 Phase two

A focus group was suggested by the service user group as opposed to individual interviews as it was hoped that a group setting would feel a familiar supportive environment to collect data, given the participants experience of working in groups for skills training as part of their therapy. The focus group setting aimed to encourage participants to generate discussion amongst themselves to develop a greater depth of information with the researcher acting as a moderator or facilitator, encouraging discussion between the participants, rather than a discussion directly with the interviewer (Plummer, 2017). Krueger (1994) highlights the

importance of selecting a homogenous sample for focus groups to promote engagement and a willingness to fully participate in group discussions to generate useful data.

## 3.3.3 Phase four

Focus groups were chosen over individual interviews for phase four of the study. Primarily, the choice was driven by the expectation that a rich debate could take place amongst the participants to give insight into any conflicting views and individual interpretations of clinical guidelines or clinical decision making. It was anticipated that a focus group environment would give the participants confidence to share any perceived shortfalls between theory and practice. Conversely, the group environment could inhibit the disclosure of any personal anxieties around their team's clinical practice, individual knowledge deficits or the therapeutic environment. A further recognised limitation of focus groups is the risk of dominant individuals crowding out the opinions of more introverted participants, however, the moderator can mitigate this behaviour by actively encouraging the opinions of all participants (Onwuegbuzie, 2009). A further driver for selecting a focus group over individual interviews was the time constraints, given this was one phase of a multi-phase design. A focus group would grant access to higher numbers of participants in a short time frame and also limit travel for the researcher. Given the small pool of therapists to recruit from, a pilot study to test the interview schedule and format of the focus group in advance was not feasible. The researcher therefore accepted that some of the focus group time may be taken up with the clarification of terminology or rephrasing of questions.

## 3.4 Study design: quantitative phase

#### 3.4.1 Phase three

Quantitative research can fall into three categories of research: descriptive, correlational, or experimental (Stangor, 2011). Phase three of the study falls into the descriptive category as the aim was to define the characteristics and trends of a specific population and unlike experimental research, there was no manipulation of the variables, only observation and description. Typical methods of data collection in descriptive quantitative research include surveys, observation, and case study designs. For this third phase of the study, a cross-sectional survey was chosen to gather the data as the aim was to generate an illustration of

the prevalence of complex trauma and PTSD in eating disorder patients and the impact this has on their eating disorder symptomology. A survey was the most appropriate method to gather the necessary information to address the research question for this phase of the study, with the added benefits of it being simple to administer and allowing data to be collected quickly.

Much consideration was given to who was best to administer the survey across the different sites and a decision was made to involve the patient's therapists in this process to ensure adequate support to the participants, should they become distressed or have difficulty regulating their emotions as a result of discussing their trauma history. The therapist would be on hand to debrief them and to aid the patient to utilise skills to manage their emotions. As the questionnaires would be completed alongside the usual assessment process, any information about trauma that was revealed through the questionnaires could be included in the diagnostic formulation and this would lead to discussions around the treatment pathway and the usual support that a therapist would offer a patient when trauma is disclosed. All patients entering eating disorder treatment are routinely asked questions about traumatic life events during the assessment process by their individual therapists who are skilled at responding to emotional distress. The management of mood and distress is a key feature of eating disorder therapy and risk assessment is an ongoing and pivotal part of psychotherapy, so the questionnaires would not be introducing topics that would be alien to the therapist or participant.

## 3.5 Ethics

## 3.5.1 Ethical approval

Ethical approval was granted by the University of Stirling (see appendix 3 for approval letter) and permission was granted by NHS Highland, NHS Tayside, NHS Grampian and NHS Lothian Research and Development Departments for data collection to take place on these sites. The North of Scotland REC (research ethics committee) also requested that the study should be peer reviewed by an external reviewer. A senior colleague at The University of Edinburgh kindly agreed to undertake this and made several suggestions which were discussed amongst the supervisory team and incorporated into the study (see appendix 4).

#### 3.5.2 Phase one ethical issues

Telephone interviews were chosen over face-to-face interviews to offer greater flexibility and to be more convenient, reducing the burden of intrusion and inconvenience to the participants. Confidentiality has been maintained by ensuring the names and place of work have not been included on any presentations, reports, or publications. All hard copies of data were stored in a locked filing cabinet in the researcher's locked NHS office. Electronic data was stored on The University of Stirling Box storage which is encrypted and password secure (data storage was the same for all phases of the study).

## 3.5.3 Phase two ethical issues

Phase two involved recruiting patients from the Personality Disorder Service to a focus group to discuss their experiences of treatment and their visions for service development. The questions focused solely on their treatment experiences and their views of service provision, rather than any focus on individual trauma histories. This group was chosen specifically as the participants had completed treatment and were in recovery. This was to ensure greater resilience and a reduced vulnerability to emotional distress than those patients actively undergoing therapy. Should participants have become distressed as a result of the focus group they had the opportunity to access support from the therapists in the day service immediately after the focus group. These therapists have specialist skills in teaching distress tolerance and emotional regulation tools and are highly experienced in assessing and managing risk. The researcher was mindful of the risk of participants over-sharing details of their trauma within the focus group and the need to manage this safely without invalidating the individual or shutting down the opening to relevant data. Careful consideration was given to the wording of questions to avoid participants needing to frame their answers around their trauma experiences.

If a participant were to divulge sensitive information, there was a plan in place for the researcher to validate the participant and move the conversation back to the focus on treatment. Even if the participant themselves felt safe to share the information, there is a risk of the details triggering other participants. "Triggering" is a term used for the recall of a traumatic memory which is paired to a psychological stimulus and can evoke strong emotional reactions and physical sensations in response to the autonomic branch of the sympathetic nervous system being activated (Foa et al, 2008). Both the researcher and independent

observer were alert to signs of elevated stress and had discussed this prior to the group commencing. The observer agreed to support anyone in distress during the focus group and the researcher discussed with the observer the need to be monitoring body language for signs of increasing discomfort and to check there was active participation from all group members to spot signs of dissociation early. Patients with complex trauma often experience dissociation when exposed to high levels of distress and this is a common coping mechanism for those who have experienced childhood trauma (Vonderlin et al, 2018).

Participants had the option to leave the focus group at any point if they became upset. A plan was also in place to pause the discussion and stop the audio recording if a participant became upset and the observer could allow them some time out of the room with the invitation to rejoin if they chose to. All participants were required to sign a non-disclosure statement as part of consenting to the study to ensure that the confidentiality of group members was maintained. Care was taken when recruiting patients at the site of the researcher's place of work to not involve any patients currently in receipt of therapy from the researcher. No identifiable information was collected from the participants and the names of participants were removed during transcription.

#### 3.5.4 Phase three ethical issues

Phase three of the study involved recruiting a potentially vulnerable group of patients presenting for assessment of an eating disorder. The study involved asking participants about a history of trauma and it was recognised that these questions may lead to an increase in emotional distress. However, all patients entering eating disorder treatment are routinely asked questions about traumatic life events during the assessment process by their individual therapists who are skilled at responding to emotional distress. The management of mood and distress is a key feature of eating disorder therapy and risk assessment is an ongoing and pivotal part of psychotherapy. Should there be a concern that a patient is at risk of suicide or significant self-harm, the usual protocols for responding to this would be followed involving the wider care team. Alongside the usual assessment tools, two additional questionnaires (ACE and IES-r) exploring adverse childhood experiences and screening for the presence of PTSD were included. This was not felt to be excessively burdensome for therapists as it was expected to take up to 10 to 15 minutes extra within a session so should not have caused any significant disruption to treatment. Additionally, the information gathered on these forms

could aid the therapist and patient to formulate a greater understanding of the development of the eating disorder.

Therapists were not directly involved in recruiting patients to the study to avoid any impact this may have on the therapeutic relationship or to make patients feel coerced into taking part. Instead, the administrator at each site was responsible for disseminating participant information sheets to those who attended for assessment and invited them to take part. Participants were asked to give written consent and were informed they could opt out if they did not wish to continue. It was made clear that their treatment would not be affected whether they chose to participate or not. Patients who were sectioned under the Mental Health Act or who were deemed to lack capacity (due to severely impaired decision-making abilities, as determined by a medical practitioner) were not to be included in the study. All of the data that was collated was transferred by the therapist to a data collection sheet to be handed back to the researcher. This ensured that no identifiable information was recorded as part of the study, other than email addresses (only if participants had requested a copy of the findings).

## 3.5.5 Phase four ethical issues

The participants were asked to suggest a venue that suited them best to minimise disruption to their working routine and the service provision. There was a risk of participants disclosing shortfalls in practice or decision making. However, the likelihood of serious malpractice being disclosed was deemed to be minimal as the participants would all be known to each other as part of the managed clinical network for eating disorders and all participants work within multi-disciplinary teams with close clinical supervision. Participants were required to sign a non-disclosure statement as part of consenting to the study to ensure that the confidentiality of all participants was maintained. The job title and work base of each participant was removed during transcription to ensure confidentiality.

## 3.6 Potential benefits to participants

As highlighted by the comments from the service user group (all of whom had a history of complex trauma), there was overwhelming agreement that asking questions about trauma histories and features of post-traumatic stress is a crucial part of the assessment process.

Service users suggested some patients may find it hard to find the right time or the right words to express these issues. Gathering this information about trauma histories should help tailor future treatment packages appropriately or to signpost those wanting to engage in traumafocused therapy to the right service. The participant information sheet clarifies that the participation in the study will not impact directly on the current treatment the patient receives, but it indicates that they will be playing a role in helping to shape treatment services for the future. It is anticipated that this research will contribute to the development of future policies and care pathways. The service user group for the personality disorder (PD) service has co-produced policies, pathways, and teaching material with clinicians in the PD service. This is a model which could be replicated in eating disorder services once the data has been collected regarding the areas for service improvement.

## 3.7 Reflexivity

As discussed in the introduction chapter, the researcher is a doctorate student with a clinical role as a Cognitive Behavioural Psychotherapist and, having had experience of working with patients with complex trauma and delivering treatment for PTSD, this creates a position where objectivity from the subject matter is not possible. Reflexivity in qualitative research can be described as the researcher's awareness of their subjectivity and individual bias and how this can impact on the whole research process (Finlay and Gough, 2008). Reflexivity is suggested to be a good way to support qualitative researchers to increase rigour and enhance the quality and trustworthiness of work (Teh and Lek, 2018). Berger (2015) suggests there are three positions a researcher can hold in regard to reflexivity: i) that of an insider, sharing the opinions and beliefs of the participants; ii) a situation where the researcher moves from a position of outsider to that of an insider throughout the course of the study; and iii) the outsider, where the researcher has no experience or familiarity of the matter being studied. The researcher in this study positioned herself as an insider, having an awareness of the treatment approaches on offer, familiarity with common terminology, and having been involved with service developments in the fields of ED and trauma. This insider position arguably influences many dimensions of the research process, impacting on all phases of the study and thus introduces both advantages and disadvantages which are now discussed.

It is possible that the relationship with other therapists across the MCN may have aided with recruitment for phases three and four of the study as most colleagues would be keen to

support insider research. Attempts to recruit patients to phase three from sites where the researcher was not known failed, possibly due to gatekeeping issues and not having the relationship capital noted above. Semi-structured questions were used in the interviews and focus groups and the fluidity and direction of the questioning will have been influenced to some extent by the researcher's own knowledge base. Additionally, there was a risk of response bias, particularly in phase four of the research as colleagues across the MCN may have attempted to give the "correct" responses. Introducing an outsider to conduct these interviews and focus groups may have mitigated bias here but this was not feasible within the realms of this doctoral study. The data analysis stage of the study required a great awareness from the researcher as to how her own knowledge may cloud her understanding of the responses from participants and honesty was crucial when interpreting the qualitative findings. Data analysis was a joint undertaking with the researcher's primary supervisor to enable an independent viewpoint as an outsider. The analysis was checked repeatedly in an attempt to diminish the risks of bias.

## 3.8 Conclusion

To summarise, a convergent mixed methods approach was used due to the multifaceted subject to be addressed, and the multiple research questions within this study. A qualitative approach was used for phases one, two and four of the study, allowing for comparisons of opinion between the experts, service users and therapists. A quantitative approach was employed for phase three, surveying the patient group accessing specialist outpatient ED treatment. These four phases allowed for the triangulation of results, increasing validity. The researcher positioned herself as an insider and recognised the possible benefits this may bring to recruitment and data collection, and attempts to reduce bias during the data analysis were made by undertaking this process jointly to invite additional objectivity. The views of service users with a lived experience of complex trauma were sought at the outset of the study design to explore potential ethical issues and to discuss the best ways to gather the data from ED patients.

## **Chapter 4: Methods**

## 4.1 Introduction

This chapter describes the design of the research, justifying the choice of methods used to answer the individual research questions. The research methods include a combination of semi-structured interviews, focus groups and a survey. Each phase of the study is presented individually, detailing the population and sampling, recruitment process, the process of data collection, and data analysis approaches. The ethical considerations are also discussed.

## 4.2 Qualitative: phase one

## 4.2.1 Data Collection

Phase one utilised individual one-to-one interviews to address the research question: "How do experts in the field of psychological trauma define trauma-informed care and envision its implementation across mental health services?". Semi-structured brief telephone interviews of up to 60 mins were conducted with participants at a mutually agreed time. The interviews were audio recorded with consent and transcribed verbatim by the researcher. A brief interview schedule was devised in advance (see appendix 5) to guide the discussion and to ensure the interview remained relevant to the research question. The questions used as a guide were:

- 1. How are eating disorder services across Scotland responding to psychological trauma?
- 2. Are there any new developments happening locally, nationally, or internationally regarding the integration of trauma-informed care into eating disorder services that you are aware of?
- 3. Have you any examples of good practice regarding trauma-informed care?
- 4. Where do you see trauma specific treatment (e.g. Prolonged exposure, Eye Movement Desensitization and Reprocessing (EMDR)) sitting in ED services (should this be offered internally or externally)?
- 5. Do you know of any other experts in this field?

When developing the interview schedule, only a small number of interview questions were included, to allow for in-depth answers and for additional material to be offered. A 'dry run' of the interview questions was undertaken within supervision prior to commencing this phase and some recommendations on pacing and the use of additional prompts for further probing were suggested. The questions were open-ended to encourage wider discussion and within the interview, participants were encouraged to expand and elaborate their answers to clarify any ambiguous responses. Reflection was used to ensure their answers had been interpreted accurately. The final question was included as a snowballing exercise, as discussed later in the recruitment section. The researcher then read over the notes which had been taken and participants had the opportunity to correct anything which had been taken down inaccurately. The researcher advised how many interviews had been conducted and the aim of recruiting a total of six participants. A brief overview of the overall study was described, and the participants were reminded of the right to withdraw from the study should they choose. The data collection period ran from February 2017 to April 2017. Phase one was terminated at this point due to the timing of the NHS Education for Scotland 'Transforming Psychological Trauma' framework (NES, 2017) and the desire to complete the interviews before this was published.

## 4.2.2 Sampling

The target population included eating disorder service leads, experts in the field of psychological trauma, or those in a position of developing and implementing eating disorder or trauma policies. A sample size of six was chosen to provide sufficient diversity of specialist knowledge regarding service provision and development. As this was one phase of a multiphase study, the sample size was capped at six to reduce the risk of burden to the single researcher. This was felt a feasible number in supervision discussions when consideration was given to the process of recruitment, undertaking six hour-long interviews, followed by the transcription and data analysis. An estimation of the experts (based on contributors to NICE guidelines and SIGN guidelines, and those working in flagship treatment services or contributing to the literature) would indicate there may be around 30 people with specialist expertise in this specific area. The need for data saturation in any one phase of the study was reduced due to the overall mixed methods design allowing for other phases of the study to shore up any phases which were weaker. Data saturation in the context of data collection can be defined as reaching a point where no new themes or context is emerging (Given, 2016).

#### 4.2.3 Recruitment and consent

Homogenous purposive sampling was used to recruit six key informants from across the UK who all shared the characteristic of having a specialist knowledge of complex trauma or eating disorder treatment provision. This is a non-probabilistic approach (Creswell and Plano Clark, 2017) which was appropriate to the research objectives for this phase of the study as it was targeting a group of individuals who were knowledgeable about a particular phenomenon. Purposive sampling poses a high risk of researcher bias, due to the recruitment process being entirely dependent on the judgement of the researcher (Sharma, 2017). The addition of a linear snowballing exercise aimed to reduce some of this bias. Snowballing is a sampling technique which relies on existing participants to identify and recruit future subjects from their own acquaintances (Noy, 2009). Participants were not expected to directly recruit any subjects for this study, instead to suggest names of further experts in the field. This method of sampling offers the advantages of uncovering hidden populations but also introduces the risk of selection bias (Faugier and Sargeant, 1997). The risk of bias can be reduced by recruiting a diverse range of initial participants, so despite the experts having a common expertise in this particular field, they were recruited from both clinical and academic backgrounds and from across the whole of the UK to encourage some diversity within the sample group.

Two names were suggested by several phase one participants as experts in the field and these two people were then successfully recruited to the study, taking the sample size to six, requiring no further snowballing. It is likely that the participants recruited through snowballing will have shared similar views to those who suggested the names, and this is one of the risks of snowballing. No stipulation was made when discussing snowballing that the views of the participants had to be diverse or shared, simply that they were deemed to be an expert in the field. Given that trauma-informed care was in its infancy across the UK at the commencement of this study and there was minimal literature in the field of trauma-informed care specific to eating disorder treatment, this method of sampling was deemed to be the most appropriate for accessing the experts in the field. A participant information sheet was circulated to potential key informants via NHS mail (appendix 6) along with a cover letter (appendix 7). A further email was sent a week later inviting them to take part in the study. If they volunteered to participate, a consent form was emailed for signing and returning to the researcher ahead of the interview (see appendix 8 for an example of the consent form).

## 4.2.4 Data analysis

Given the multiple phases of this study, and the volume of qualitative data produced, Framework Analysis (Ritchie & Spencer, 1994) was chosen as a means of managing and analysing this data. Framework analysis sits under the broader umbrella of thematic analysis which seeks to draw conclusions from themes within the content of qualitative data (Smith & Firth, 2011). It is unique in its approach as it does not purport to support a particular epistemological, philosophical, or theoretical stance (Gale et al, 2013). It is particularly useful in research that involves large datasets, assuming the data to be homogenous and comparable. Large datasets can be reduced to manageable themes to enable a synopsis of the information. Framework analysis allows for analysis to move back and forth between the data, constantly honing and defining the themes, affording greater transparency of the process (Ritchie and Lewis 2003). This method of analysis enabled the transcript of each interview in phase one to be analysed independently, and the focus groups of phases two and four to be analysed separately. Across-case analysis was then used to tie together emerging themes amongst the phases collectively.

Where framework analysis is positioned on the inductive-deductive continuum very much depends on the research question. The approach to this study was largely inductive, allowing for themes to naturally emerge from the data, filtered through the researcher's lens. QSR NVivo (version 11) software was used to code and catalogue the data into emerging themes and then exported to Microsoft Word to build a visual framework for cross-referencing between the phases. There are also disadvantages to using framework analysis. It is renowned for being laborious and time consuming and it is most successful when used as part of a multi-disciplinary team with a principal expert leading the study (Gale, et al, 2013). The analysis in this study was undertaken by the researcher alone but under the close guidance of supervisors. Work was shared via NVivo and the coding and trees could be reviewed by the researcher's supervisor and the creation of the thematic framework was overseen by Dr Tessa Parkes to support the trustworthiness of the coding process.

The interviews were digitally recorded and transcribed verbatim by the researcher and all identifiable information was removed during this process. The transcribing occurred within a couple of weeks of each interview and were reviewed numerous times in an attempt to improve the accuracy of the transcription and therefore maintain the integrity of the data. Although this was a very time-consuming option, the transcribing process helped the researcher immerse herself in the data and make early notes on salient points and emerging

themes during the process. Framework analysis allows for the researcher to have a priori knowledge of a subject area, and this was one of the driving forces for selecting framework analysis as a means of organising and analysing the data. The researcher's familiarity with particular terminology was advantageous when cataloguing data in this respect.

## 4.3 Qualitative: phase two

#### 4.3.1 Data collection

A focus group was chosen to address the following research question: "How do patients with a history of complex trauma want to be treated within an ED outpatient service?" The data was collected in July 2017. Consideration was given to choosing a setting that would make participants feel comfortable and not imitate the clinical environment of a consultation room. A neutral meeting room was chosen within the hospital and was booked in advance to avoid any disturbance. Care was taken to ensure no questions encouraged participants to divulge any personal information regarding their specific trauma history. The focus group was limited to 90 minutes to avoid burden to the participants. The questions focused on their treatment experiences and their views of service provision, rather than any focus on individual trauma histories. Semi-structured questions were used as a guide.

Written notes were taken by the interviewer throughout the focus group and additional questions were used to clarify answers and explanations offered for the terminology in the discussion (e.g. what a tier three service is). An independent observer was present throughout the focus group and they did not take part in the discussion. The observer's role was to observe the participants and be on hand to respond to any emotional distress in response to the material discussed, by suggesting a pause in proceedings or linking the patient into the therapists in the day service. This group was chosen specifically as the participants had completed treatment and were in recovery. This should ensure greater resilience and a reduced vulnerability to emotional distress than those actively undergoing therapy. Once the focus group had finished, debriefing took place, to read over the notes taken and to inform participants of the remaining phases of the research. Participants were reminded they could withdraw from the study at any point. Participants were reminded of the non-disclosure statement ensuring that the confidentiality of group members was maintained before they left the room. Care was taken during recruitment not to involve any patients currently in receipt of care from the researcher.

#### 4.3.2 Sampling

In this second phase of the study, participants with a diagnosis of Emotionally Unstable Personality Disorder (EUPD), also known as Borderline Personality Disorder (BPD), were recruited. These were people who were in phase three of treatment with the personality disorder service through an outpatient service in Scotland (where the primary focus of treatment is not about changing existing psychological and interpersonal structures and processes, but more focused on the future, including new leisure activities, occupational or educational activities, the creation of new roles and relationships). They were in remission from BPD and were focussed on recovery. They had completed phase one of treatment which focused on stabilisation of their BPD symptoms. They had also completed phase two of therapy which involved treatment for active symptoms of PTSD related to their early trauma experiences. These patients had a history of complex trauma and had experienced several tiers of clinical services before engaging in this part of the personality disorder service. The maximum number of patients in this service at any given time would be a total of 10. The aim was to recruit as many patients as possible to a focus group, with the maximum being all 10 patients. However only three female patients were recruited to a single focus group, following which, one participant withdrew leaving a single focus group of two.

#### 4.3.3 Recruitment and consent

This population was chosen through typical-case purposive sampling as the patients had all experienced all phases offered in a phase-based intervention for complex trauma. This meant that they could offer a unique insight into trauma provision across specialist and broader mental health services. Typical- case purposive sampling cannot be used to generalise findings to a wider population but is intended to be illustrative which met the research objects of this phase of the study. This is an appropriate sampling approach when studying a specific attribute within a select group of individuals (Onwuegbuzie and Leech, 2004). The Personality Disorder service-user group leader distributed patient information sheets (PIS) and cover letters to those attending the Personality Disorder (PD) day service to take away and read at a later time. The researcher met with the PD group leader beforehand to help prepare them to answer any potential questions from patients about the study. Ten PIS and cover letters were disseminated in total.

The inclusion criteria stipulated that patients needed to be aged 18 or over, have capacity to consent and not be subject to treatment under the Mental Health (Care and Treatment) (Scotland) Act 2003. Participants needed to have completed stabilisation work to help manage their emotional and behavioural symptoms of Emotionally Unstable Personality Disorder. The participant information sheet clarified that participation was entirely voluntary and that there would be no consequence to their care should they choose to be involved or not. The Personality Disorder service leader asked the service users the following week if individuals would like to be involved in the study. Those who chose to be involved were talked through the consent form by the PD leader. The consent forms were then returned to the researcher ahead of the focus group.

## 4.3.4 Data analysis

The focus group was digitally audio recorded and was transcribed by a recognised University of Stirling transcriber who was bound by the confidentiality agreements of the university. The decision to use a transcription service for this focus group was driven by the pressure of time. Previous transcribing had been very time consuming but greater time was available to the researcher in the earlier phases of the study. The transcript was read several times by the researcher and compared to the audio recording to ensure accuracy before being transferred to NVivo for coding and analysis. Framework analysis was used for the organising and analysis of the data (see above). Coding is not merely the identification of particular phrases within the raw data, but rather the process of the researcher selecting the relevant descriptive words she believes the data is signifying (Corbin and Strauss, 2008). This relies on a level of confidence from the researcher to know what to look for and, again, the support from the supervisory team to ensure important data was not missed. The NVivo data was then saved in word format and was distilled further by separating the quotes and salient points of the discussion. Each individual quote was then transferred into a printable format with sub-headings to allow for notes to be made in the margins.

## 4.4 Qualitative: phase four

## 4.4.1 Data collection

A facilitated focus group was chosen to gather data from ED therapists from mixed professional disciplines. The focus group lasted 90 minutes and was audio recorded with consent from the participants and notes were written by the researcher. The discussion was guided by nine semi-structured questions which generated wider discussion and allowed additional themes to emerge. Follow-up questions were asked by the researcher to gain clarity and to encourage inclusion and expression of opinion from all members of the group. The data was collected in March 2018.

## 4.4.2 Sampling

The aim was to recruit between four to eight therapists to two focus groups at two outpatient sites (NHS Tayside and NHS Grampian). This sample size was chosen to allow for a diverse skill mix of professionals within each group while also being feasible within a single researcher, multi-phase, doctorate project. The team the researcher worked with was not included in this phase of the study as the researcher's colleagues had been involved in discussions around the development of the research. This could potentially have elevated the knowledge of traumainformed care within the therapists at this site which would skew the results. Choosing to exclude this team should not bias the data as this service is also part of the same Managed Clinical Network (MCN) for Eating Disorders. An MCN is defined as: "linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a coordinated manner, unconstrained by existing professional and Health Board boundaries, to ensure equitable provision of high quality clinically effective services throughout Scotland" (Baker et al, 2000). Each outpatient ED service within the network operates in a parallel manner, with therapists having similar core professions and having undergone equivalent training and having access to the same training days. New developments and updates within the field of ED are cascaded across the whole network and the model of treatment at each service is comparable. One site withdrew from the study due to staffing issues and having to prioritise patient care. This left only one remaining site to recruit from. Four participants were recruited to one focus group.

#### 4.4.3 Recruitment and consent

Participant information sheets and cover letters were emailed to therapists across the two sites to be recruited from. They were invited to contact the researcher to discuss the information sheet or to clarify any points. It was made clear that participation in the study was entirely voluntary. Consent forms were then forwarded via NHS email to those who volunteered to take part.

## 4.4.4 Data analysis

The focus group was digitally audio recorded and transcribed by recognised University of Stirling transcriber and the data from this focus group was analysed in the same method as data from focus group two (see above).

## 4.5 Quantitative: phase three

## 4.5.1 Data collection

A quantitative observational approach using a cross-sectional survey design gathered data from patients attending for assessment for outpatient eating disorder (ED) treatment to answer the following research questions: How prevalent is complex trauma in ED patients and does exposure to psychological trauma or symptoms of PTSD increase the severity of ED symptoms? In order to aid analysis, the question was broken down further into the following parts: (i) how common are post-traumatic stress disorder symptoms in patients with complex trauma? (ii) do higher adverse childhood experiences result in a greater severity of eating disorder symptoms? and (iii) do post-traumatic stress disorder symptoms have an impact on the severity of eating disorder symptoms?

The survey included questions regarding the outpatient ED treatment site, participant demographics (age and gender), ED diagnosis, body mass index (BMI), co-morbid diagnoses and the number of any previous episodes of treatment, and the use of three validated questionnaires to measure complex trauma, PTSD and ED severity. ED severity was measured through the global scores of the Eating Disorder Evaluation Questionnaire (EDE-Q) (Fairburn and Beglin, 1994) (see appendix 9). This is a 36-item screening tool used to evaluate ED symptoms and has subscales scored across the four core clinical dimensions of EDs: eating

concern, body shape concern, weight concern, and restraint. It has a global score ranging from 0 to 6, with higher numbers denoting a higher severity of eating disorder symptoms and behaviours. Scoring assesses the frequency of behaviours over a 28-day period as well as scoring the severity of eating disorder attitudes and beliefs. Berg et al (2012) undertook a systematic review of the literature exploring the psychometric properties of the EDE-Q and found data to support the test—retest reliability of the EDE-Q subscale scores and in terms of validity, the overall data supported the EDE-Qs ability to differentiate between cases and non-cases of EDs. The EDE-Q was chosen as it is a tool which is already in use in clinical practice and is widely considered to be a reliable screening tool in research (Mond et al, 2004).

Participants then completed two additional questionnaires with their therapist gathering data on complex trauma and PTSD. The Adverse Childhood Experiences (ACE) scale (Felitti, et al., 1998) (see appendix 10) is a self-report questionnaire designed to capture the common subtypes of traumatic events occurring before the age of 18. This is a ten-item tool which explores common examples of childhood physical abuse or physical neglect, childhood emotional abuse or emotional neglect, childhood sexual abuse, parental mental health issues and adversity. Each question requires a yes or no answer, with a yes response scoring: 1, and no scoring: 0. Any score of one or above would indicate there is a history of trauma. The ACE questionnaire is widely used in clinical practice and is recommended by the Centre for Disease Control and Prevention (CDC) as a tool for screening for psychological trauma and predicting the lifetime risks associated with this (mental and physical health probems and social difficulties) (Redding, 2016). Zanotti et al (2018) conducted an examination into the test-retest reliability of the ACE questionnaire and found a modest test-retest coefficient r = 0.71, p < 0.001. They recruited 141 student athletes and adminstered the questionnaire 12 months apart and found a higher stability coefficent in the items relating to househould dysfunction, r = 0.65, p < 0.001 compared with the items relating to abuse and neglect, r = 0.52, p < 0.001. The variation in responses over time can possibly be attributed to the nature of the questions within the questionnaire, subjective interpretations of what constitutes as abuse and neglect can vary within in an individual over time, whereas the household dysfuntion questions generally use more objective descriptions. Adversities also often co-occur (Lacey and Minnis, 2020). Validated interview-based questionnaires have been cited as the gold standard for assessing retrospective accounts of adverse childhood events (Bifulco et al, 1994), however, the use of an interview-based questionnaire was not feasible within the realms of this study. The ACE questionnaire was chosen as it is a simple questionnaire which captures the broad

areas of childhood trauma and is free to use in research. The survey data was collected by the patient's therapist as part of the routine assessment process.

Participants who indicated a trauma history were then invited to complete the Impact of Events Scale-revised (IES-r, Horowitz et al, 1979) (see appendix 11). This is one of the most commonly used questionnaires for assessing for the presence of symptoms of post-traumatic stress disorder (PTSD) (Weiss, 2004). It is a 22 item self-report questionnaire which assesses for common symptoms of PTSD over a seven-day period using a five-point Likert scale with each answer ranging from a score of 0 ('not at all') to 4 ('extremely'), yielding a total score ranging from 0 to 88. These symptoms are grouped into sub-categories of hyperarousal, intrusions, and avoidance. This is based on Horowitz's (1976) emotional processing model of trauma which identifies the alternating states an individual will experience between intrusive thoughts and feelings, and the use of avoidance strategies until the memories have been psychologically assimilated. Scores greater than 33 are indicative of the presence of PTSD and higher scores indicate greater symptom severity. Beck et al (2008) studied the psychometric properties of the IES-r and deemed it to be a sound measure of post-traumatic phenomena for both clinical and research purposes. Briere (1997) reports the internal consistency of the three subscales to be very high, with intrusion ranging from 0.87 to 0.92, hyperarousal ranging from 0.79 to 0.90 and avoidance ranging from 0.84 to 0.86. The IES-r tool was chosen because it is easy to administer and score and is commonly used in clinical practice.

These two additional questionnaires took approximately 15 minutes to complete. Data was then transferred to a data collection sheet (see appendix 12) and participants given a code to ensure anonymity. The original data collection period was fixed at 12 months, but an agreement was made to extend this due to the data collection being limited to two sites. Extending this period needed careful consideration to ensure the sample was not likely to have changed over the period of time since recruitment started. The sample could be at risk of changing for multiple reasons, for example, changes to the referral criteria could suddenly exclude certain patients from entering treatment or introduce a previously unknown cluster of participants to the service. Increased media coverage of a particular ED diagnosis could prompt patients to approach their GP with symptoms they hadn't recognised as an eating disorder and this would amplify referrals for a particular diagnosis, skewing the numbers over that period. Also, as more staff became increasingly aware of trauma-informed care, they may start to adapt their style of assessment and broach the topic of trauma differently. Participants may also become more familiar with trauma terminology through media exposure of trauma

or their experience of treatment in other services who have already adopted a trauma-informed approach. This may increase their readiness to share their history, inflating the number of patients with a trauma history who volunteer to participate in the study. In the short term, the supervisory team felt there was not likely to be a huge cultural shift and, should that have happened, this would have introduced the option to either cease data collection at that stage or to identify all those who were recruited after that stage and to make comparisons between the two groups. Neither of these were necessary. It was also felt that the quantitative data being collected (ACE, IESr, EDEq, BMI, age, gender, ED diagnosis and previous episodes of treatment) should not be impacted upon greatly by any improvements in trauma-informed care. The data collection period ran from March 2017 to August 2019.

## 4.5.2 Sampling

At the time of data collection, approximately 800 referrals were received annually across the four specialist outpatient eating disorder services being recruited to this phase of the study. When this figure was adjusted for inappropriate referrals and non-attendees, the figure for patients attending for assessment was approximately 650 patients a year. Recruitment was anticipated to be difficult, based on previous experience of collating patient satisfaction questionnaires yielding low response rates. The original aim had been to recruit a sample size of 128 to give a 0.5 effect size with a power of 0.8 with 2 tailed t test. However, the site with the largest annual referrals (NHS Lothian) withdrew from the study at the start and an agreement was made to adjust the target to a sample size of 65 participants which would not afford a formal power calculation but would generate descriptive data. Principal investigators (PIs) were identified to oversee the recruitment process at the remaining three sites. NHS Grampian withdrew from the study after several months and had not recruited any participants in this time. Recruitment was also slow in NHS Highland and NHS Tayside. Due to concerns regarding the lack of data, approval was then granted for two additional sites (NHS Glasgow and NHS Dumfries and Galloway) and PIs were identified for these sites. However, these two sites then withdrew due to the commencement of their own research projects locally and pressure on time. The decision was then made to extend the data collection period, as described above.

Attempts were made by the researcher to try to engage with the staff, to promote the study, and to problem solve the lack of recruitment from NHS Grampian. The researcher met the PI

face to face on two occasions and on a third occasion by video link. The PI admitted on the third occasion that the study had 'dropped off the radar' due to staffing issues and the lack of a service administrator. A fourth meeting was arranged when a new administrator was in post and the researcher agreed to meet with the therapists who would be recruiting to the study. Many of the therapists did not have knowledge of the study. Concern was expressed from the therapists about the time commitments for completing the data collection sheet. A fellow doctoral student from the University of Stirling then volunteered to act as a data collector, to collate the data and transfer this to the data collection sheets for the therapists. A follow-up email a few weeks later suggested 'a couple of patients' had been recruited to the study at that site. However, when arrangements were made for the data collector to visit the team, it emerged that there has been a misunderstanding and no patients had actually been recruited. The PI also had a period of sick leave and, further to this, the researcher received an email to clarify that this site was withdrawing its participation. A total of 44 patients were recruited across two sites (NHS Highland and NHS Tayside), the results section (page 125) will describe the sample in greater detail.

## 4.5.3 Recruitment and consent

Participants were required to be aged 18 or over, have capacity to consent and not be subject to treatment under the Mental Health (Care and Treatment) (Scotland) Act 2003. Participants were only recruited if they had an ED diagnosis which could be defined by DSM-V (2013). The team secretaries / administrators at each eating disorder outpatient base disseminated participant information leaflets and cover letters to patients attending for their first assessment appointment. Therapists were not involved in recruiting patients to the study to avoid any impact this may have on the therapeutic relationship or to make patients feel coerced into taking part. The researcher recorded a short video podcast and posted this online to introduce herself to participants and to explain the purpose of the study. A link to this video was placed on the participant information sheet so that participants could be given an overview of the study and an introduction to the researcher. The researcher met with the administrators and PIs at each base beforehand to discuss recruitment and data collection. In response to the comments from the external peer review, a flow chart was created to simplify their role in the study. It detailed the process of recruitment and data collection with the aim of preparing the administrators to take participants through the form and to feel equipped to respond to any queries (see appendix 13). It also aimed to help forge a connection with the PIs and enthuse them to be involved in the study. The participant information sheet explained that participation was voluntary with no impact on their treatment, whether they chose to take part or not. Consent forms were handed out by the administrator and completed forms were handed to their therapist before taking part in the study.

## 4.5.4 Data analysis

The quantitative data from the data collection forms was entered into and analysed with IBM SPSS (Statistical Package for the Social Sciences) software (version 27). Missing data was given a value of 99 to avoid being included in the results. This is discussed further in the results section.

Frequency analysis was used to:

 understand how common PTSD symptoms (IES-r scores) are in the patients who present with complex trauma (ACE scores).

A Spearman's r test of correlation was used to:

- examine the relationship between a history of complex trauma (ACE scores) and the severity of ED symptoms (Global EDE-Q scores).
- examine the association between PTSD symptoms (IES-r scores) and the severity of ED symptoms (EDE-Q global scores).

#### 4.6 Conclusion

In summary, mixed methods research was deemed to be the most suitable approach to addressing the four research questions in this study. Data was collected through a mixture of individual interviews, focus groups and a survey. Framework analysis was used to organise and analyse the qualitative data. A convergent parallel design complemented the four phases of the study, allowing for data to be collected across all phases within the same time frame and the point of integration occurring after the data had been analysed separately for each phase. Recruitment was a particular challenge in phases three and four of the study due to NHS Grampian withdrawing from the study, with phase three recruiting 44 of the already revised target of 65 participants, and phase four recruiting a small focus group of four. Phase one reached the target recruitment of six participants, and phase two recruited a small focus group

of two participants. Recruitment had been a concern from the inception of the study design and was a main driving force for selecting mixed methods to support a descriptive illustration of complex trauma through the eyes of experts, service users and therapists.

# Chapter 5: Qualitative results: Phase 1 – interviews with key informants

## 5.1 Introduction

This chapter reports the findings of the interviews undertaken in phase one of the study, examining how trauma-informed care has been interpreted by key informants. It will draw on the similarities and divergence of their views, analysing the dialectics that emerged, and a summary of the key themes which were identified during the data analysis will be presented. This chapter will form a point of reference to relate back to when exploring both the views of service-users and professionals working in the field of eating disorders. Six key informants were interviewed to gain an understanding of their interpretation of the principles of trauma-informed care. These key informants came from a variety of professional backgrounds, including clinicians specialising in trauma, and academics contributing to the development of policies and guidelines in either the field of trauma or eating disorders, or both. Each had a core profession in mental health. The sample characteristics of the participants are detailed in Table 5.1. No other demographics were collected.

Table 5.1 Sample characteristic phase one

Participant	Profession	Gender
1	University Professor	Male
2	Consultant Psychiatrist	Male
3	Lead Nurse	Female
4	Psychiatrist	Male
5	Consultant Psychologist	Female
6	Consultant Psychologist	Female

Three were men and three were women. There were five main themes which emerged from the data: 1) assessment; 2) treatment; 3) complex PTSD (post-traumatic stress disorder); 4)

staff care; and 5) implementing trauma-informed care. The process of how these themes were identified is covered in greater detail in the methodology chapter (page 39). These themes will be described in turn in the findings and the COREQ checklist (Tong et al, 2007) was used by the researcher to aid the reporting of the qualitative phases of the study (see appendix 14).

## 5.2 Findings

#### 5.2.1 Theme 1: Assessment

The process of assessment was highlighted as being a fundamental means for understanding an individual's experience of both traumatic life events and the presence of PTSD symptoms, along with identifying any ongoing risk. When asking key informants how they interpret trauma-informed care, a couple of participants quoted their belief that at its core, there has been a shift in approach from asking "what is wrong with you" to "what has happened to you", putting people, or the difficulties or problems that people present with, in the context of what's happened in their life and idioms to link the effects of traumatic events to the distress and dysfunction that people experience. All the participants made the point that assessment can take many forms, and the level and depth of enquiry needs to be applicable to the environment and professionals involved. They also described the importance in the ability to respond appropriately to the information that is provided during assessment, and not asking intrusive questions with no plan of how to respond to these. Two participants went on to describe an appropriate response, with these including offering psychoeducation, signposting to specific trauma treatment, or simply validating the individual through listening to their story and understanding how their experiences have contributed to their current presentation. Two participants discussed the need to assess for 'small t traumas', feeling these are often overlooked when taking a standard trauma history, as most people associate psychological trauma with physical or sexual abuse, or neglect. One participant described some of the areas that should be routinely discussed during assessment to help identify potential small t traumas:

"... assessment of their background, of their childhood, of their upbringing, of their time at school, of their underlying schemas, and what they learned as a result of those experiences." (Participant 6)

Another participant suggested that emotional abuse is often overlooked and is one of the best predictors of poor clinical outcomes. Additionally, they highlighted that trauma is subjective and stressed their view that how one person perceives an event may be entirely different from another:

"It's not me as a clinician who says "oh yeah, that was a trauma", 'cause it might not be for that person; it's the person that needs to be identifying it as traumatic." (Participant 2)

According to participants, asking about a trauma history is distinctively different from assessing for active symptoms of post-traumatic stress disorder (PTSD) which may arise as a result of exposure to traumatic events. Three of the participants warned against making assumptions that exposure to traumatic events results in active PTSD symptoms. PTSD can be screened for separately but a discussion which includes direct questions about common areas of psychological trauma was suggested as a crucial part of any psychological assessment. Psychological trauma could include physical and emotional abuse and neglect, and sexual abuse.

The need for routine enquiry into a trauma history as a standard part of an assessment was highlighted by participants to avoid the pitfalls of relying on self-disclosure. Self-disclosure was recognised to be unreliable as it depends on there being an intact memory of an event and also a level of awareness from the patient of what trauma is. One participant described the phenomenon of trauma being disclosed mid-therapy, which is a common issue highlighted by a couple of participants as a result of minimising or skating over trauma, either consciously or otherwise in the assessment phase of treatment:

"There's stuff they're not aware it was actually traumatic to them though it did actually traumatise them and they only become aware of that in the course of therapy." (Participant 4)

One participant stated there will always be covert traumas and efforts to intentionally cover up shameful trauma memories, however, there was a consensus that assessment needs to include questions about "what has happened to you?", rather than "what is wrong with you?". The use of questionnaires to help structure a trauma assessment was included in most of the discussions, with the following tools being mentioned: ACE questionnaire (Felitti et al, 1998), dissociate experiences scale (Carlson and Putnam, 1993), multi-modal life history questionnaire (Lazarus, 2005), rating scale for borderline personality disorder questionnaire

(Zanarini et al, 2003), and the schema questionnaire (Young and Brown, 1994). Overall, assessment was identified as being central to trauma-informed care, as it allows the opportunity to open discussions around sensitive topics, takes the onus off the patient for raising the matter and helps to label trauma for what it is. Labelling the trauma allows the patient to realise the impact of their past experiences. The assessment places the responsibility to be asking the questions with the clinician and ensure trauma becomes 'everybody's business'.

## 5.2.2 Theme 2: Treatment

According to the participants interviewed, assessing and understanding the aetiology of an individual's pathway into an eating disorder is not only helpful for the assessing clinician, but also a crucial step in building a formulation with a patient. The role of the formulation was mentioned several times by five of the interviewees. Interviewees acknowledged that the formulation helps the patient to conceptualise the problem and to understand how psychological trauma contributes to the early development of schemas and maladaptive behaviour patterns:

"I suppose if you think about what some of the treatments are trying to do, it's trying to put the story together and make sense of what's happened and to allow the person to think that through without becoming overwhelmed by emotions and I suppose the formulation in a way helps to do that." (Participant 2)

The formulation was also identified to be helpful in forging links between overlapping symptoms, for example, bulimia nervosa and depression, or anorexia nervosa and obsessive-compulsive disorder. Formulation helps the clinician and patient link back to the psychological trauma and developing a hypothesis for the mechanisms that cause and maintain the psychological symptoms. The process of formulation leads to individualised, tailored CBT which is "formulation driven" as opposed to "protocol driven" CBT. Protocol CBT or manualised CBT has its merits as it prevents therapist drift, is time limited and is goal orientated. However, many of the interviewees felt this was an unsuitable approach for patients with complex trauma, commenting that it was not sophisticated enough to meet the patients' needs. It was highlighted that patients with complex trauma, or personality disorder, will often present with multi-impulsive behaviours and this can create a division and debate about which service is best suited to addressing their needs. However, trying to offer the most

appropriate, tailor-made service is not only a matter of understanding the overlapping and trans-diagnostic nature of the symptoms, but also a matter of constraints on services as a result of numerous issues, such as limited resources or a lack of training for therapists.

One participant commented on the tension that has been created between the ideal and the constraints of an underfunded, stretched NHS. Resources alone are not the only barrier to creating the ideal service, with much debate being expressed between participants regarding the advantages and disadvantages of developing integrated trauma services, so that active symptoms of PTSD can be addressed 'under one roof', with a clinician the patient already has a therapeutic relationship with. None of the participants were aware of such a model of integrated trauma work being part of an eating disorder service nationally, despite trauma being prevalent in eating disorder (ED) patients. One of the major drawbacks that was raised by one participant was that of managing risk. Offering ED patients treatment for PTSD in adult mental health services was thought to be an unsatisfactory solution due to the multiple risks that these patients can present with. Physical health risks are of particular concern in EDs, such as low BMIs, electrolyte imbalances and cardiovascular issues. Clinicians working in adult mental health services often lack expertise in treating ED and have had no formal training in assessing or managing ED risks. They will also lack the robust support of a multidisciplinary team who can monitor the physical risks unique to low weight and blood biochemistry. Undertaking PTSD work can often lead to decompensation and a return to previous high-risk ED behaviours which had previously stabilised.

Conversely, participants also flagged there is a gap in training in ED services and it was felt that ED clinicians are not routinely trained to deal with PTSD or feel equipped to treat personality disorder and consequently have to refer patients outside of the ED service for specialist treatment. Broadening out the scope of ED services to be able to address these wider issues may seem the ideal, this could however increase waiting times, but it was felt this should not be a reason to dismiss patients the opportunity to get their needs met within one service. One of the interviewees stated:

"I think there's always a risk when you've got untapped demand. I would never see a fear of a waiting list being good rationale for not giving people the service they deserve." (Participant 5)

Regardless of where the PTSD treatment is offered, some participants identified there should be a greater emphasis on joined-up working and services being recovery focused, and there

being flexibility to the evidence-based approach. This is sometimes referred to as "taking an eclectic approach". One participant mentioned the psychological therapies strategy (The Matrix; Campbell, 2011) and the emphasis this placed on patient-centred care. One participant noted that, not only is there often a lack of specific trauma treatment, but trauma is often medicalised, with a genetic aetiology focus, rather than there being an understanding of the neuroscience and the bio-medical connection between the emotional and physical state. Teaching patients about interoceptive awareness and the autogenic state was felt by one participant to be a crucial step in teaching patients to be able to recognise emotion:

"What's coming out of neuroscience at the moment is that the self-healing of the mind, of the brain, is very much dependent on the autonomic, peripheral autonomic nervous system." (Participant 4)

This same participant highlighted that the medicalisation of trauma has historically led to patients missing out on psychological therapies and being offered medication as an alternative, or symptoms being divided into very separate diagnoses and being treated as separate.

Continuity of care and avoiding disjointed working was a key concern when discussing treatment options with a desire to see greater partnership working to avoid patients having gaps in treatment and care pathways highlighting co-morbidity and complex presentations. Most of the participants highlighted the importance of distinguishing between the different phases of interventions when dealing with trauma; phase one is focused on stabilisation and phase two is dealing with active symptoms of PTSD. Phase-based interventions were felt to be the gold standard when treating patients with PSTD and complex trauma and there was an acknowledgment that this needed to be integrated into inpatient and outpatient eating disorder settings if they are to be trauma-informed. Phase one, or the process of stabilisation and maintaining safety, is generally well understood in eating disorder services and is a main priority for any patient entering treatment and this was discussed widely amongst participants.

Treatment approaches are aligned to address the eating disorder behaviours and restore weight and lower the risks. There was much discussion about the primary goals of phase one, with all of the participants recognising the need to be targeting physical health, with a focus on refeeding and BMI. A low BMI was highlighted because of the impact this has on cognitive functioning, how psychologically minded patients are and also how starvation syndrome can

impair decision making. For some eating disorder patients, maintaining a low weight serves to block traumatic memories and dampen unwanted emotions, so taking a behavioural approach alone to target the weight restoration may result in patients disengaging from therapy:

"If you completely focus on weight restoration you might lose a significant number of patients who are just not ready to do that behavioural work and often there are good reasons, you know, there's a lot of secondary gain from that starvation state, from being at that low weight, you know, in terms of blocking traumatic emotions."

(Participant 6)

Although CBT is recognised as the evidenced based treatment for eating disorders, interviewees discussed different modalities of CBT and third wave therapies which may be of particular benefit to patients presenting with complex trauma. These included: CAT (cognitive analytic therapy), CBT-E (CBT for eating disorders), CFT (compassion focussed therapy), DBT (dialectical behaviour therapy), FBT (family-based therapy), mentalisation, schema therapy and eclectic patient-centred models. There was also some discussion regarding the benefits of individualised versus group treatment and the use of inpatient treatment for those most at risk. Self-management was also seen as a high priority, teaching people to manage the consequences of trauma more effectively. The majority of participants also identified that treatment for these ED patients with a trauma history will be lengthier, depending on the severity of the eating disorder symptoms and the nature of PTSD symptoms (e.g., avoidance, hyperarousal or intrusions). Regardless of the treatment approach used, an understanding of trauma and treatment approaches needs to be embedded in a clear pathway of care.

A further suggestion raised by two participants was to develop treatment streams within outpatient eating disorder services to target individuals with more complex needs. The treatment streams were suggested as a way of avoiding a one-size fits all situation which ignores complex trauma or the need to address PTSD symptoms following initial stabilisation. It was noted that it is not uncommon for PTSD symptoms to be considerably worse by the end of phase one, with patients reporting an increase in traumatic memories. A skills-based approach to teaching distress tolerance and emotional regulation is used in the treatment for emotionally unstable personality disorder (EUPD) and adopting these skills in eating disorders could help patients reach a point of safety and containment and prepare them for the option of starting phase two work. One participant who has experience in the field of EUPD also

highlighted that whilst some patients may recognise the need for specific trauma work and explicitly request it, they may also lack insight into their skills deficits:

"Stabilisation and reprocessing is a broad category and there's detail within that, but just knowing that to start with, because sometimes what the person wants isn't what they need and people can come in to services and say I want to talk about this terrible thing that's happened to me but they don't have the skills to manage the distress that goes along with that." (Participant 2)

Phase two treatment involves the targeting of PTSD symptoms and supporting patients to process traumatic memories. There are many different approaches used in this phase of therapy and clinicians often base their treatment of choice on their own training and the one that feels most familiar to them, with participants highlighting the importance of therapist choice. Interviewees discussed the merits of EMDR (eye movement desensitization and reprocessing, Shapiro, 1989), trauma-focussed CBT (Cohen et al, 2017), STAIR (Skills Training for Affective and Interpersonal Regulation, Cloitre et al, 2002), prolonged exposure (Foa, 2011), and imagery re-scripting (Holmes et al, 2007). It was commented on by a participant that much of the evidence base for these therapies is for type one, single event traumas and the evidence base for complex trauma has been extrapolated from that. One participant raised this concern and suggested further research is needed into phase two interventions with complex trauma. The timing of phase two work and readiness criteria for this was also debated; with a couple of participants flagging the risk of re-traumatisation should patients feel compelled to be working on PTSD symptoms:

"It's that kind of setting up a re-traumatising situation, maybe not with the intervention per se, but by the power imbalance of pushing somebody into something they're maybe not entirely comfortable with." (Participant 5)

The final phase of trauma work, phase three, is invested in supporting individuals to pursue their own longer-term goals and to pursue wider opportunities. It was noted that the phases of trauma work need to be approached sequentially and that phase three is often over-looked as there is no specific psychological intervention for phase three and it is the least documented phase of treatment and hardest to measure. One participant described phase three as offering patients the kind of worthwhile lives they want, helping them to work

towards jobs and education, relationships, rules, a sense of self, and being part of society and the community in a fulfilling way. They also flagged that it is not possible to skip phases one and two before concentrating on this work though. It was also recognised that phase three can often be delivered by third sector organisations, including the voluntary sector and wider community. This does not necessarily have to be something that needs to be delivered 'inhouse' by the NHS. Participants described the need for NHS services to be utilising third sector organisations for this work, using resources that already exist elsewhere.

The value of a robust therapeutic relationship and the therapeutic environment was seen as being equally as important as to the choice of which therapeutic model to use when addressing trauma. Patients who have experienced complex trauma have often experienced invalidating relationships in the past and this can create issues around building trust and maintaining boundaries within interpersonal relationships:

"...you need to have a very safe environment for them and a secure relationship with the therapists and involve them all the way, that this is coming, that they know that they're doing this." (Participant 3)

However, it was noted that this relationship doesn't need to be with a specific person, or with a particular professional background, so long as there is the opportunity to build rapport. One participant suggested this relationship can be forged between the patient and a group, or the patient and a wider service. Some of the components for promoting a strong therapeutic relationship with patients with complex trauma that were mentioned included: strict boundaries, a safe therapeutic environment, working within a 'window of tolerance' and giving them the ability to share their story and feel validated when they do, without the need to offer advice. A collaborative approach was a universal expectation from everybody when discussing the therapeutic relationship. Within this, there was a strong belief that patients should have choices around which service, delivering phase two treatment, best suits their needs. It was acknowledged these requests may not always be met as collaboration requires the needs and limitations of both parties being respected. The greater number of therapists who are trained in delivering trauma work will therefore increase patient choice and make it more likely that their preferences can be accommodated. Equally, the type of therapy that is offered for phase two can be a patient choice too, not just led by the professional's preference.

As well as patient satisfaction, there was a general recognition that ED services should routinely be measuring treatment outcomes in therapy to ensure that treatment has been effective and that treatment meets a certain standard, this should help to identify variations in care provision and ensure that therapists are adhering to a therapeutic model. In addition to specific PTSD measures, other outcomes to be measured included: eating pathology, anxiety, depression, and the therapeutic alliance. All of these measures can be used as a balance metric for patient improvements over the course of treatment.

Whilst there appears to be some common beliefs amongst participants about the need to build a formulation, assess risk appropriately and ensure that staff have the appropriate expertise and skill mix to work with trauma, it appears there is not a firm treatment model or flagship service which can be emulated to reproduce the ideal trauma-informed eating disorder service. The advantages and disadvantages of creating a trauma-specific treatment model within eating disorders services emerged through the interviews, with concerns for fragmented treatment, the impact this may have on the therapeutic relationship and the difficulty in ensuring co-morbidities are addressed and treated appropriately. Monitoring treatment outcomes and patient satisfaction is central to delivering an effective treatment package.

## 5.2.3 Theme 3: Complex trauma

Much discussion took place as to the meaning of complex trauma and how complex PTSD can be defined, as this has not been recognised formally within diagnostic frameworks. The overlap and interchangeable labels of complex trauma and emotionally unstable personality disorder (EUPD) was suggested to be confusing by some as EUPD is focused on underregulated behaviours and emotions and complex PTSD does not necessarily suggest that a patient will present with behavioural or emotional regulation issues. Complex trauma also could be used to define the adverse events that a person is exposed to, or it could also be used to describe PTSD symptoms that are present following exposure to these experiences. One person commented on the need to be tailoring psychological interventions to these patients with complex trauma and this is why we should seek to avoid confusion around the terminology used. It was also stressed by one participant that patients who have experienced complex trauma often do not have active symptoms of PTSD. The notion of mental disorder being generated by an external event was discussed by several participants, with some

highlighting how there has been a recent shift in this viewpoint from the traditional biomedical model, positing that mental disorders are diseases of the brain, requiring pharmacological intervention. It was also recognised that individuals will have varying levels of awareness and memory of their exposure to adverse events depending on their age when they experienced it and how it was framed by those around them.

There was one participant who felt that there has been a historical avoidance in psychiatry of acknowledging the link between mental illness and external events, believing this has been a means to separate out the mentally ill from the rest of society:

"Psychiatrists opposed it almost, apart from some outstanding exceptions and the emphasis that is put on the genetic aetiology to try and distract from environmental causes throughout the history of psychiatry is part of the them and us thing, you know, to try and make out that the mentally ill are quite a sort of separate category of people and not to look at the social causes in terms of economic deprivation, hardship and trauma." (Participant 4)

Emotional abuse and neglect were described as being responsible for the development of marked schemas. A schema can be described as a framework for interpreting information based on previous experiences and these schemas may present future problems in the forming and maintaining of prospective relationships (DiMaggio, 1997). These schemas were also felt to be a source of internally generated trauma, where patients are forecasting a loss of control or visualising themselves as fat. It was noted several times by several participants that emotional trauma during childhood is closely connected to eating disorders and most closely linked with future PTSD:

"We know very well from the evidence that when we look at all the traumas together, the one that makes the big difference to people with eating disorders is emotional trauma in childhood." (Participant 1)

Complex trauma was very much seen as being co-morbid to other mental disorders, with interviewees mentioning eating disorders, substance misuse, personality disorder and depression. It was also noted that there would often be several co-morbidities, with patients presenting with many symptoms. A further point was made that co-morbidities are often missed within eating disorder patients:

"I think that we have to be up front about the fact that personality disorders and complex trauma are often under diagnosed within the eating disorder population." (Participant 6)

Resilience was described on several occasions as a protective factor in terms of adverse experiences. Those patients with higher levels of resilience can avoid a future risk of PTSD or the onset of mental illness following the experience of psychological trauma. Resilience was portrayed as having supportive parents or even informal support from a wider network:

"...frankly if you've got a supportive parent you can get through most of childhood, but if it's emotional trauma and you haven't got that support, then you're in real trouble."

(Participant 1)

One participant described the importance of resilience, believing when resilience is present, it can aid a natural recovery, suggesting the majority of the population who are exposed to a traumatic event can pull on natural resources to aid recovery. One participant quoted a figure of 50 - 60% of people that have experienced an adverse life event will be resilient enough to make a natural recovery over a short period of time and not need any professional support to aid this process:

"And we've got to assume that the natural recovery is... you know, most people, the majority of people, 50/60% of people will make a natural recovery and they will make that natural recovery by using their own resources and resilience and they will talk through their trauma over a gin with their friends or at the bus stop, you know, women after they've given birth obsessively telling their birth story to everybody who'll listen to it, is the natural process of making sense." (Participant 5)

PTSD is not the only impact psychological trauma has on an individual, according to one participant. They stated that PTSD is often the second or third most common impact of trauma. Other common symptoms that arose during discussions included: dissociation, hyperarousal, maladaptive coping skills, physical health problems, emotional dysregulation, interpersonal difficulties, and severe and enduring eating disorders. Attempting to address some of these symptoms was felt to be removing learned coping techniques: typically these would include dietary restriction, binge eating, and self-induced vomiting. This was flagged as

a particular issue in patients with eating disorder behaviours. It also came back to the issue of skills deficits and the importance of skills training during phase one work:

"It's like basically asking them to take off their old shoes and not having any new shoes ready for them to put on, they'll get frost bite. That's why we get stuck I think with so many of our anorexic patients is because, you know, we're asking them to give up something that actually does have a lot of survival values for them." (Participant 2)

In summary, complex trauma appears to have been an under-diagnosed and under-recognised issue which presents in parallel with other mental health disorders. It was felt there is a shifting culture and a growing awareness of both complex trauma and PTSD, as well as other associated symptoms. However, it appears further work in raising awareness and understanding how to respond to these issues is needed. Supporting people to build resilience links back to the importance of getting the assessment and treatment process right for these patients.

#### 5.2.4 Theme 4: Staff care

A key component of trauma-informed care was that of staff care. This was talked about by all participants during the interviews and 'staff' was a term used for clinicians offering psychological therapies, as well as personnel external to this who come in to contact with patients having experienced complex trauma. Education was flagged as an important starting point for staff, as there is a need to build competence within the workforce and to help staff recognise and respond to trauma. It was noted that this will hopefully address problems with staff ignorance and reduce judgments made towards patients engaging in harmful behaviours, to stop patients being labelled as being a nuisance or manipulative. The national framework (Transforming Psychological Trauma, NHS Education for Scotland, 2017) was mentioned which has as one of its aims to skill the entire workforce. This is extensive to include any service where a patient with a trauma history may present, such as primary care, social work, police, and education, encouraging these services to adopt a trauma-informed approach. And more specifically, there will be trauma specialists within healthcare settings who will be responsible for delivering highly specialised trauma interventions. Two participants described the danger of assuming that those trained in psychological therapies will have knowledge of complex

trauma. They discussed the lack of teaching on trauma within the core training for psychological therapies and how trauma work is frequently viewed as a specialism. One participant described their ideal when considering the training needs of eating disorder staff:

"So really what we need is eating disorder clinicians who are also competent working with trauma and with personality disorders and with more complex pictures."

(Participant 6).

Educating professionals also addresses the use of appropriate language to define and describe complex trauma. Three participants highlighted the issue of language and how addressing deficits here can help to reduce confusion across the workforce and that further work needs to be undertaken to develop the correct terminology.

Two participants went on to discuss the need for further development of policies and procedures at local and national levels. They discussed the rolling out of the national framework and use of the matrix document as a clear protocol for governance to ensure delivery of evidence-based interventions. It was widely acknowledged by participants that there has been a culture of avoidance in broaching or discussing trauma by mental health professionals and one of the objectives of trauma-informed care is to address this issue:

"...the conditioning of psychiatrists in mental health services in general is still sort of way behind in terms of the times but I suppose the other big factor I think is that we all, all human beings have a very deep seated, instinctive, well it's an instinct almost to avoid the subject of trauma. To stay happy and sane and all the rest there's just lots of things you just don't think about." (Participant 4)

There were various suggestions offered as to why this subject is so difficult to approach for many clinicians. Anxiety was a recurring theme that was discussed, and this included the fear of feeling unskilled and the fear of doing harm. Doing harm was voiced by a couple of participants who described worries of re-traumatisation for the patient. The lack of skills was related to not knowing how to respond appropriately to trauma being disclosed, not knowing a clear pathway for treatment or how to sign-post on when trauma or PTSD is identified. It was also felt that the best way to address this issue is to train and offer support to staff.

Compassion fatigue was offered as a further possible explanation as to why certain clinicians will not actively respond to trauma, trivialising small-t traumas, feeling they do not warrant further exploration. This can lead to failure to identify active symptoms of PTSD requiring

treatment. One participant mentioned that therapists may also be avoidant of undertaking phase two work themselves due to their own adverse experiences. Given the widespread incidence of adverse childhood experiences and the potential for traumatisation, it is likely that there will be clinicians with personal experience of psychological trauma who are wishing to avoid the risk of triggering their own re-traumatisation:

"We're going to have a workforce for whom many of this will be personal experience or where there's maybe people feel quite avoidant of these issues, we've got to overcome quite a lot of resistance to all of that." (Participant 5)

Supervision was highlighted by four participants as a vital component of staff care. Supervision was felt to offer some safeguarding against the risks of vicarious trauma, as prolonged exposure work and imagery re-scripting exposes the therapist to the trauma narrative in detail and the risk of them also becoming traumatised by an account of the events. One participant felt there needed to be a culture shift for some staff, as supervision is often seen as having little value other than to address caseload management issues.

Staff care is a broad subject area which needs to be approached sensitively, to ensure clinicians have a choice in how they develop their own skills and to what extent they become involved in trauma treatment, along a trajectory from being trauma-informed to becoming a trauma expert who offers specialist PTSD treatment. Careful supervision, monitoring for and responding to compassion fatigue and protecting against vicarious trauma are crucial in trauma work. Mobilising the workforce towards a trauma-informed approach appears to be dependent on the appropriate level of training, from the broad awareness-raising education that is necessary to ensure trauma is recognised and the correct language is used, through to the specific training for the treatment of PTSD. Personal limitations of staff should also be respected.

## 5.2.5 Theme 5: Implementing trauma-informed care

A trauma-informed workforce would require a shift in culture within mental health service provision and a belief that trauma is everyone's business, according to two participants. One participant described there being a need for individual services to consider what trauma-informed care means for them and how they will need to adapt their own practice, to interpret the knowledge and skills framework for themselves. Others flagged that the process

is likely to be slow and be adopted in phases over a five-to-ten-year period, possibly with pilot sites to inform others on the detail of innovation. One participant suggested that commissioning is a way of ensuring services adopt evidence-based practice and develop in a patient-centred way:

"The only way it's ever going to get addressed is commissioning. If commissions are informed about what's good for the patients they're buying services for, then they can tell services." (Participant 1)

The Massachusetts Child Protection System (Bartlett et al, 2016) was mentioned by one participant as an example of how trauma-informed practice is being approached overseas. The Massachusetts Child Protection System is a state-wide introduction of trauma-informed practice. The interviewee described that there had been training offered to thousands of people in order to help them identify, recognise and deal with routine issues, and affect dysregulation, as well as rapidly signpost up to high intensity psychological interventions. The prevalence rates of trauma were discussed as being high at present and as the workforce gets better at recognising trauma, this will likely unveil a vast amount of unmet need which will require services to respond to this need, according to one participant. A further participant made a similar comment but spoke specifically about the rates of complex trauma within the eating disorder population.

The need to be working within the frame of evidence-based practice was raised by several participants, but the field of complex trauma was also described by two participants as being an emerging evidence-base, with greater research being necessary around the treatment of PTSD symptoms for those with complex trauma. One participant mentioned SAMHSA (Substance Abuse and Mental Health Services Administration) as a reference point, acknowledging that much of the terminology used in the national framework is borrowed from SAMHSA definitions. This same participant championed the need for services to be adopting the 'four R's' which are key assumptions in a trauma-informed approach: realisation, recognition, responding, and resisting re-traumatisation.

"And the key thing I think that often gets overlooked with trauma-informed care is the fourth R of resist re-traumatisation that we really need to think very systematically around what does it mean to be at risk of re-traumatisation and how do organisations need to really consider their processes and approaches reactively to mitigate against the risk of this." (Participant 5)

Another participant made the point that there may be some excellent examples of traumainformed care already in existence in the field of eating disorders that we could be championing, only staff are not aware there is a name for the work they are doing with patients with complex PTSD:

"...we didn't call it that, it didn't have a name. I guess it's a wee bit like evidence informed, you know, you use the evidence but we didn't know that that was a term coined for it until about 10 years ago kind of thing" (Participant 3)

Finally, one participant described the responsibilities of mental health professionals to be promoting trauma-informed care and to be driving the changes in practice. Implementing trauma-informed care was felt to be everybody's business and will be slow to roll out and require different strategies, depending on the individual service. The knowledge and skills framework should help to guide staff through this process and general awareness raising and training will be an integral part of a shifting culture to a trauma-informed workforce.

#### 5.3 Conclusion

To conclude, this chapter provides an overview of some of the key areas necessary for providing a trauma-informed service from the viewpoint of the participants. A robust assessment on entering treatment, with a clear focus on explicitly asking about traumatic events, using routine enquiry to include questions about 'small-t traumas' was deemed to be important. Assessment of trauma histories and also using questionnaires to check for the presence of active symptoms of PTSD was cited to be crucial in tailoring treatment appropriately. Participants highlighted the need for a compassionate approach and using the correct language when offering a trauma-informed service. Consideration for the treatment pathways, a phase-based approach and continuity of care were also central themes, along with robust supervision for staff and an awareness of the risks to healthcare providers when exposed to other people's trauma histories. These themes offer a benchmark for assessing how the views of service users and service providers map on to this construct. These findings will be discussed separately in the following chapter. The points of overlap and contrast within these themes from the key informants, the service users and the eating disorder therapists will be discussed more widely in the discussion chapter. The potential implications for clinical practice will also be discussed.

# Chapter 6: Qualitative results: Phases 2 and 4 focus groups

#### 6.1 Introduction

This chapter will review the results of phases two and four of the study - the focus group with service users and the focus group with eating disorder (ED) therapists. It will explore the views on trauma-informed care from the following perspectives, utilising the lived experiences of service users having engaged with various psychological therapies, and the experiences of therapists who have been responsible for the assessment and delivery of treatment to patients with a diagnosis of complex trauma. The chapter will be split into two parts with each focus group described individually. The results of these findings will be explored in the subsequent discussion chapter, along with the findings from the interviews with the key informants.

## 6.2 Findings: phase 2 focus group with service users

This focus group invited service users with a diagnosis of complex trauma to share their views and experiences regarding their engagement with mental health services. The two female participants in this focus group had accessed trauma-specific specialised treatment and, over many years, wider mental health services. No further demographic data was gathered from these participants in order to protect their anonymity within these results. They were invited to share their views on their experience of treatment and to give examples of where things had worked well for them, as well as areas they felt could have been improved. They were encouraged to share their perceptions of trauma-informed care and their vision of the ideal service, intervention, attitude or approach for service users with a history of complex trauma. Having an insight into how service users would like trauma-informed services to be shaped provides a helpful comparison with Phases one and four of the study. Four key themes emerged from this focus group: 1) assessment; 2) the therapeutic relationship; 3) attachment; and 4) treatment.

#### 6.2.1 Theme 1: Assessment

Both participants highlighted that up until recent years, no mental health professional had specifically asked about their trauma history. They had been assessed at various entry points to mental health services and at each assessment appointment they felt there had been a missed opportunity to ask participants specific questions about trauma:

"I think for me when I first came into mental health services quite a few years ago I was never asked specifically about trauma. I, it was kind of skirted around" (Participant 1)

Both participants described the self-disclosure of traumatic events later in their treatment histories. They also criticised the use of 'fluffy language' to ask indirect questions and how this led to confusion about the level of detail required when answering and what they felt comfortable disclosing, feeling unsure of what the clinician wanted to hear. One participant described not being sure what information to share and how much detail to give, with information about their trauma history being built up over a number of separate assessment appointments during different treatment episodes:

"... it probably came wriggling through, drips and drabs that way." (Participant 2)

In response to this comment, the other participant suggested direct questioning may create some anxiety but is necessary to get specific details:

"I've got so many things going around in my head that it was very difficult for me to pinpoint or focus them and pull out the right things. So being asked very direct questions was actually a good thing because as much as being asked direct questions terrifies me, it gave me a good opportunity to then say, you know, a very specific answer to something." (Participant 1)

Both participants felt that more guidance would avoid 'swimming around' a subject and bring focus to the assessment, along with explanations of why the questions are being asked. The terms used in these questions was also deemed to be important by the participants. They believed the use of the word 'trauma' would help to de-mystify broad questions regarding life experiences. They both felt this word was avoided being used by clinicians, from their experiences. The structure of the assessment was flagged as critical to 'setting the scene' and allowing service users to feel prepared for difficult questions and have an opportunity to revisit them if they did not feel able to answer the questions at the time they were asked. One

participant had been involved in a trauma-specific assessment and described being asked for a detailed trauma history, along with a helpful explanation of why a trauma history is taken (to help the patient understand that their childhood experiences may impact on who they are and their resilience in later life).

Participants raised anxiety regarding the consequences of disclosing a highly sensitive trauma history as a reason for being guarded about the level of disclosure during assessment, particularly with professionals they had not established a therapeutic relationship with. Concerns were expressed in relation to the comments documented in notes and who will have access to this information, and the level of detail included in correspondence between healthcare professionals. An example was given of how a detailed history had been summarised and assumptions had been made where the detail was missing. This had led to an inaccurate account of events which had been distressing for the patient to later hear about. The participants gave examples of conditions which would encourage them to feel safe to share information, starting with a belief that the assessor had an interest in what the participant had to say and that there is a reason the assessor wants to know the detail. Frustration was voiced by both participants at having been asked questions about trauma and having shared personal details, and then being offered no support to address the complex trauma or any signposting to other services to access support. Feedback and validation from the assessor would be necessary to create a feeling of comfort and be helpful according to the participants.

Reflecting on these points, the important factors during assessment appear to be direct questioning from the assessor to avoid any lack of clarity regarding the level of disclosure around trauma, as well as information regarding the purpose of asking those questions. How this information is then recorded and disseminated, and to whom, are equally important details which service users feel they have a right to know. Presenting this information in a formulation to aid the service user to understand how their early experiences have contributed to their mental health and the treatment options that are then on offer to them was also believed to be a fundamental part of a collaborative assessment process. The terms used and the feedback from the assessor during this process merits careful consideration. This is pertinent when the assessment is undertaken by a clinician whom the service user has never met before and has not had the opportunity to build rapport with.

### 6.2.2 Theme 2: The therapeutic relationship

The participants highlighted a wide variety of qualities that they valued in healthcare professionals they had worked with. These included the following key words: 1) openness; 2) non-judgmental; 3) humanistic; 4) challenging; 5) holistic; 6) enabling; 7) helpful; 8) skilled; 9) experienced; 10) validating; 11) safe; 12) interested; and 13) collaborative. The group of professionals the participants believed had had the greatest impact on them and validated them the most throughout their experiences in mental health services were community psychiatric nurses (CPNs). Even though neither participant had engaged in any trauma-specific work with CPNs, there was an acknowledgment of the value of the strength of the rapport and the bearing this had on their self-esteem and modelling a healthy boundaried relationship; something which had been difficult to establish in other areas of their life. Further examples of validation were described in other settings, with one participant describing feeling validated during a recent trauma-specific assessment:

"But you know, I found that really helpful and very, I don't know, very enabling really because I have steps to follow through something that was incredibly chaotic. I was then able to, and I felt included in that. And involved. And mostly listened to"

(Participant 1)

There were also some examples of experiences that had not gone well and how the disclosure of traumatic material was not approached in a sensitive manner or responded to in a way that felt validating for the patients. This was experienced by participants with various healthcare professionals, including psychiatrists, community psychiatric nurses and inpatient staff. Examples of invalidation included feeling dismissed by the healthcare professional, or the clinician giving the impression they are not interested in the patient's story or not knowing what to do with the information once it has been voiced:

"I did disclose to my first psychiatrist some stuff and from that point it was kind of chaotic because nobody seemed to know where to put me or where to send me or who to talk to about it and all that kind of stuff. So I'd, yeah, I had kind of shared this one big thing with this person and then it was kind of well actually we don't know what to do with that so put it away kind of thing basically." (Participant 1)

Participants described feeling small and having a sense that nobody cares. There was a fear of being judged or being labelled dramatic, or not being believed. Not being asked about trauma also felt invalidating. There was an acknowledgement of a power imbalance within the

therapeutic relationship and the therapist being perceived as the expert which made it difficult to interrupt or drop things into the session without it being explicitly directed by the therapist. One participant described a psychiatrist giving the impression that asking questions which encourage disclosure of traumatic memories was 'somebody else's job'.

Inconsistency was raised as a detrimental factor in building rapport and trying to establish a safe trusting relationship. There were descriptions of seeing different professionals from appointment to appointment. In particular, they described outpatient psychiatric review appointments as being a situation where they would often see a different psychiatrist on each occasion. A high turnover of personnel in some areas had led to a change of therapist on a fairly frequent basis too. One of the fears that was expressed regarding a high turnover of staff was that of assumptions being made by clinicians. Both participants described anxiety around the documentation of a disclosed trauma history in the clinical notes and this creating preconceived ideas from the therapist being formed about the patient before they had actually met with the therapist. If there is a need to be transferred to a new member of the team, the participants expressed a desire for this to be a collaborative and transparent process. Participants also spoke about meeting healthcare professionals outside of mental health and outside of their own direct care team and the anxiety this can create. These are often brief interventions where participants have not had the opportunity to share their 'story'. An example was given by one participant of their experiences of presenting in accident and emergency following self-harming or suicidal behaviours where they were not known to the healthcare professionals. There were mixed descriptions of these experiences, with some examples of staff demonstrating warmth and empathy to the participant and recognising they were in crisis and emotionally dysregulated, to staff being cold and judgmental and labelling the participant as being manipulative or attention seeking. Both participants felt wider education for these groups of staff who they encounter periodically would be beneficial.

A further impediment to establishing rapport was a lack of interpersonal effectiveness skills in the patient. Both participants voiced concerns in this area; particularly, difficulties with assertiveness skills. This was felt to hamper disclosure or the ability to voice any barriers to disclosure. One patient described what she called 'good girl syndrome', passively accepting what is on offer, not questioning other treatment options or being able to express dissatisfaction with a treatment plan. The other participant used another term for this: 'fearful compliance'. She described this as passively going along with things to avoid any conflict or not feeling able to express an opinion. They recognise these traits are very much a product of their

early life experiences and both believed these would be common characteristics in many patients with a history of complex trauma. They both voiced it would be helpful if staff were alert to the risk of patients being passive in sessions and said they would like to be included more in shaping their individual sessions. They also wanted collaboration over decision making and the overall treatment plan.

In summary, the therapeutic relationship appears to play a pivotal role in trauma-informed care, regardless of the care that is being offered and by whom. The need for clinicians to validate patients by listening to their story in an interested manner, to be able to show warmth and not be afraid to ask direct questions, appear to be important features for building rapport. Collaboration, transparency and offering treatment choices also seem to be significant ingredients in a strong therapeutic relationship with patients who have a trauma history, as is consistency and avoiding having a rapid turnover of staff and the need to be repeatedly rebuilding the therapeutic relationship with somebody new.

#### 6.2.3 Theme 3: Attachment

Alongside the importance of establishing a strong therapeutic relationship, the need to consider the ending of relationships was flagged as being equally important. The participants recognised that therapy needs to be time-limited and that there needs to be an avoidance of creating dependency on the therapy or therapist, but both gave examples of having difficulties with treatment endings and feelings of resentment that have arisen at these times. They described the resentment being related to growing anxiety about feeling unsupported after therapy and a feeling of abandonment, a common trait in patients with a history of complex trauma given the impact this has on attachment styles (Palihawadana et al, 2019). They also described a sense of being punished. This related to the timing of discharge and, rather than feeling rewarded for having put a lot of work into therapy and reaching a point of stabilisation, they felt treatment was abruptly stopped at this time:

"Despite the fact you've done all these things, you've learnt all these skills, you've done all that, you've worked through some of the goals that you've had and all that kind of stuff, then it literally stops." (Participant 1)

"Then you know the second you start to get, or appear better, whether you are or not, then that service stops. And that's quite difficult and terrifying really because you know

you've done all this work, this really good work with people, and then all of a sudden it just stops." (Participant 1)

Treatment abruptly ending was raised a few times and, on exploration, these feelings of sudden endings had been specific to a lack of an exit plan or preparation for discharge, which should be integral to the treatment. Anxiety was also expressed regarding the risk of relapse. This was connected to feeling unsupported post-treatment and not being clear about how to navigate back into treatment if needed and what would be offered at that stage if they had already completed a specific piece of work.

Distilling this belief further, they both expressed they would have liked a clearer plan of what would happen after discharge, being provided with information about other services where they can access support, who to contact if they are in crisis, and when to seek a new referral back into services should it be necessary. They had a few ideas of how preparation for discharge could be improved including the use of phase three treatment. Phase three treatment is focused on building a new and fulfilling future (Cloitre et al, 2002) and they felt this could be used as a stepping stone towards greater independence, for support in developing interests outside of mental health services, and the opportunity to build healthy relationships outside of therapy:

"I think personally but logistically I think that service, the phase three service is a very specific kind of thing if you like it's a separate entity almost, I mean it's all connected but it's a separate thing and it is like a, I don't know, it's a stepping stone I suppose between sort of being in treatment and being out in the world." (Participant 2)

One of the strongest attractions about phase three treatment for these patients was the fact that right from the introduction into treatment, the whole focus is on discharge and is 'counting down' towards it with a concrete plan of what will happen. They both felt this built confidence to take that step when discharge arrived.

The participants interpretation of how decisions are made around the length of treatment and when to discharge was discussed. Both stated decisions are made based on finances and not their individual needs, with one participant believing the 'bean counters at the top' put time restrictions on therapeutic interventions and a time limit on recovery. Both expressed that the people making these decisions did not understand the complexity of their problems or the value they get from their therapy. They both recognised that therapy should be time limited but would have liked more information from their therapist in respect to how the decision is

made regarding length of treatment and how many sessions they will receive. Participants discussed the difficulty with treatment ending corresponding with the perceived stability of the patient, and how they fear they will struggle to maintain that stability over time. One participant suggested it would have been helpful to have some form of low-level support from the therapist they have the relationship with, post-discharge, possibly through infrequent appointments to check-in throughout the year or the opportunity to access telephone support in a crisis. They suggested if there was ongoing support in this way, it may reduce the risk of relapse and the need to access high intensity treatment again.

Overall, the important factors when considering the theme of attachment appear to be the ending of the therapeutic relationship. In particular, the avoidance of any sense of abandonment and invalidation as therapy ends. Collaboration and transparency are considered critical elements in the discharge process, as is the timing of the ending and the overall length of treatment. Consideration needs to be given to how individuals can access support outside of therapy, and the access route back into treatment if necessary. The role of external agencies and phase three interventions should also be considered.

#### 6.2.4 Theme 4: Treatment

The importance of tailoring the appropriate treatment to fit with their needs was expressed by both participants. They described a belief that their treatment packages had been trial and error over the years of having spells of inpatient and outpatient treatment, and long spells not in treatment at all. They were able to identify the merits of some of the interventions they had been offered and some of the shortcomings of other treatment which they had found less effective. They spoke about an overlap between different services and experiencing multiple input at the same time, with a consultant psychiatrist prescribing medication, accessing general support from the community mental health team, and having specialist input from the personality disorder service. Communication was raised again as an issue with one participant feeling that services failed to share information with each other. They both also described a lack of awareness of their treatment options and felt that many clinicians do not have an awareness of what services are available or who is responsible for referring them on:

"...if you don't know what is on offer it's very difficult to see how things link together and why something might be useful." (Participant 2)

There was also a concern that they had been offered services that were not relevant to them as a means to fill a gap.

Feelings of frustration were expressed at not being offered the appropriate treatment at an earlier stage. One participant felt she could have avoided some of her inpatient admissions should she have been offered early intervention for trauma and had it diagnosed and addressed sooner. She believes if she had received psycho-education to understand how her traumatic experiences had led to a pattern of maladaptive behaviours, and difficultly with emotional regulation, her treatment trajectory may have been very different:

"If I had been offered the structure that I have had, I would not have ended up in hospital. I would not have ended up not being in work. And I would not, you know, that's my genuine belief. If I had gone through this process ten years ago then that wouldn't have happened." (Participant 1)

Early intervention was discussed, and the participants felt this did not necessarily need to be in the form of structured treatment. They offered three suggestions that they felt would have benefitted them at an earlier age: (i) having someone safe to approach to share their concerns with, (ii) someone to validate their behaviours and help them to understand how the behaviours related to their childhood experiences, and (iii) some basic skills coaching. Having this available at the time they were in school may have helped one participant to feel 'normal' and the participant believes it may have helped them to avoid engaging in some risk-taking behaviours.

Specialist treatment for post-traumatic stress disorder (PTSD) was discussed, with participants describing their experiences of both eye movement desensitisation and reprocessing (EMDR, Shapiro, 1989) and the prolonged exposure (PE) model (Foa, 2011). These are both traumafocused, first-line psychotherapies for individuals with PTSD. EMDR had been offered in isolation from other therapies and PE had been offered as part of phase two of a phase-based intervention approach. A phased-based intervention is a three-step hierarchical guide for therapists for the treatment of complex trauma. Phase one focuses on the establishment of a therapeutic relationship and creating a state of safety for the patient, teaching skills to regulate emotions and to tolerate distress without engaging in risk-taking behaviours. Phase two is the processing of traumatic memories and phase three is building a life that feels worth living. The phase-based approach had offered what one participant described as an outline

plan of how she was going to navigate through treatment and gave her an overview of how she was going to get there and what to expect along the way:

"I found that really helpful and very I don't know, very enabling really because I have steps to follow through something that was incredibly chaotic" (Participant 1)

The phase two work was offered as an optional part of the treatment package and she said she did not feel compelled to engage in this work. The readiness criteria for engaging in phase two work was also discussed and there was an acknowledgement that there have been previous missed opportunities to do this work as it was not available at the time when participants were in a position to engage in it. This was both from a behavioural point of view, having reached a point of stability where they are not relying on unhelpful coping mechanisms to regulate their emotions, and in terms of their motivation to embark on the work. They described difficulty in maintaining the stability required to meet the readiness criteria whilst out of treatment and waiting to be assessed by another service. The participants again described disparity and a lack of consistency in services in terms of what treatment packages are on offer and the overall difficulty they perceived in accessing phase two work.

Both participants felt that 'trauma work' does not stop, regardless of markers for recovery. The length of phase one treatment was highlighted as being important, with them suggesting that lengthier treatment is necessary for patients with a history of psychological trauma. They described the lengthier treatment being necessary in order to forge rapport, to build skills, and to plan for the future. The medical model and the use of medication had been of limited use according to both participants. They both valued being offered group work and the opportunity this gave them to meet other people with similar experiences and they had both liked the right environment this gave them to build on interpersonal relationships. Dialectical behavioural therapy (DBT) was discussed as an example of such group work that had been offered as a phase one intervention and one participant stated she wished this had been available to her at an earlier time in her life as clinicians did not know where to refer her on to when she was engaging in risky behaviours. They had both been advised that they could not be in receipt of two talking therapies at once and that one treatment episode needs to be concluded before embarking on another form of therapy. They both felt the function of this rule had not been explained fully to them.

In conclusion, clarity regarding treatment options and a comprehensive treatment plan with clearly identified services and professionals who will be delivering this care are all components

of trauma-informed care for these participants. Joined-up team working and the avoidance of sitting on waiting lists for specialist phase two work should prevent the risk of relapse and reduce anxiety and frustration for these service users too. Phase-based interventions offer a structured approach to help patients navigate through the process of trauma work and offers a lengthy episode of treatment which should be seamless, supporting them to transition to the next phase of treatment. It should also allow some flexibility should the readiness criteria for Phase two treatment not be met.

## 6.3 Findings: phase 4 focus group with therapists

### 6.3.1 Introduction

This section will review the data from the focus group with therapists. The views of four eating disorder therapists (three women, one man), included two psychologists, a nurse and a consultant psychiatrist. Their interpretation of trauma-informed care was explored, along with their visions of how services would need to adapt to be working in a trauma-informed way. Examples of how trauma is currently treated within eating disorder services, and their opinions of where (which service) and who (which professional background) are best to address specific PTSD symptoms were also considered. Different models of care were also discussed and staff training needs where considered. Four themes emerged from this discussion: 1) assessment; 2) therapists fears; 3) current treatment provision; and 4) future development in trauma-informed care. The sample characteristics for these participants are detailed in Table 6.1.

Table 6.1 Sample characteristics phase four

Participant number:	Core profession	Gender
1	Psychologist	Female
2	Psychiatrist	Female
3	Psychologist	Female
4	Nurse	Male

#### 6.3.2 Theme 1: Assessment

Participants reported that understanding trauma starts with the first contact with a patient when they enter services and attend for assessment. There were mixed opinions amongst the therapists as to how to approach this sensitive area with patients, with a lot of concern expressed about doing harm and not wanting to be too direct at that initial appointment. They all reported using standard questionnaires, which ask some questions about trauma.

"I would fill out standardised questionnaires with them. And so that might bring up issues that would prompt me to ask in a bit more detail. We do a sort of risk assessment measure here as part of our standardised measures and that asks specifically about particular types of trauma." (Participant 1)

During the assessment interview, half the participants described not wanting to probe patients, preferring instead to ask indirect questions which would allow patients to offer information if they chose to.

"I think within the assessment you are asking about history of mental health problems in their family, plus general history around about development. So if people want to mention it at that time they usually do." (Participant 4)

"I would tend not to directly ask but if you are gathering information about family background and you know early childhood and so on and so forth it may well come up. But I wouldn't perhaps probe for it. I wouldn't sort of ask a direct question you know, have there been any traumas in your life." (Participant 3)

However, two participants were in favour of routine enquiry and asking direct questions:

"Sometimes there is no inkling of it (trauma) at all and in which case again when you are taking the history you would be probing as to whether things had happened."

(Participant 2)

"I suppose it's something we are trained to ask about routinely. I guess for me it's something I would probably try and get an inclining of at initial assessment."

(Participant 1)

A delay in patients disclosing big t traumas was reported by all of the therapists, with descriptions of patients sharing information as they are approaching discharge. Big t traumas are events most commonly associated with PTSD, for example, life threatening experiences,

sexual violence and serious injury. This made it difficult to treat the issue as time was limited and there were concerns about de-stabilisation at that point in therapy if the trauma is pursued. This led to a debate as to whether routine questioning may help to avoid this. Dealing with fragmented memories, and attempting to tease information from patients, was considered to be a drawback of routine enquiry.

Participants felt that the questionnaires used often pick up on big t traumas, but small t traumas are missed. Small t traumas can include highly distressing events such as emotional abuse, bereavement, bullying or non-life-threatening injuries. They believed these are likely to be more prevalent and need separate discussions to gather information and understand how this has impacted on individuals. Relying on questionnaires alone was therefore not felt to be sufficient.

"Trauma is over a wide spectrum but straightaway we always jump to the top. Things like divorce or bad relationships with family growing up or actually present relationships, we do work on all these things. It's just we always jump to sexual abuse or post-traumatic stress or all these things as that's what trauma is. Well no it's a lot wider." (Participant 4)

Therapists expressed a reluctance to use the word trauma directly. Their preference is to enquire in an open-ended way, for fear of destabilising a patient, or creating difficulties in establishing rapport at that initial appointment.

"I am not sure I would directly call it trauma; I suppose we'd start in an open-ended way rather than a very direct way and leaving it open for people to come up with something if they want to. And I think some people, I mean you are trying to engage people and have them come back in their first assessment and they are often very scared of coming." (Participant 2)

Some participants felt probing was unnecessary and would risk discomfort for those patients who had not experienced trauma, worrying that asking the questions suggested there was an assumption that all eating disorders patients have been exposed to a traumatic event. However, participants also acknowledged that, by not asking direct questions, this then risks omitting parts of the patient's story and a 'piece of the jigsaw' is missing when it comes to undertaking a formulation with a patient. Recent media coverage of sexual abuse was felt to have raised an awareness in the general public about trauma. Therapists believed, for this

reason, that patients may feel this topic is more acceptable to talk about and may make them more likely to self-disclose sexual abuse at assessment.

It was acknowledged by participants that the patient's view of trauma is subjective and therapists need to ensure assumptions are not made that everybody who has experienced adversity has been traumatised. The participants made the distinction between small t and big t traumas and how small t traumas are often overlooked. One participant described a patient expressing regret over disclosing trauma:

She's said to me more recently I wish I'd never said anything about it because she doesn't feel it's the main issue, there is other traumas probably in her life that have, you know, been more influential above and beyond that one incident." (Participant 1)

There were concerns that patients should not be defined by a one-off incident from their past and worried that therapists 'latch on to' these events and create significance about something that a patient may not view as significant in their life. The distinction between traumatic experiences and PTSD was discussed with an acknowledgment that the risk of developing PTSD in response to trauma is mediated by the individual's resilience.

"It's difficult to tangle out, is it significant, is it not, is it the patient that has been different that hasn't been able to deal with these kinds of things or you know why have they responded in that kind of way because some of these things, well most of these things are universal to some extent." (Participant 2)

Resilience can be described as the product of the interaction between biological, social and psychological factors which determine how an individual responds to a traumatic event and predicts future coping too (Southwick et al, 2014). Patients with adequate support networks and those able to nurture themselves may be in a better position to share details of their history of psychological trauma with less impact on their wellbeing than those patients with lower levels of resilience. Gathering information that would help measure resilience may also be of benefit.

Their views were that the assessment of trauma needs to include the assessment of risk, which they describe as complex in nature. They believe risk needs to be assessed carefully in patients with a trauma history with consideration given to the patient (e.g., deliberate self-harm, suicidal behaviours, self-neglect), risks of them harming others (e.g., violence, neglect), and the risk that the trauma may be current and ongoing. Being able to assess the patient's safety and having a robust crisis plan was also deemed critical by the participants.

"You need to manage risk as well I mean some people if you are going into trauma, you have an idea of how you are going to react, the eating disorder services aren't set up as emergency services, so somebody might phone on a Monday morning and they won't get a phone call back until the Tuesday or maybe the Wednesday." (Participant 4)

Also, participants felt that there needs to be consideration given to how to respond if there are concerns that the perpetrator of historical abuse is presently posing a risk to others. It was acknowledged by participants that this is a highly sensitive issue and some participants felt this may hinder disclosure from some patients. Issues around overriding confidentiality and the damage this may cause to the therapeutic relationship was recognised. Participants expressed that these risks can be difficult to manage, alongside the physical risks that are present with patients with very low BMIs. Support from the Community Mental Health Team was felt necessary if there were high levels of risk of self-harm for example.

To summarise, participants all shared a view that the assessment of patients is the role of every therapist and that participants have their own preferences in terms of how trauma is broached with patients. The use of questionnaires ensures that big t traumas are asked about, but the use of routine enquiry regarding trauma histories causes discomfort for some participants. Risk assessment and management is seen as a major concern when dealing with the disclosure of this sensitive information, and joint working with other services to address this risk was considered to be good practice. Avoiding assumptions that all adverse events are viewed as traumatic, or lead to PTSD, was felt to be an important consideration during assessment.

#### 6.3.3 Theme 2: Therapists fears

The therapists expressed anxiety when broaching the subject of psychological trauma with patients and on how to respond if patients raised the topic. The most common fear was that of destabilisation for the patient, believing that the increased emotions that would be involved in discussing the trauma history would lead to increased use of maladaptive coping techniques, such as be dietary restriction, binge eating, purging, self-harming or suicidal behaviours:

"...people could end up restricting further and disengaging with the service if we are pushing at that." (Participant 4)

One of these participants used the term 'opening a can of worms' on a couple of occasions to describe a fear that the thoughts and emotions would be very difficult to contain once the discussion has started. Destabilisation was also used to describe fears of patients losing stability in their life, such as family relationships, their ability to work or study and function well outside of their eating disorder:

"...whereas the ones who are quite sick but still managing to juggle things they don't really want, you know they are holding down a job or holding down a course, they don't want to get things worse." (Participant 4)

The fear of making things worse was attached to a sense of responsibility held by the therapists, with the majority of them expressing a preference to discuss trauma only when it had been brought up by the patient themselves. They felt this would indicate a readiness to talk about it and would imply the patient has built a good rapport with their therapist and would feel safe to discuss it. A couple of participants felt they would be comfortable broaching trauma with patients they had a good rapport with and felt confident they had resilience or had developed skills to manage unwanted emotion without the risk of making things worse.

A further anxiety related to making things worse was expressed by a couple of participants, worrying they may re-traumatise a patient through encouraging reflection on traumatic events. This subject was raised several times and began with a discussion around how recalling a traumatic event may increase PTSD symptoms and be very distressing for the patient. This led to concerns that the therapy itself may risk re-traumatisation. Examples of the coercive nature of the treatment for anorexia, where it can often be difficult to find shared goals, particularly in the early part of therapy, was given as an example of how this may mirror abusive relationships:

"And even the trauma caused by the treatment and the disorder is inherent isn't it, it's trauma and they are traumatising themselves and then they are taken into treatment services where they are traumatised again by some of the things that are done in terms of caring." (Participant 1)

The risk of uncovering that the trauma is ongoing, whether that be to the individual patient or another person in contact with the perpetrator of the abuse, was also voiced. The responsibility of needing to act on that information, which may be against the patient's wishes, was also felt to risk re-traumatising them. Attached to this was the risk of the patient not being believed or creating disruption within their family or community.

A central thread within much of this anxiety was a belief from therapists that they lacked the skills needed to be able to respond appropriately to complex trauma or PTSD. A lack of expertise was voiced by most participants, and this surrounded the language that is used and the knowledge of specific trauma-focused interventions.

"I mean I've done the basic training that we do. But I guess I sort of worked in general adult for three years before I then focussed in on eating disorders so I feel my sort of area of specialism is more dealing with that than it is the sort of more complex trauma." (Participant 3)

Most therapists felt they would be able to signpost patients on to other services where they could get specific treatment if they needed to work on PTSD symptoms. There was anxiety expressed around how smooth a transition this would be, with an acknowledgement there would likely to be long waiting times before the patient would engage with that service. There was also a sense of responsibility for keeping that patient safe in the interim. The culture of the eating disorder service was also raised with recognition that trauma-specific therapy has not been part of the eating disorder service and therefore it was not felt to be any one therapist's responsibility.

Trauma-specific therapy had not been identified as a training deficit by those therapists who had not been trained in this and several reasons were offered as to why this was the case. Some felt this was related to a lack of resources and personal limitations, but there was also acknowledgement that it was partly due to personal willingness or a lack of interest in expanding their knowledge and 'skills base' in psychological trauma. Workload and existing pressures, such as waiting times, other training needs and service development plans, had also contributed to the reasons for not pursuing specific trauma training. The evidence base for eating disorders changes rapidly, as does service demand and widening the services remit was deemed to be impractical by some participants.

"Quite often training like EMDR is very expensive, quite often it involves three different levels so it's not enough to do the basic you have then got to go on and do level one and level two and I think a lot of trainings are going that way now. And you are always up against that thing of well can you justify this money you know. How many of your patients is this likely to benefit." (Participant 4)

A general feeling that therapists are risk averse was aired as a reason for not testing some of these assumptions and beliefs that patients are fragile.

"We would tend to think oh no you know their BMI must be a certain level before we get into that. And I mean that is very much perpetuated by the Fairburn model and you know this notion that you know don't even attempt it." (Participant 2)

Examples were given of therapists they know who work in a different way and do take risks and they felt this was related to their wider experience of trauma work and their ability to assess risk appropriately and assess the patient's readiness to discuss trauma. An additional worry was that of complacency and appearing cold and detached when discussing a trauma history. Participants spoke about trauma being widespread and the worry that exposure to this may impact on a therapist's own schemas. This could create a need to harden themselves and avoid any emotional response to what they are hearing, with descriptions of behaving in a cold and numb manner:

"...you become so used to it that it doesn't actually faze you much when you hear horrendous details and you know you can become quite jaded and your perception of normal life you know and go home and think well actually that's, you know don't bother me with that. I've heard much worse today when actually it's relative isn't it?" (Participant 2)

The risks to the wider members of the team were also discussed, particularly the risk of vicarious trauma and a worry that exposing staff, who do not get offered supervision for psychological therapies, to detailed descriptions of traumatic events may be harmful. They spoke about the risk to the team secretary when typing up assessment letters:

"I think we need to be careful of our secretary, I don't know if she has said anything, but she sometimes has to do typing for the other psychologists and a couple of times she's mentioned to me about upsetting things she's had to type up for people."

(Participant 3)

Therapist's anxieties appear to play a key role in their willingness to approach the topic of trauma and their overall interests in developing trauma-specific skills. These fears surround causing harm to the patient and escalating risk which was felt may be difficult to contain in a specialist eating disorder service. Worries about the psychological impact that repeatedly hearing detailed trauma histories can have on staff was also raised. These fears were coupled

with a sense of inadequacy and a lack of conviction in their own abilities and the belief these issues would be better addressed with experts in the field of trauma.

## 6.3.4 Theme 3: Current treatment provision

The core business of the treatment offered in a specialist eating disorder service was discussed with consideration of treatment models used and how this applies to patients who present with complex trauma. The participants described a belief that the service they worked in mirrored that of other specialist outpatient eating disorders services. The main focus of the work they described with eating disorder patients is that of stabilisation, addressing primarily the physical health risks attached to eating disorder patients. Stabilisation covered weight restoration and behavioural changes such as changing eating patterns and ceasing compensatory behaviours. They described a goal of attempting to support the patient to do this as an outpatient, avoiding hospital admission. Maintaining the safety of these physically compromised patients was deemed to be the foremost function of the therapy. In addition to this, supporting patients to function, for example, completing their exams or remaining in work, was also felt to be stabilisation work. Participants highlighted that underweight patients will not be able to engage in meaningful in-depth psychological therapy due to their starved brains and this was also a reason they had for prioritising physical stabilisation. The Fairburn treatment model was described by participants (a transdiagnostic treatment model endorsed by NICE (National Institute for Clinical Excellence, 2004), Fairburn et al, 2008) as this has a clear treatment pathway to lead therapists through the phases of eating disorder treatment and the stabilisation process:

"I guess I would tend to be focusing on the situation now and what the kind of immediate issues are, in a hope to, I mean, I suppose, because a lot of our patients come to us quite physically compromised, you are always aware of just the basic level of functioning or are they safe first of all before you want to go into any kind of detailed stuff." (Participant 2)

All of these stabilisation requirements were believed to trump any trauma-focussed work.

Once stabilisation has been achieved, the default response to treating PTSD or complex trauma was to refer on to psychological services:

"I guess locally if I felt a patient had complex trauma I would probably want to look at stabilising them in terms of their eating and then I guess I would be considering

referral onto our local psychotherapy service for longer term trauma focussed input."
(Participant 1)

The prevalence of co-morbidities was raised when discussing complex trauma, particularly emotionally unstable personality disorder and the struggles therapists have accessing specialist services for personality disorders locally for these patients. The participants highlighted the difficulties this can create, having to offer crisis intervention and having to build links with other services, such as psychology and community mental health teams. Some of the skills that were described with the early work with these patients included motivational interviewing to prepare them for change, and emotional regulation skills to deal with the loss of disordered eating as a coping skill for emotional dysregulation. Co-morbidity was raised as a thorny subject as the therapists described receiving increasing numbers of referrals where the eating disorder was a smaller component of a much more complex picture and this created some confusion as to the best service to be treating them. Examples were given of patients being passed from service to service and the impression of treatment being disjointed due to a lack of continuity. There was a sense of responsibility expressed in terms of maintaining the physical stability of these patients whilst they awaited access to specialist services. The participants could see that keeping hold of these patients until they are picked up by another service then creates a bottle neck for the eating disorder service by increasing waiting times.

Treatment for PTSD was discussed and it was acknowledged that phase two interventions are generally not offered as a routine intervention by the therapists within the specialist eating disorder service. One member of staff was cited as being an exception to this rule as they had worked in a separate service and had a different skill set, having trained in autogenics and EMDR (eye movement desensitisation and reprocessing) for the treatment of PTSD. EMDR was raised as an intervention that had been offered to patients with PTSD symptoms outside of the service, but this was not offered 'in-house'. None of the participants had been trained in EMDR and they did not view it as a core treatment in an eating disorder service. However, most of the participants described non-specific trauma-focused work they do with patients on a day-to-day basis. Participants described a willingness to listen to a patient's story and to allow them time to disclose information. Giving patients freedom to discuss traumatic events and allowing it to be added to the session agenda was universal across participants:

"I think if somebody was you know talking and wanting to talk about it then I would go with that, with them. I wouldn't, I don't think I would say no we are not here to talk

about that today, we are here to talk about what your meal plan is like."
(Participant 3)

The time frame was felt to be an important factor in this, with long-term patients being most likely to self-disclose trauma and to feel safe to talk about their story in a well-established therapeutic relationship. Participants described high numbers of university students who return home at the end of term or the end of their course and a reluctance to embark on indepth work for fear of leaving them unsupported.

Avoidance that evokes strong trauma memories was flagged by participants as being a barrier to recovery and there were examples of how exposure work could address this, particularly if the avoidance was around particular foods or eating habits. Avoidance was also described in the context of emotions, with participants giving examples of trauma being described in a detached, disconnected way with no emotion present, or patients becoming defensive when wanting to avoid discussing anything uncomfortable. Exposure was felt to be an area that could be targeted with patients in long term therapy. Psychoeducation was also recognised as being critical to help a patient understand the role trauma has had in the development of an eating disorder and general ability to cope. A survive and thrive group (psycho-education for survivors of complex trauma) was mentioned by participants as a useful resource that they can refer patients to. It was felt this psychoeducation helped to normalise the patient's experiences and assure them that they are 'not going mad'. Again, the difficulty of referring patients on to other services was raised with the need for patients to be safe and stable.

The current treatment provision adheres to NICE guidelines and appears to reflect the complex needs of this patient group, as well as the skill set of the therapists within the service. Whilst some deficits were highlighted in treatment provision for those with PTSD, it is not clear which service is best placed to treat these patients. Limitations around therapist training is an issue, as well as difficulty accessing more specialist services. However, more informal trauma-informed work is being offered to those with trauma histories, and therapists described this being most often delivered when patients are well established into treatment and have formed a secure therapeutic relationship with the therapist.

### 6.3.5 Theme 4: Trauma-informed care and future developments

Participants were asked to articulate their interpretation of trauma-informed care and they foremost described the need for professionals to have an awareness of psychological trauma,

how this may have impacted on the patient, and be related to the symptoms that are displayed. They also discussed a need to elevate the awareness of trauma to other healthcare professionals and the importance of valuing patients:

"I suppose for me it's just about an awareness that these issues that many of our patients may well come with and it may well explain the symptoms that they have. And I guess it's about a willingness to address that. Particularly if the patient feels that's the most pressing issue in their history." (Participant 4)

An awareness of the clinical environment was also felt to be important, with consideration given to waiting areas and consultation rooms, to ensure comfort and privacy. These areas are at risk of being a sterile environment, creating unnecessary anxiety. Protecting the therapist was voiced as an important component of trauma-informed care. Therapists described the need to be aware of the risks of repeated exposure to hearing detailed accounts of traumatic events, how this may impact on the therapist, and the importance of recognising their own limitations. Access to regular structured clinical supervision was offered as a safeguard for maintaining the wellbeing of therapists working in this line of work. A description of having somewhere safe to 'offload' was given and this could also be offered informally within the bounds of the supportive relationship amongst team members.

Other key ingredients that were discussed were the role of the therapeutic relationship, considering how therapists engage patients, offering compassion and being non-judgemental when patients struggle to engage or make changes. Being able to validate a patient's experiences and acknowledge the difficulties this creates for them was reported to be part of a trauma-informed approach. The process of talking about trauma in a psycho-educational position rather than an exploratory way was also discussed with examples of how the "survive and thrive group" helps patients to understand their symptoms:

"Sometimes perhaps talking about trauma in that way, rather than delving into their own personal experiences is incredibly useful to some folk I terms of trying to understand why they feel like they are going crazy or mad or whatever." (Participant 1)

Early intervention to reduce the length of suffering and to give patients the opportunity to address these issues at an earlier point may help to reduce the longevity of the illness, according to some participants. Trauma-informed care does not need to be structured PTSD work, according to the participants, and they were keen to stress that they believe the basics of trauma-informed care were very much part of the staple work offered by therapists within

specialised eating disorder services. However, they also had ideas of how trauma-informed care could be improved across the service. This started with an acknowledgment that they need to refresh their knowledge of the current evidence base for the treatment of complex trauma and to look to what other eating disorder services in different geographical areas are doing. One participant proposed that the topic of complex trauma needs greater precedence within the field of eating disorders and needs to be talked about more, with suggestions including the delivery of trauma workshops at eating disorder conferences or clinicians cascading trauma training to other members of the team.

Deficits in training and skills would need to be assessed across a whole service as participants highlighted that this has not been included in many of the participants core training and had left them believing that trauma work was a specialism. This resulted in them referring on to experts. Participants emphasised that increased funding would need to be allocated for training to happen but also pointed out the cost-benefit of this as high numbers of patients are likely to benefit. They flagged the need to gauge the current level of unmet need in the eating disorder population coming through services. Cross fertilisation of training and creating a role for a specialist within a service who could 'trickle down' information regarding developments in the field of trauma and be a point of expertise was offered as a potential solution to keeping the costs of training down. Alongside the expense of training, a further barrier was highlighted in that therapist time is so pressured that getting time away from practice to attend courses and to adapt practice can often be difficult. Having an option of being able to access different levels of training and to be able to top up their knowledge in a modular way, through short courses, CPD and micro-credentials was suggested as a practical way of addressing training, rather than having to commit to lengthy training programmes. The importance of considering the training needs of the wider team, not just therapists, was also discussed. Finally, participants voiced that any major shift in service provision or service development should involve the views of patients and considerations for how to include them was discussed.

Awareness appears to be the key theme for a trauma-informed approach, whether that be the awareness of how trauma affects the individual, awareness of the need for a sensitive clinical environment, or an awareness of the training needs of staff, as well as the risks of vicarious trauma. Listening skills and validating the individual go hand in hand with maintaining a therapeutic relationship, which seems central to offering trauma-informed care.

### 6.4 Conclusion

Both focus groups generated discussion around the assessment process, the language used and the different styles of approach that healthcare professionals take to addressing trauma histories. Treatment provision was also a common theme amongst the two focus groups with phase-based interventions and the need for clear treatment pathways and joined up working being of importance. The patient group highlighted the importance of the therapeutic relationship, building rapport and the difficulty with attachment and the need for support and preparation for discharge planning. Therapists highlighted feelings of incompetence at times and the need for greater, improved or more training for therapists regarding trauma-informed care and the importance of frequent clinical supervision. The impact of psychological trauma on an individual's functioning and quality of life resonated with both focus groups. Both service users and therapists could identify how this often leads to destructive high-risk methods of coping with the long-term emotional fallout from psychological trauma.

Some of the themes that emerged from the two focus groups overlap, with many shared opinions between therapists and service users. There were also points of disagreement where the opinions of therapists and service users were at odds. For example, the avoidance of direct questioning around traumatic experiences for fear of doing harm and the urge to minimise risk is an illustration of where the beliefs start to diverge. Service users suggested direct questioning removes ambiguity and believe this can be undertaken in a validating manner, helping to forge rapport and support the development of the formulation. These common and diverging themes will be explored in detail, along with the themes from the interviews with key informants in the discussion chapter. The overall aim will be to address the research questions and understand how these views from key informants, service users and therapists intersect and what can be learned from this when striving for a trauma-informed service within an eating disorder setting.

# **Chapter 7: Quantitative results: Phase 3**

### 7.1 Introduction

This chapter will review the results of phase three of the study; a quantitative observational approach gathering data from patients attending for outpatient eating disorder (ED) treatment at two adult outpatient eating disorder services in Scotland. The key aim of this phase of the study was to explore the prevalence of complex trauma in ED patients and its relationship with ED severity. This aim was addressed through the following three research questions:

- how common are post-traumatic stress disorder symptoms in patients with complex trauma?
- 2. are adverse childhood experiences associated with severity of eating disorder symptoms?
- 3. is there a relationship between post-traumatic stress disorder symptoms and the severity of eating disorder symptoms?

A description of the sample and the statistical tests and findings will follow. This was a convergent mixed methods design, as described in the methodology chapter, and the synthesis of the overall findings from each phase of the study will be explored in detail in the discussion chapter.

## 7.2 Study sample

The sample consisted of 44 patients, of whom 98% (n=43) were women. Men are typically assumed to make up 25% of those affected by eating disorders (Royal College of Psychiatrists' Section of Eating Disorders, 2012), yet the number of men presenting for therapy across these two outpatient services is significantly lower with clinicians reporting less than 10% of annual referrals being men. This suggests men are underrepresented in this sample. Two-thirds (68%; n=30) of participants were recruited from Highland Eating Disorder Service and 32% (n=14) from Tayside Eating Disorder Service. Their ages ranged from 18 to 59 years and the mean age was 28. BMI (body mass index) values ranged from 15.7 to 40.4. The mean BMI was 23.6 and mode was 17.4. Within the field of eating disorders across the UK, a healthy BMI in an adult is deemed to be between 20 to 25 (WHO, 2000). A BMI below 17.5 is the cut-off for a diagnosis

of anorexia nervosa. BMIs below 20 deem an individual to be underweight, whilst a BMI of 25-30 is classed as overweight, and above 30 is obese. BMI data was missing for four participants and there is no indication from the data collection sheet why the therapist had not recorded this data. It is possible it was an error when completing the form, it is also possible the patient's weight had not been recorded at that stage of assessment. The eating disorder diagnosis was made by the patient's therapist and was based on the criteria from the Diagnostic and Statistical Manual of Mental disorders: DSM-IV (American Psychiatric Association, 2013). Bulimia nervosa was the most common diagnosis with 43% (n=19) of patients meeting the criteria for this or atypical bulimia nervosa. This diagnosis is used when a patient closely corresponds to the diagnostic criteria but not all that is specified. Just over a third (39%: n=17) had a diagnosis of anorexia nervosa or atypical anorexia nervosa. This label is used primarily when a patient's BMI is above the diagnostic threshold. 18% (n=8) had a diagnosis of EDNOS (eating disorder not otherwise specified). A third of patients (36%; n=16) had previously been treated for an eating disorder and 64% (n=28) of patients were presenting for their first treatment episode. Table 7.1 details the sample characteristics:

Table 7.1 Sample characteristics phase three

Participant Number	Age	Gender	ВМІ	ED Diagnosis	Previous Treatment Episodes
1	21	Female	20.5	Anorexia Nervosa	Yes
2	20	Female	19.1	Bulimia Nervosa	Yes
3	20	Female	*	EDNOS	No
4	24	Female	24	Anorexia Nervosa	No
5	30	Female	38.7	Bulimia Nervosa	Yes
6	19	Female	23.4	Anorexia Nervosa	Yes
7	26	Female	16.4	Anorexia Nervosa	No
8	57	Female	17.4	Anorexia Nervosa	No
9	29	Female	22	Bulimia Nervosa	No
10	18	Female	21.5	Bulimia Nervosa	Yes
11	18	Female	20.6	Anorexia Nervosa	Yes
12	20	Female	28.1	Bulimia Nervosa	Yes
13	33	Female	35.1	Bulimia Nervosa	No
14	44	Female	40.4	Bulimia Nervosa	Yes
15	22	Female	17.3	Anorexia Nervosa	Yes
16	48	Female	40	Bulimia Nervosa	No
17	50	Female	26.7	EDNOS	No
18	19	Female	21.2	EDNOS	No
19	18	Female	28.1	EDNOS	Yes

20	46	Female	26.6	EDNOS	No
21	18	Female	15.7	Anorexia Nervosa	No
22	18	Female	21.8	Bulimia Nervosa	No
23	34	Female	21.5	Bulimia Nervosa	No
24	21	Female	19.1	Anorexia Nervosa	Yes
25	22	Female	19.6	Anorexia Nervosa	No
26	20	Female	18.2	Anorexia Nervosa	Yes
27	27	Female	19.2	Bulimia Nervosa	No
28	20	Female	24.2	Bulimia Nervosa	No
29	59	Female	*	Bulimia Nervosa	No
30	27	Female	27.1	Anorexia Nervosa	No
31	30	Female	23	Bulimia Nervosa	No
32	33	Female	22	EDNOS	Yes
33	39	Male	39.2	EDNOS	No
34	34	Female	22.9	Bulimia Nervosa	Yes
35	20	Female	*	Bulimia Nervosa	No
36	20	Female	20.3	Anorexia Nervosa	No
37	20	Female	22.3	Bulimia Nervosa	No
38	19	Female	17.9	Anorexia Nervosa	No
39	28	Female	24.6	Bulimia Nervosa	No
40	19	Female	17.4	Anorexia Nervosa	Yes
41	39	Female	21	Bulimia Nervosa	No
42	20	Female	18.5	Anorexia Nervosa	No
43	20	Female	21.6	Anorexia Nervosa	Yes
44	30	Female	*	Bulimia Nervosa	No

<sup>\*</sup> missing data

EDNOS (eating disorder not otherwise specified)

# 7.3 Complex trauma and post-traumatic stress disorder

The majority of patients had experienced at least one adverse childhood experience (82%, n=36) with 18% (n=8) declaring no trauma history, as measured through the ACE questionnaire (Felitti et al, 1998). The maximum number of ACEs experienced by any individual was 8 and this accounted for only 2% (n=1) of the participants. The experience of a single ACE event was the most frequently reported, with 27% (n=12) reporting this. The average number of reported traumatic events for those in the group with a trauma history was 3.6. The most common forms of trauma reported were invalidation (41%; n=18) and parental separation (41%; n=18). Next most common were household mental illness (34%; n=15) and emotional abuse (32%; n=14), followed by physical abuse (18%; n=8) and sexual abuse (16%; n=7). Neglect was reported by 11% (n=5) and domestic violence was also experienced by 11% (n=5)

of patients. A household member going to prison was experienced the least with only 5% (n=2) of patients reporting this. Figure 7.1 illustrates the proportion of participants who had reported experiencing each of the traumatic events assessed in the ACE questionnaire.

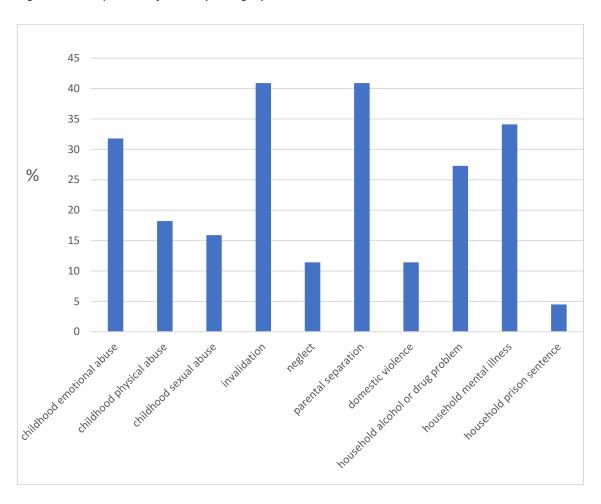
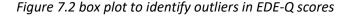


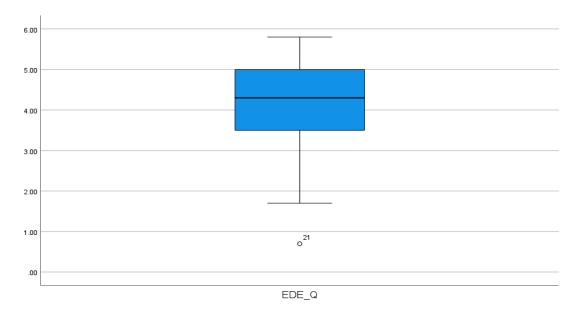
Figure 7.1. Proportion of ACEs by category

In order to answer research question one: "how common are post-traumatic stress disorder symptoms in patients with complex trauma?" the IES-r questionnaire (Weiss et al, 1997) was administered to the 82% (n=36) of patients who reported a trauma history. Of those 82% who had self-reported complex trauma, 50% (n=18) scored 33 or over on the IES-r questionnaire. Whilst the IES-r is not designed as a diagnostic tool, scores of 33 or above are indicative of the presence of PTSD. The mean total IES-r score was 32.7 (SD=24), median was 33 and mode was 0. The overall prevalence rate for PTSD within the 44 participants who took part in this study was 41% (n=18).

# 7.4 Complex trauma and eating disorders

The EDE-Q was to be completed by all 44 participants in the study, but data was missing for two participants (there are no details as to why the data is missing). Of the 96% (n=42) who completed the EDE-Q, global scores ranged from 0.7 to 5.8, with a mean score of 4.1 (SD=1.2), median of 4.3 and mode of 5.2. The subscales were disregarded for the purpose of this research and the overall global score was used as the marker for severity, with clinical significance being assumed at a cut-off score of 4 or above. This classifies an individual to be within the clinical range for a diagnosis of an eating disorder (Carter et al, 2001). There was one clear outlier in this data set (see boxplot in Figure 7.2) who recorded a low EDE-Q score, possibly reflecting the omission of certain sections of the form which would skew the scoring, or possibly a deliberate attempt by the patient to downplay the ED symptoms. Anecdotally within therapy, it is not unusual for patients to admit to under-rating the severity of their eating disorder when first asked about the specific behaviours due to high levels of shame. Unfortunately, the data collection sheet did not provide the scope for therapists to record any additional information that may have given an indication as to why the scoring was low. The outlier was a participant with the lowest BMI (15.7) and they scored below the threshold for an ED diagnosis on the EDE-Q, scoring 0.7. This outlier was removed from the data set for analysis. The mean, median and mode EDE-Q scores were recalculated to reflect the omission of the outlier, with the global score then ranging from 1.7 to 5.8. The mean score was 4.2 (SD=1.1), median 4.3 and mode 5.2. The analysis was run a second time to include the outlier and it did not materially change the results.





To address research question two: "are adverse childhood experiences associated with severity of eating disorder symptoms?" a Spearman's correlation test was applied to explore the association between the total EDE-q scores of the 41 participants and the total number of ACEs recorded in those individuals. A small positive correlation (r=.2) was found but this was not significant (p=.211) (see Table 7.2).

# 7.5 PTSD and eating disorders

A further Spearman's correlation test was conducted to address research question three "is there a relationship between post-traumatic stress disorder symptoms and the severity of eating disorder symptoms?". This test was employed to explore the association between the EDE-Q scores and the IES-r scores. Of the 36 patients who had completed the IES-r questionnaire, two were removed from the analysis as the EDE-Q data was missing, along with the outlier, leaving 33 patients for the analysis. A moderate significant positive correlation (r=.551, p <.05) was found (see Table 7.2). This indicates that greater PTSD symptoms are related to a greater severity of symptoms of an eating disorder. Whilst this test only indicates there is a relationship between the PTSD and ED symptoms, and is not an indication of causality, it could be speculated that the behaviours exhibited in ED patients escalate with higher symptoms of PTSD, as a means to cope with the psychological distress. One of the subscales within the IES-r questionnaire measures for avoidance, a common symptom of PTSD, and dietary restriction and binge eating behaviours are well documented means of avoiding negative emotions (Haynos et al, 2011). It is not clear from these results whether treating the ED symptoms alone would reduce PTSD symptoms, or conversely, whether removing an individual's means of coping through their dietary restriction or binge eating as part of their ED treatment may escalate PTSD symptoms further. Further research to explore this would strengthen arguments for introducing specialist trauma-focused treatment into ED therapy.

Table 7.2 Spearman's correlation between eating disorder severity and childhood trauma (ACE) and symptoms of PTSD (IES\_r)

		Eating disorder severity
		(EDE-Q)
ACE	Spearman's rho	.20
	Sig. (2-tailed)	.21
	N	41
IES-r total	Spearman's rho	.55
	Sig. (2-tailed)	.00
	N	33

#### 7.6 Conclusion

This phase was a small study with low numbers but the results suggest complex trauma is common in ED patients, with 82% of patients having experienced at least one adverse childhood experience. However, exposure to psychological trauma alone does not automatically cause PTSD symptoms: only 50% of participants with a trauma history reported PTSD symptomology. While there was a moderate association between higher PTSD symptoms and a greater severity of ED symptoms ,there was no significant relationship between complex trauma and eating disorder symptom severity. PTSD appears to be a prevalent presentation, with 41% of the total sample population self-reporting through the questionnaire active PTSD symptomology at the point of engaging with this study. Further research is required to understand the links between PTSD and ED symptoms and the possible value of treating PTSD symptoms as part of a phase-based approach for ED treatment. A larger study with greater participant numbers would also enable greater insight into the role complex trauma plays in ED presentations.

# **Chapter 8: Discussion**

#### 8.1 Introduction

This chapter will critique the overall findings of the study, relating back to the literature and highlighting the new knowledge produced in this research study. Recommendations will then be considered for areas of development within clinical practice, policy, and for research. To recap, the study aimed to understand interpretations of trauma-informed care from the perspective of professional key informants, service users with a lived experience of complex trauma, and therapists delivering ED treatment, with a goal to inform future ED service development, through addressing the following research questions:

- 1. how do experts in the field of psychological trauma define trauma-informed care and envision its implementation across mental health services?
- 2. how do patients with a history of complex trauma want to be treated within an ED outpatient service?
- 3. how prevalent is complex trauma in ED patients and does exposure to psychological trauma or symptoms of PTSD increase the severity of ED symptoms?
- 4. how do therapists working in an ED outpatient setting interpret trauma-informed care?

An overview of the triangulation process will follow to aid understanding of the process of synthesising the data from the distinct phases of the study. The discussion will initially focus on the individual research questions before broadening out to address the wider themes which emerged.

# 8.2 Triangulation

As discussed in the methodology chapter, a convergent parallel mixed methods design (Creswell and Creswell, 2018) was utilised to give equal weighting to the qualitative and quantitative phases of this study, with the purpose being to add detail and illustration from multiple viewpoints. It was anticipated that the quantitative phase of the study might recruit low numbers, so the purpose of the quantitative phase was to illustrate the prevalence of complex trauma and PTSD symptoms amongst people with eating disorders. The qualitative

data in phases one, two and four were collected from different types of informants which is an important form of triangulation, offering diverse perspectives (Groenewald, 2004). Phase one of the study gathered the opinions of key informants. All of the participants in phase one of the study had been recruited as they were deemed to be experts in the field of trauma and/or eating disorders. These collective findings, along with the findings from the literature review, acted as a point of reference and a means to corroborate the findings from phases two and four when exploring the beliefs and expectations of trauma-informed care from the perspective of service users and therapists.

Phase two (focus group with service users) was directly compared with phase four (focus group with therapists) to gain insight into the gaps in understanding between these two groups. The focus groups were coded and analysed separately before comparison was made between the two groups. The use of comparative groups in qualitative research is a helpful tool to identify the presence or absence of phenomena, and the variation between groups (Richie et al, 2014). It is particularly helpful when making comparisons between patients' and healthcare professional's perspectives, allowing for a better alignment of health care delivery to the patient needs through highlighting the assumptions that are made from healthcare professionals regarding patients' preferences (Lindsay, 2019). These are important factors when striving for patient centred care. Focus groups were chosen as a means to gather data in order to match the data collection methods across these two comparison groups.

QSR NVivo (version 11) software was used to code and catalogue the data into emerging themes and then exported to Microsoft Word to build a visual framework for cross-referencing between the qualitative phases. Each phase was analysed and coded separately, and key terms were identified within each dataset. A framework matrix helped to draw comparison between the nodes from the two focus groups, along with handwritten notes. The nodes from the interviews with key informants then acted as a benchmark to compare how the focus groups aligned with the expertise of the key informants, cross-referencing across all three qualitative phases to explore the links between the themes that had emerged. The four main research questions relate to the four phases of the research and the results section addresses these phases individually. This section takes a wider view of how these separate findings have presented some common themes and therefore aims to make sense of differences of opinion and points of overlap amongst the different participant groups. The underpinning literature and the findings and statistics from phase three illustrate the presentation of complex trauma in the adult ED outpatient population in Scotland.

# 8.3 Review of the research questions

# 8.3.1 How do experts in the field of psychological trauma define trauma-informed care and envision its implementation across mental health services?

The key informants defined trauma-informed care in several ways and much of the language used was repeated across the interviews. There was a shared belief expressed that there has been a shift in the approach from asking 'what is wrong with you?' to 'what has happened to you?'. This puts the person, or the difficulties or problems that people present with, in the context of what has happened to them during their life, linking the effects of traumatic events to the distress and dysfunction that people experience. The relational aspect of care was also raised, taking into consideration that trust has been broken and recognising it will take additional interpersonal resource to develop trust within a care setting. The ability to be able to respond in a way that is supportive and helpful when trauma has been identified was also of great importance.

When considering the implementation of a trauma-informed approach in ED services, the need to overcome a wider fear of doing harm was voiced. Several areas for development were suggested, including: (i) a robust assessment on entering treatment, with a clear focus on explicitly asking about traumatic events, using routine enquiry to include questions about 'small-t traumas'; (ii) the use of questionnaires to check for the presence of active symptoms of PTSD; (iii) the need for a compassionate approach; (iv) the importance of using the correct language; (v) consideration for the treatment pathways; (vi) the possibility of adopting a phase-based approach; (vii) continuity of care; and (viii) staff supervision and an awareness of the risks to healthcare providers when exposed to other people's trauma histories.

# 8.3.2 How do patients with a history of complex trauma want to be treated within an ED outpatient service?

The service users with a lived experience of complex trauma spoke of their frustration at not being asked about trauma at an earlier point in their treatment trajectory and a desire for clarity regarding their treatment options once their trauma had been assessed. They described difficulty with woolly language and preferred that clinicians were direct and asked clear questions and labelled trauma. Their treatment ideal included a comprehensive, collaborative

plan of care which clearly identifies the services and professionals who will be involved. The service users wanted joined-up team working to avoid sitting on waiting lists and they praised phase-based interventions as it had offered them a structured approach to navigate through the process of trauma work.

# 8.3.3 How prevalent is complex trauma in ED patients and does exposure to psychological trauma or symptoms of PTSD increase the severity of ED symptoms?

Complex trauma, as measured by adverse childhood experiences (ACEs) was found to be common in ED patients, with 82% of patients having experienced at least one adverse childhood experience. Only 50% of participants with a trauma history reported PTSD symptomology. There was a moderate association between higher PTSD symptoms and a greater severity of ED symptoms, but no significant relationship between complex trauma and eating disorder symptom severity. PTSD appeared to be a prevalent presentation with 41% of the total sample population reporting active PTSD symptomology at the point of engaging with this study.

# 8.3.4 How do therapists working in an ED outpatient setting interpret trauma-informed care?

When discussing trauma-informed care, a key theme voiced by the therapists was an awareness of how trauma affects the individual. This was paired with listening skills, validating the individual and maintaining a strong therapeutic relationship. The therapists were mindful of the need for a sensitive clinical environment to avoid retriggering patients who enter therapy. Appropriate training in trauma specific therapies for PTSD was also flagged as important for some therapists and joint working with other specialist services was deemed to be good practice. The risk of vicarious trauma was highlighted and the importance of supervision and caring for the whole team was valued as a principle of trauma-informed care. Assessment, risk assessment and risk management were also key themes. The use of questionnaires to ensure traumas are asked about was discussed, but there was a split amongst the therapists regarding their opinions of the use of routine enquiry, with some therapists expressing discomfort with this and the fear of doing harm. The fear of doing harm related to concerns of escalating risky behaviours such as increased ED behaviours or self-harming behaviours which may be difficult to contain in a specialist eating disorder service.

# 8.4 Discussion of findings

## 8.4.1 Prevalence of complex trauma and PTSD

The wider literature offers robust evidence for trauma-informed care across the broad workforce in Scotland (NHS Education for Scotland, 2017). The findings from this study further substantiate the requirements for a trauma-informed approach within the field of eating disorder services. The results from the quantitative phase of the study demonstrate adverse childhood experience are widespread in this ED outpatient service user group and a number of these patients also presented with PTSD symptoms. The presence of complex trauma, as measured by the presence of ACES was 82% in this sample. This is higher than the findings from the large National Epidemiologic Survey on Alcohol and Related Conditions-III (NESARC-III; Forrest, 2020), quoting a prevalence rate of 60.2% of ACES in participants with EDs. This may reflect the differing sample groups, with this study collecting data from patients engaged in outpatient ED therapy, in contrast to the NESARC-III which was a community-based survey which identified the presence of ED through interview. Those engaged in treatment for an ED are most likely to have greater severity of symptoms which would prompt them to seek therapy which may explain the higher ACE prevalence in this study, in comparison to the NESARC-III figures.

Assessment of PTSD takes a snapshot in time and measures active symptoms of avoidance, hyperarousal, and intrusions in relations to the traumatic experience. However, PTSD is not the only response to trauma, and many responses can fall below the threshold for a PTSD diagnosis, with individuals instead presenting with co-morbid chronic mental health issues (e.g., depression, substance misuse, and self-injury) (SAMHSA (2014). Within this study, the experience of psychological trauma alone did not appear to be associated with an increase in ED symptom severity. However, there was a positive correlation between active symptoms of PTSD, with higher PTSD scores being associated with a greater severity of ED symptoms. An awareness of this link suggests that there is a place for treatment of PTSD in conjunction with ED treatment as usual, as a greater severity of ED symptomology would significantly affect the quality of life of the individual.

Poor quality of life is a well-recognised issue in patients with anorexia nervosa (Bamford et al, 2015; Sy et al, 2013). It affects physical and reproductive health, can be disabling, and disrupts psychosocial functioning (Treasure et al, 2020). It can also place a significant burden on the family (Van Hoeken and Hoek, 2020). It is associated with increased risk, with anorexia

nervosa having the greatest mortality rate of all mental illnesses (Arcelus et al, 2011). The impact of prolonged starvation on physical health is part of that risk, and these physical complications can include liver, renal, osteoporosis and cardiac failure. These physical complications also place a burden on primary care services and specialist medical facilities (Birmingham and Treasure, 2010). Long term follow-up studies demonstrate a considerable number of former ED patients will continue to meet the full diagnostic criteria for an ED decades later (Fichter et al, 2017). This treatment resistance places a strain on ED services as it can lead to lengthier episodes of treatment, with above average numbers of outpatient appointments, and the potential requirement for inpatient treatment, as well as the 'revolving door' pattern of relapse and re-referral. This is costly and creates waiting time implications for services.

#### 8.4.2 Trauma-informed approach in eating disorder services

At the onset of this study, there was no 'gold standard' regarding trauma-informed care in ED services, and the concept of trauma-informed care was only starting to trickle down through services with mixed levels of understanding of the term and, anecdotally, some confusion amongst colleagues regarding how this should be interpreted. Since the data collection in phase four (focus group with ED therapists), NHS Education for Scotland and the Scottish Government have published a framework in 2017 entitled Transforming Psychological Trauma – A Knowledge and Skills Framework for the Scottish Workforce. This offers a detailed structure for addressing trauma presentations across many services at different thresholds, from promoting an awareness of what trauma is and how it impacts on the individual, through to implementing highly specialised trauma-specific treatment approaches. It includes guidance to clinicians as to how to adapt their knowledge and skills and to organisations on how to develop services, being sensitive to the needs of the service users. Whilst this NHS Education for Scotland framework does not detail how ED services individually should treat PTSD, it offers a guide for service development.

One year later, Brewerton (2018) published his paper offering an overview of trauma-informed care and practice for eating disorders, reviewing the principles for treating individuals with comorbid ED alongside PTSD and trauma. In this paper he discusses some of the intricacies of integrating PTSD treatment into ED therapy, utilising current evidence-based treatments, considering the views of service users and clinicians with the goal of improving the overall treatment outcomes. This research suggests a radical overhaul of treatment provision

in ED outpatient services is required, based on the knowledge of current treatment delivery across the sites involved in this study. Many therapists would therefore need additional training in PTSD treatment which is costly and time consuming. Blending evidence-based therapies introduces the risk of straying from the fidelity of the model, and service users and clinicians may have different opinions regarding the favoured approach.

The 'four R's' were quoted by the key informants in phase one of this study as the pillars for a trauma-informed approach. These include: (i) realisation (realising the impact of trauma); (ii) recognising (looking for signs, conducting trauma assessments and managing risks); (iii) responding (offering education, treatment, and validation); and (iv) resisting retraumatisation. The findings from the focus group with ED therapists in phase four of this study identified there was a mixed understanding of the phrase 'trauma-informed care', and a wide variation in the level of specialist training around trauma and PTSD amongst the different disciplines, including psychiatrists, psychologists, and nurses within the group. There was a general agreement that ED services had room for improvement regarding trauma-informed care and mixed opinions as to how to approach this and whose responsibility this was. Many clinical examples were offered regarding patients presenting for ED therapy with trauma histories and an acknowledgement that trauma is prevalent in this patient group. Phase two (focus group with service users) illustrated that patients with a lived experience of complex trauma have felt let down by services over the course of their treatment history. They believe their experiences of mental health services could have been improved if their trauma histories had been assessed at an earlier point and they had been offered the appropriate treatment in response to this, a further indication of the need for a trauma-informed approach within ED services.

#### 8.4.3 Assessment

Prior to data collection commencing, the ED outpatient services recruited to the study did not routinely screen for adverse childhood experiences or utilise questionnaires to assess for trauma or PTSD. All therapists within the focus group were using an assessment form to structure their assessment interview but, beyond this, the style of assessment for trauma varied significantly from clinician to clinician. Some therapists were utilising validated tools of their own choice and others voiced discomfort at asking intrusive questions, avoiding probing patients, especially during their initial assessment appointment. The discomfort was driven by the fear of doing harm by increasing risky behaviours such as self-harm, dietary restriction and

purging, and concerns that rapport and the therapeutic relationship may be damaged. There was hesitation for fear of 'opening a can of worms'. Havens et al (2012) argue against this avoidant approach, encouraging professionals to purposely approach the topic of trauma, describing it instead as 'opening Pandora's box'. They highlight the implications of failing to identify trauma exposure, and note that PTSD can escalate emotional dysregulation, preventing these patients from developing effective behaviours for self-regulation. The key informants in phase one of this study echoed this approach, stressing the importance of a thorough assessment and highlighting that gathering details regarding an individual's trauma history enables the therapist to understand the patient's experiences, something that is fundamental to measuring risk. Risk in ED is predominantly risk to the individual through poor physical health, the risk of self-harm, suicide, self-neglect, or substance misuse (Lock et al, 2001). There is also the risk of exploitation by others, risk to children, and risk of harm to others, which all need to be assessed. Additionally, it helps to identify if trauma or abuse is current and ongoing, whether this be a risk to the patient or others and encourages clinicians to consider their response for managing that risk.

Some of the therapists described an avoidance of using the word trauma, and a manner of asking indirect questions which would allow patients to volunteer information if they chose to. This was driven by their fear of destabilising the patient, and a belief that patients would feel more in control of what they share regarding their trauma history. This culture of avoidance was noted to be widespread by the study key informants, and the service users also described experiencing this. The service users described their experiences of assessments over the years and difficulty with an indirect approach and 'woolly' questioning techniques. They emphasised the anxiety that this approach creates due to a lack of direction in what they needed to share. They voiced doubts regarding the relevance of the information they were giving, and the level of detail they should be sharing. A direct approach removes the onus of trying to find the right time to volunteer sensitive information, and with whom to share it.

The key informants raised how easy it is to overlook 'small t' traumas, as these are often under-recognised in the individuals who have experienced them and may not be voiced unless questions are asked directly. There was a strong consensus amongst the key informants that there should be a clear plan of how to respond to any information indicating exposure to psychological trauma that is given during a trauma assessment. The key points raised were to ensure patients felt validated, and that there should be psychoeducation offered and a clear treatment plan or signposting onwards to other services. The patient group shared examples

of feeling invalidated after sharing details of their trauma history with different mental health professionals and having a lack of clarity as to why it was asked and who the information was shared with. There was also frustration over the lack of clarity regarding the relevance of the trauma history to their treatment options. This reinforces the importance of therapists having a clear rationale for asking about psychological trauma and a plan of how to respond to it, as well as the need for transparency with the patient.

Routine enquiry was championed by the key informants which avoids some of the issues discussed above. The key informants also suggested the word trauma needs to be voiced so that patients can label their experiences and begin to understand what they have experienced. Routine enquiry offers a clear direction to the patient as to what information is important, the level of detail to go into and the ability to capture some of the small-t traumas which may otherwise be overlooked. Service users in other studies have described feeling comfortable with the use of routine enquiry and their trauma history being documented in their medical notes (Goldstein et al, 2017). Some of the therapists from the focus group were already using this approach and could identify the merits of doing so, whilst other therapists voiced anxiety about this approach, specifically regarding the issue of fragmented memories and how to deal with this. The reluctance expressed by some of the therapists to use routine enquiry at assessment is not uncommon. In their systematic review, Read et al (2018) found that most people who access mental health services in the UK are not asked about abuse or neglect, and that routine enquiry is very far from the norm. Waalen et al (2000) suggest a number of reasons for this, including absence of training, lack of time, uncertainty regarding the appropriate interventions, as well as fear of offending the patient. The key informants, along with the supporting literature (Cukor et al, 2010; SAMHSA, 2014), recognise the importance of a thorough trauma assessment, utilising routine enquiry, with a clear explanation to the patient as to why the questions are being asked, how the information will be used, and what the treatment options are.

The service user participants were in favour of this approach and some of the therapists within the focus group were already aligned with this way of working. Some of the other therapists could benefit from reassurance that they will not be causing harm or offence by asking these intrusive questions and this then leads on to further issues around treatment planning, particularly in the case of the treatment of PTSD. According to the key informants, assessing and understanding the aetiology of an individual's pathway into an eating disorder is not only helpful for the assessing clinician, but also a crucial step in building a formulation with a

patient. Formulation or case conceptualisation is the process between the clinician and patient of collaboratively making sense of the patient's experiences (Johnson, 2018). The key informants acknowledged that the formulation helps the patient to conceptualise the problem and to understand how psychological trauma contributes to the early development of schemas and maladaptive behaviour patterns. The service users also valued this collaborative approach and laying this out early in treatment helps the patient to understand why the assessment needs to be so detailed and why questions around trauma are relevant to the treatment approach.

#### 8.4.4 Therapeutic relationship

One of the factors influencing the avoidance of routine enquiry which was mentioned above was the fear of damaging rapport. The therapists in this study recognise the value of the therapeutic alliance in eating disorder treatment. It is a commonly held belief amongst psychotherapists more widely that the strength of the alliance is the most potent ingredient in psychotherapy and there is a strong evidential grounding for this. One of the soundest predictors of individual psychotherapy outcomes was found to be the alliance-outcome relationship in the meta-analytic review by Horvath et al (2011). The patient experience and willingness to engage with the therapy is a critical aspect of the treatment in cognitive behavioural therapy and the therapeutic alliance is a crucial component of this (Okamoto et al, 2019). The therapist's use of self as an instrument of care in the therapeutic relationship can be described as the catalyst in the patient's journey to recovery Wright (2021). Forging a therapeutic relationship with patients who have experienced complex trauma presents additional barriers due to anxious and avoidant attachment styles (Lahousen et al, 2019). Unconditional warmth and conveying a liking for the patient can help to strengthen the alliance (Farber and Doolin, 2011). In addition to the therapeutic alliance, fidelity to model and therapist competency are also important ingredients for positive psychotherapy outcomes (Perepletchikova, 2007). Fidelity to model can be described as the adherence to an evidencebased treatment (Schoenwald et al, 2011).

Many patients with complex trauma have a diagnosis of emotionally unstable personality disorder, or borderline personality disorder (BPD). Interpersonal difficulties, characterised by unstable relationships, an unstable sense of self and others, and a fear of abandonment, are diagnostic markers for this disorder (American Psychiatric Association, 2013). BPD can be

characterised by life threatening behaviours which create barriers for establishing therapeutic relationships and cause stigma (Romeu-Labayen et al, 2000). While attitudes from mental health nurses towards patients with BPD have improved over the last couple of decades, negative reactions from healthcare professionals remain, creating counter-therapeutic conditions and reducing the likelihood of establishing a strong therapeutic relationship (Stevenson and Taylor, 2020). An integrative review exploring the interactions between student nurses and service users with a diagnosis of PD highlighted the importance of the student recognising their own attachment experiences, and the implications for transference and countertransference when establishing therapeutic relationships (Jones et al, 2021). Amongst the key informants, some of the components for promoting a strong therapeutic relationship with patients with complex trauma that were mentioned included: strict boundaries; a safe therapeutic environment; working within a 'window of tolerance'; and giving patients the ability to share their story and feel validated when they do so without the need to offer advice. The role of the therapeutic relationship was valued highly by the service users in this study, creating a sense of safety and validation.

Complex traumas, specifically those associated with interpersonal violence, neglect, or abuse have been shown to severely impact on an individual's ability to form and maintain relationships (Pearlman and Courtois, 2005). This in turn creates barriers for others to relate to them, leading to increased social isolation and a lack of supportive relationships, both of which are known to buffer the effects of the original traumatic experience (Bowlby, 1969). Those who have experienced complex trauma often go on to form relationships with others who also have unresolved trauma experiences (Van der Kolk et al, 2005), resulting in additional interpersonal damage, furthering feelings of abandonment and loss, and the mistrust of others (Basham and Miehls, 2004). The results from phase three of this study, as measured in the ACE questionnaire, demonstrate these interpersonal traumas, often from caregivers, are prevalent in this ED patient group and thus appear to have a significant impact on the patient's attachment styles. Attachment should therefore be a key consideration in ED therapy when considering the importance of the therapeutic alliance and process of formulation.

Therapists themselves will bring their own attachment styles to the therapeutic relationship and this dynamic acts as an important ingredient in their attitude to trauma-informed care. Robertson et al (2021) investigated the relationship between the attachment styles and ACEs in a group of school teachers, and how these impact on their attitudes to trauma-informed practice. They found that previous experience of adversity was not related to attitudes to

trauma-informed care (as measured by the ARTIC questionnaire, Baker et al, 2016) but insecure attachment styles posed a barrier to positive attitudes towards trauma-informed practice, despite training having been offered in trauma-informed practice. Insecure attachment is typically measured in two dimensions: anxiety and avoidance (Fraley et al, 2011), and secure attachment styles are characterised by the ability to recognise and respond to the emotional states of others and to manage relationships (Lokkeholt et al, 2019). The teachers with insecure attachment styles were most likely to use traditional behavioural approaches to managing difficult behaviours through the endorsement of rules, consequences, and accountability. In contrast, those respondents with secure attachments were able to view safety, kindness, and relationships as agents of change.

The concept of the therapeutic relationship as an agent of change is not new. A relational framework was suggested by Pearlman and Courtois (2005), utilising the therapeutic relationship as a "testing ground" to address difficulties with emotional regulation, low self esteem, and the ability to sustain relationships. Allowing these difficulties to naturally surface in therapy provides an opportunity to explore and resolve them safely. The therapeutic relationship was highly valued by all participants within this study, with a collaborative approach being a universal expectation. The service user's main requirements of the therapeutic relationship were validation, transparency, warmth, collaboration, and consistency. They gave examples of poor therapeutic relationships and the impact this had on their willingness to share information and to engage in treatment, as well as increasing unwanted emotion.

These views have been backed by Ormhaug et al (2014) and Zorzella et al (2015) with the therapeutic relationship being cited as a central component in a trauma-informed approach. Briere and Scott (2015) stress the importance of maintaining a positive and consistent therapeutic relationship, along with the provision of a safe and stable environment when tailoring effective trauma-informed therapy. Secondary to the difficulty in establishing the therapeutic relationship, the service users also discussed their difficulty with treatment endings. They described a fear of abandonment, a sense of rejection, and re-traumatisation, at this stage in the therapy. This again relates to attachment styles and highlights the importance of robust discharge planning, collaboration, and transparency throughout all stages of treatment.

#### 8.4.5 Treatment options within an outpatient eating disorder service

With 41% of the eating disorder patients in this study self-reporting through questionnaires as meeting the criteria for active symptoms of PTSD, it is apparent that there is a need for specialist PTSD treatment, but the debate as to where this is best placed is unclear. The therapists had a clear understanding of what they called the 'core business' of eating disorder treatment, and this included stabilisation, primarily addressing the physical health risks attached to eating disorder patients. Stabilisation covered weight restoration and behavioural changes such as changing eating patterns and ceasing compensatory behaviours such as purging or compulsive exercise. They quoted the evidence base for their treatment approaches (Fairburn et al, 2008; NICE, 2004). When discussing specific treatment for complex trauma and PTSD, the consensus from the therapists was that this was not what the ED service had been set up to do.

When discussing this same topic, the key informants recognised there are limitations to what can be offered within specialist ED outpatient services but talked of a treatment ideal which was formulation-driven (as opposed to protocol-driven), with a phase-based approach to trauma. Empirically-Supported Treatment (EST) protocol driven CBT has improved the quality of CBT that therapists deliver over recent years but has been criticised as failing to address comorbidities, which are the norm rather than the exception in clinical practice (Persons and Lisa, 2015). These points were also highlighted by the key informants. They recognised that protocol-driven CBT prevents therapist drift, is time limited, and goal orientated. However, many of the key informants felt that this form of CBT was an unsuitable approach for patients with complex trauma, commenting that it was not sophisticated enough to meet the patients' needs.

One of the most recent developments within the field of ED treatment provision has been the launch of CBT-T (Waller et al, 2019). CBT-T is a 10-session therapy developed to offer brief interventions to non-underweight patients with eating disorders (including atypical AN, BN, and BED). The therapy was developed to tackle waiting times and offer early intervention to patients with eating disorders, as studies suggest the clinical response to treatment diminishes the longer the disorder persists (Ambwani et al, 2020). Early intervention was also the focus of the pilot study "FREED" (first episode and rapid early intervention), a transdiagnostic model offered to adolescents presenting with their first onset of ED symptoms (McClelland et al, 2018). Former studies have established that there is a favourable long-term outcome when early intervention is employed in first episode illness across other psychiatric conditions

(Marshall et al, 2005; Penttila et al, 2014). However, these time-limited, protocol-driven interventions, may fall short of the specifics detailed by the service users when describing their ideal environment for a trauma informed approach.

There has been a shift towards protocol driven treatments of late with NICE guidelines (2017) recommending a time-limited manualised approach for AN, with either CBT or MANTRA (Maudsley Anorexia Nervosa Treatment for Adults) as a first line of therapy. SSCM (specialist supportive clinical management) takes a more person-centred approach, encouraging the patient to decide on the focus of therapy in addition to the goal of weight restoration. SSCM was originally designed as a control arm of treatment in a trial comparing CBT and IPT (interpersonal psychotherapy) and has now been adopted as a frontline treatment for AN off the back of these results (Kiely et al, 2022). IPT has since been removed from the latest NICE guidelines due to the lack of evidence for its efficacy, despite anecdotal feedback from patients that they found the therapy beneficial. Recommendations for BN and BED include a tiered approach to treatment, with the first line approach being guided self-help. This can be stepped up to individual CBT therapy if there is no response to treatment within the first four weeks (NICE, 2017). Emphasis is placed on a multidisciplinary approach addressing the psychological, medical, and nutritional needs of the individual, ideally in an outpatient setting (NICE, 2017).

This protocol-driven approach to ED treatment reflects the wider trend in treatment models across mental health services adopted in England. The IAPT model (Improving Access to Psychological Therapies; DoH, 2008) is a disorder-specific method of delivering CBT for anxiety and depression, designed to make evidenced-based interventions more accessible to the public and to meet economic targets for treatment. It was initially launched in 2008 and over time has been lauded as a highly effective treatment for symptom reduction, with a 50% recovery rate and an ability to treat large volumes of clients (Clark, 2018). However, it has also been criticised for neglecting other treatment models, favouring technical manuals, and placing the diagnosis at the centre of therapy (Leonidaki, 2021). This adherence to protocol and focus on therapist competency (as measured through the competency framework; Roth and Pilling, 2007), neglects to integrate the "therapist effect" which can be defined as the effects of the therapist on patient outcomes beyond the therapeutic technique applied or the treatment modality implemented (Lutz and Barkham, 2015). Therapist effect has been found to contribute to a 5% variability in outcomes (Baldwin and Imel, 2013). This reinforces the previous points raises above regarding the importance of the therapeutic relationship.

Both the IAPT model and the trend towards protocol driven treatment for ED fail to acknowledge the importance of patient choice, and collaboration was highlighted above as an important ingredient to patients when considering the strength of the therapeutic relationship. Giving patients a choice in treatment interventions and allowing therapists to take a flexible approach has been demonstrated to increase patient satisfaction and reduce attrition or drop-out during therapy (Lindheim et al, 2014). An alternative "relational pathway" including psychodynamic and relational integrative therapy has been suggested as a suitable alternative for patients seeking help for childhood or relational trauma (who do not meet the criteria for PTSD), (Leonidaki, 2021). This approach uses the analogy of therapy being a conversation, rather than a prescribed medication targeting specific symptoms.

The discussions so far have centred around phase one interventions (safety and stabilisation) which is a fundamental function of ED treatment. Phased-based interventions typically adopt three broad stages: i) stabilisation; ii) treatment of traumatic memories; and iii) reintegration of previous life goals (NHS Education for Scotland & Scottish Government, 2017). An example of an empirically tested phase-based intervention for complex PTSD in BPD is Dialectical Behaviour Therapy with Prolonged Exposure (DBT-PE)(Linehan, 2014). The key informants also felt strongly that specific treatment of PTSD should be integrated into any treatment package on offer within ED services, although they were not aware of any ED services modelling this approach. The key informants suggested that treating PTSD within an ED service would avoid having to refer on to specialist trauma services and disjointed care. Separating ED therapy and PTSD treatment would require the patient having to build rapport again and the worry of having to sit on a waiting list for another service. It was also highlighted by the key informants that ED patients cause anxiety for therapists in general adult mental health services as the therapists may not feel equipped to assess or manage the physical risks of anorexia nervosa or bulimia nervosa and may not have the same support of primary care that ED services have established. Trauma specific treatment such as EMDR (eye movement desensitisation and reprocessing) or PE (prolonged exposure) may prompt a return to some previous ED behaviours as a means to self-regulate for patients if the treatment strays outside of the therapeutic window of tolerance.

Service users also spoke about their dissatisfaction with disjointed care and the difficulty in having to repeatedly share their story, having to invest in new relationships with different clinicians, and the anxiety of relapse during the transition between services. Waiting times were a particular worry and having a time gap between different services increased their fear

of relapse. Referring on to specialist services for co-morbidities, including complex trauma and PTSD, was routinely the approach taken by the ED therapists. However, therapists acknowledged that there are issues with these transitions and that there can be significant waiting times for some services with little or no support for patients during these transitions.

Their reasons for referring on to specialist services were primarily a lack of resources within the ED service, with the fear of driving up their own waiting times by increasing treatment times for patients already in treatment, as well as a lack of training, with only a couple of the therapists having trained in trauma-specific treatment (EMDR and PE). The key informants described the danger of assuming that those trained in psychological therapies will have knowledge of complex trauma. They discussed the concerns there may be a lack of teaching on trauma within the core training for psychological therapies creating the illusion that trauma work is a specialism. This was certainly an issue previously in mental health nurse training, although there is evidence now that there has been a shift in the curriculum, with nurse education moving away from a diagnostic model of trauma care to a psychological, trauma informed approach (Young et al, 2019).

The key informants made the point that, regardless of where the PTSD treatment is offered, there should be a greater emphasis on joined-up working. They suggested that services should be recovery focused, and that there needs to be flexibility to the current standard evidence-based approach. Other suggestions included different modalities of CBT and third wave therapies which may be of particular benefit to patients presenting with complex trauma, including: CAT (cognitive analytic therapy; Ryle, 1979); CBT-E (CBT for eating disorders, Fairburn, 2008), CFT (compassion focussed therapy, Gilbert, 2009); DBT (dialectical behaviour therapy, Linehan, 1993); FBT (family-based therapy, Lock and Le Grange, 2013); MBT (mentalisation-based treatment, Allen and Fonagy, 2006); schema therapy (Young et al, 2003); and eclectic patient-centred models. The timing of phase two interventions was also discussed, with a note to ensure patients are meeting the readiness criteria to commence trauma work. Specialist trauma work can be interpreted in many ways by service providers and, as noted above, the diagnosis can vary. Patients can present with different features and symptoms, with labels being used interchangeably including PTSD, complex PTSD, complex trauma, and BPD.

#### 8.4.6 Staff care

Staff care was a common theme that cannot be overlooked when dealing with trauma. 'Staff' also includes non-clinical members of the team, as secretaries are also exposed to trauma histories when typing up clinical letters and there is no structured support for these colleagues. Delivering trauma specific therapies carries the occupational hazard of exposing the therapist to developing vicarious trauma, secondary trauma, and burnout (Kapoulitsas and Corcoran, 2015). Vicarious trauma can cause changes to a professional's cognitions, schemas, and world view. Secondary trauma can cause PTSD symptoms in relation to another's experiences. This can lead the therapist to be preoccupied with the patient outside of the session, to develop hyperarousal, and experience intrusions around the images based on the patient's descriptive experience (Knight, 2013). Burnout is characterised by a loss of motivation and compassion fatigue. All of these issues may significantly impact on many different areas of a therapists' life, both inside and outside of work, and can be triggered by a single encounter. Vicarious trauma is a slow cumulative process that develops over time, not in response to one individual patient, yet the onset of symptoms can appear very suddenly (Sabin-Farrell and Turpin, 2003).

Choy (2009) highlighted the role of the organisation in moderating the influence of vicarious trauma including the availability of specialist training, peer support, clinical supervision and the opportunity to debrief. Careful supervision, monitoring for/responding to compassion fatigue, and protecting against vicarious trauma, will be crucial elements when trying to mobilise the workforce towards a trauma-informed approach. Alongside supervision and training, Trippany et al (2004) suggest limiting trauma caseloads and enhancing personal coping mechanisms. The traumatised professional can struggle with professional boundaries, doubt their own skills and knowledge, and have difficulty regulating their emotions in front of the patient (Pearlman and Saakvitne, 1995). Salston and Figley (2003) promote therapists setting firm boundaries and recognising their own limitations, to counter the effects of dealing with traumatising material. A point raised by the current study's key informants was the potential for therapists themselves to have experienced adverse childhood experiences. These experiences will shape the therapist's own approach to assessing and treating trauma and possibly create hesitancy for fear of re-traumatisation in themselves. The link between vicarious trauma and a therapist's own personal trauma experiences is well recognised (Resick, 2000; Rosenthal, 2000).

A further risk to the therapeutic relationship from the traumatised professional is the risk of countertransference which can lead to the inclusion of the therapists' own painful experiences in the therapeutic session (Collins and Long, 2003). Van der Merwe and Hunt (2019) acknowledge that countertransference cannot always be mitigated against and suggest it needs to be acknowledged and closely monitored through supervision. If it is not resolved, the therapist may need to engage in trauma therapy themselves. Ensuring clinicians have a choice in how they develop their own skills, and the extent to which they become involved in trauma treatment, along a trajectory from being trauma-informed to becoming a trauma expert who offers specialist PTSD treatment, may be a way of mitigating the risk of therapists feeling coerced into adopting therapies. As mentioned earlier, many professionals, not just therapists, come into contact with trauma material. Having an awareness of who has access to this material is important when considering who needs to be included in training and education regarding trauma, as is the opportunity to debrief as formal supervision may not be available.

#### 8.4.7 Resilience

Resilience was mentioned several times by the study's key informants to be a protective factor when there has been exposure to adverse experiences, aiding natural recovery. Resilience can be described as the ability to regain normal physiological and psychological functioning in the face of adversity (Herrmann et al, 2011). It is thought to be the product of the interaction between biological, social, and psychological factors which determine how an individual responds to a traumatic event, which predicts their future ability to cope (Southwick et al, 2014). It is seen as a protective factor which helps an individual to adapt and continue to thrive after having experienced psychological trauma or adversity (Luther et al, 2000). These definitions of resilience could potentially be misleading, suggesting that the patient has a skills deficit and are to blame for not being resilient with the trauma symptoms their fault. Meichenbaum (2009) stresses that resilience is not a personality trait but rather a complex interactive process with an emphasis on the relational concept of resilience. A stable family environment and supportive relationships are both external factors associated with resilience building when faced with adverse childhood experiences (Cairns et al, 1994). 82% of the ED patients in this study experienced complex trauma and only 50% of these patients presented with active symptoms of PTSD. This could indicate that 50% of the patients have been protected from the development of PTSD through resilience. In comparison, exposure to a single or multiple traumatic events would generate a prevalence rate of PTSD of

approximately 10% in the general population (Kilpatrick et al, 2013). However, as mentioned above, PTSD is not the only symptom of complex trauma, it could also be argued that developing a diagnosis of an eating disorder is evidence that resilience was not a protective factor for these patients.

Measuring resilience is notoriously difficult (Joyce et al, 2018) but there are various self-report measures in circulation (Windle et al, 2011) which may benefit the assessment process in ED treatment. There is also growing support for resilience training programmes (Macedo et al, 2014), with a suggestion that resilience can be improved through the cultivation of an individual's own resources (Smith et al, 2008). However, it has also been noted that measuring the outcomes of these training programmes is not straightforward given resilience training may improve overall functioning and mental health symptoms yet not improve the individual's own resilience, and vice versa (Erogul et al, 2014). In addition to specific resilience programmes, self-compassion is recommended as a means to build resilience, protecting against ED symptomology and promoting a positive body image (Hazzard et al, 2021; Turk and Waller, 2020).

The therapists in this study believed that patients with adequate support networks, and those able to nurture themselves, may be in a better position to share details of their history of psychological trauma with less impact on their wellbeing than those patients with lower levels of resilience. They believed that gathering information that would help measure resilience may also be of benefit. A couple of therapists stated that they would be comfortable broaching trauma with patients they had a good rapport with and felt confident they had resilience or had developed skills to manage unwanted emotion without the risk of making things worse. As mentioned in the discussion around assessment, there is a culture of 'fragilising' patients and being afraid to ask difficult questions due to the fear of de-stabilising the patient. This also links in with the concept of resilience. There has also been an increase in neural and molecular studies of resilience suggesting there may be opportunities for pharmacological interventions, and genomic studies which may help to identify those most at risk of trauma-related psychopathology (Horn and Feder, 2018). This is encouraging when considering holistic approaches to trauma-informed care and may offer a role for psychiatry when exploring adjuncts to talking therapies.

# 8.5 Strengths and limitations of the study

Treatment options for complex trauma is an under-researched area in the field of eating disorders and this study offers a unique contribution utilising a cross-section of perspectives to gain an enhanced understanding of the subject and indicate areas for further research and development. The use of a narrative approach to the literature review may have limited the rigour in this part of the study, but was intended as a scoping exercise. With hindsight and formal training in this area, there may have been value in conducting a systematic review at the start, middle and end of this process, given the fast-moving growth in knowledge in the field of complex trauma and trauma-informed care. The strength of any research study lies in the design, along with transparency in recognising the areas that could have been improved upon (Creswell, 2013). The mixed methods approach gathered multiple layers of data to create a broad picture of complex trauma and trauma-informed care across eating disorder (ED) services. Each of the four individual phases of the study contributed important insights into trauma-informed care, yet it is the sum of these parts which provides the comprehensive view. Complex trauma and ACEs have been studied in EDs previously, but the opinions of service users and therapists is an area which has not been well researched.

The use of comparison groups in phases two and four was a particular strength as it shed important information on the gaps in knowledge and assumptions that are made about patients from therapists. Lindsay (2019) argues that the use of a comparison group in qualitative research can add rigour and reduce bias within a study. The involvement of service users in the study design was a particular strength, helping to shape the terminology used and reinforce the significance of the research. This encouraged me to explore a sensitive topic and ask questions which others might have been too afraid to broach.

Phase one of the study intended to gather the opinions of key informants and the snowballing style of recruitment may have introduced some bias. The snowballing exercise was used to recruit two of the participants to this phase, with these two names being suggested by two other key informants. This may suggest that these four individuals shared common values and beliefs, limiting the views which were expressed at interview. It is also possible that there was a conflict in my role as both researcher and ED therapist. Whilst I specifically omitted my own patient group and ED outpatient site from the study, I undertook the interviews and focus groups. This may have had an influence on the responses from the therapists in phase four of the study as I am known to most of the participants who took part. Recruiting a separate

researcher to undertake this phase of the study may have reduced the potential for bias but was not possible given this was a postgraduate student project.

A mixed methods approach was purposely chosen for this small descriptive study to offset some of the drawbacks of low numbers across the separate phases. However, recruitment remained a major limitation of this study, with low numbers recruited across all four phases. The low response rate was a result of one site failing to recruit and withdrawing from the study. Numerous attempts were made to address this issue throughout the data collection period. This included attempts to engage with the gatekeeper and wider staff at the site to promote the study and problem solve the lack of recruitment. Several meetings were arranged with the PI, including face to face and by video link. Staffing issues and the lack of a service administrator were cited as the reason for recruitment failing to get off the ground initially. When I met with the wider team, many of the therapists did not have knowledge of the study, and on reflection, it would have been prudent to meet with the team as a whole before commencing recruitment, rather than assuming the information would be disseminated by the PI.

The therapists expressed concerns regarding the time commitment for completing the data collection sheet in phase three of the study. I attempted to problem solve this by arranging for a fellow doctoral student from the University of Stirling to act as a data collector, to collate the data and transfer this to the data collection sheets for the therapists. Despite these attempts to promote the study and problem solve the barriers, recruitment failed to get off the ground at this site. Staff shortages and clinical caseloads which increase the pressure on time will undoubtedly have contributed to these issues. However, there was a wider sense of this doctoral study being of low perceived value to the gatekeeper and therefore there was little impetus to drive forward my research. On reflection, careful consideration should have been given to the selection process when identifying a suitable gatekeeper, although the decision at the time was driven by the chosen PIs previous knowledge and expertise in research. The withdrawal of that site from the study also affected the geographical spread of the data which had intended to be a descriptive picture of ED outpatient services across Scotland. With only two sites contributing to the data, it is difficult to present the results as a picture of EDs across Scotland.

Phase three (the quantitative research with ED patients) was always intended to be descriptive only but the numbers recruited were considerably lower than anticipated and therefore cannot be generalised. The characteristics of the group were also limited. Whilst we know that

ED is more prevalent in women (Fairburn, 2008), the number of men recruited to this study was not representative of the gender split across the services they were recruited from. Males are typically underrepresented in eating disorder research and this is most likely a result of the stereotypical view of EDs being a female disorder and the stigmatisation this creates for men (Roberts et al, 2018). Other factors which may skew the findings were the list of exclusion criteria. For ethical reasons and the difficulty with obtaining informed consent, patients who were detained under the mental health act were omitted from the survey. These patients are likely to have the greatest severity of ED symptoms and as this was one of the variables in this study, not having access to that data is limiting the wider picture. The patients who volunteered to take part in this study may only represent a specific cohort of ED patients and may not be representative of the wider population. The study was also specific to adult ED outpatient services, with a minimum cut-off age of 18. The exclusion of inpatient services which would have included patients with a greater severity of eating disorders, and child and adolescent mental health services (CAMHS), may have offered distinct and unique data to the statistics in this study.

Additional limitations can be found in the data collection methods. The ACE questionnaire relies on a self-reported retrospective recording of traumatic events. This could give rise to recall bias and also fails to identify very early traumas which occurred in the first years of life, prior to language development. The ACE questionnaire has a modest test-retest reliability (Zanotti et al, 2018) and the gold standard for gathering this data is through interview methods, measuring retrospective accounts of childhood adverse experiences and allowing the interviewer the opportunity to query responses. This was not practical in this study and use of the 10-item questionnaire was employed and completed in the presence of the patient's therapist. The ACE questionnaire omits any questions around school bullying which has a well-established association in ED aetiology (Lie et al, 2019). There is an extended version of the ACE which captures a broader spectrum of traumatic events, but this is time consuming to complete and would not have been practical within the realms of this study due to the burden on the therapists collecting the data.

A further limitation of the study is the delay between the data collection period ending and the completion of the thesis due to this being a part time doctorate with a period of leave of absence. The field of complex trauma has grown significantly during the process of this study but the research remains salient and of importance within the eating disorder treatment sector in Scotland. The literature search was re-run on two occasions and new literature

retrieved added into the review. Further reading around policies and updates in guidelines have also been included in the study to bridge the gap between the original findings and the current climate of trauma-informed care. Opinions, beliefs, and clinical practice may well have significantly shifted since the onset of this study, given that trauma-informed care has become more widely acknowledged and further guidance has been published.

## 8.6 Implications for clinical practice

The results from this study demonstrate the high prevalence of complex trauma in this patient group, and deficits and disparities in the assessment process. The Managed Clinical Network (MCN) has a quality assurance subgroup which has a role in standardising procedures across the health boards who are members of the MCN. It aims to ensure an equitable experience for all patients entering treatment, regardless of geographical location. There is an opportunity to open discussions around standardising the assessment process to include validated assessment tools to screen for both complex trauma and PTSD. The use of routine enquiry should also be promoted, and therapists should be educated around the process of this, and this may reduce some of the anxiety around doing harm or damaging rapport. Study findings connect with writers such as Cloitre (2015) in making a strong argument for the introduction of a phase-based approach to trauma in ED outpatient services: phase one is already well established with therapists offering highly skilled interventions for ED patients. It is apparent that there are training deficits in phase two interventions, which is the trauma-specific treatment, and a range of possible interventions that could be on offer here. These could include EMDR, PE, and third wave CBT treatments. An audit of the interventions that therapists across the MCN have trained in, and a debate around which treatments to include and what opportunities for training are on offer, would be a useful next step. Offering inhouse trauma-focussed treatment will inevitably place a burden on services which are already stretched. Increasing ED therapist numbers would be one method of accommodating this demand and prevent the need to be referring on to external services.

Operating an ED service that has the capacity to treat all ED presentations and co-morbidities may be unrealistic, and there will inevitably be a need to refer on to various specialist services for some patients. There is scope here to consider how joined-up working can be improved, particularly relating to how to support patients in the transition between services to avoid relapse and deterioration of ED symptoms, and also to reduce the anxiety and distress this

causes patients. There is a gap in the treatment provision of phase three interventions for ED patients. Phase three interventions would allow patients a clear exit pathway from treatment and the opportunity to be working towards longer term life goals. The possibility of including external agencies for phase three interventions could be explored. The debate around resilience suggests that there may be some benefit in incorporating resilience training to ED therapy. However, it can also be argued that ED standard treatment promotes the building of resilience through teaching skills to manage distress, to regulate emotions, and address some of the areas in life that the eating disorder has deprived the patient from engaging in, such as meaningful activity and relationships. Given the difficulties with treatment endings that patients have described, greater consideration can be put into discharge planning. Monitoring treatment outcomes and patient satisfaction are crucial elements in service development, as is the process of audit.

There is a growing evidence base for trauma-informed care in eating disorders (Brewerton, 2018), and guidance available to steer professionals towards the development of services. "Trauma-informed practice: a toolkit for Scotland" (Scottish Government, 2021) was recently published and offers clear advice on transforming services to become more trauma-informed. Raising awareness of this document, along with Transforming Psychological Trauma: Knowledge and Skills Framework for the Workforce (NHS Education for Scotland & Scottish Government, 2017), is a first step, and collaborating with colleagues to agree on a plan to move forward with the adaptations will then be necessary. These documents encourage services to consider the therapeutic environment and language that is used. Seubert and Virdi (2019) published a book entitled Trauma-informed Approaches to Eating Disorder, and they also promote a phase-based approach to ED patients with a trauma history. Their suggested phases of treatment are somewhat different to the phase-based interventions discussed above but cover the same broad stages of therapy: (i) preparation, (ii) psychoeducation, (iii) trauma processing and ED treatment, and (iv) relapse prevention, re-evaluation, and reintegration.

Whilst there is a requirement to be delivering evidence-based, cost-effective treatment, demonstrating good clinical outcomes, this needs to be balanced with the importance of offering patient choice, considering quality of life outcomes, and factors which help to retain patients in treatment. Consideration of formulation driven CBT and relational pathways as an alternative to standard protocol-driven CBT may benefit some patients. The therapeutic relationship and attachment styles in both patients and therapists should be considered

important elements of therapy. Measuring therapists' attitudes related to trauma-informed care could be a helpful tool to pinpoint factors creating barriers to forming and sustaining a robust therapeutic relationship.

NHS Education for Scotland and Scottish Government (2017) promote the creation of 'trauma champion' roles to take the lead on service development. While trauma champions have a role in raising awareness and encouraging and influencing the development of trauma-informed care, it is recognised that they need to have the power to influence change at all levels. Identifying a trauma champion locally may help to rally staff and smooth the process of adopting change. There are 'four R's': realisation, recognising, responding, and resisting retraumatisation, (Substance Abuse and Mental Health Service Administration, 2014)) which are key assumptions in trauma-informed care. These are central to creating a trauma-informed approach and could act as a benchmark when looking to modify ED services. Recognising how the organisation and environment could act as a potential trauma trigger for a patient is part of this trauma awareness and thus striving to do no harm is crucial. Making the distinction between the trauma tiers (NHS Education for Scotland & Scottish Government, 2017) from trauma-informed, trauma skilled, trauma enhanced, through to trauma specialist, is also important when setting goals for service development and considering the appropriate training needs of therapists. Training alone will not automatically ensure the implementation of a trauma-informed approach. Several studies have highlighted resistance to transforming services following trauma-informed education for staff, with barriers to change including inadequate time and challenging working environments (Goldstein et al, 2018; Hall et al, 2016). Resistance to change was most prevalent in the members of staff with the lengthiest service (Baker et al, 2018).

Staff care is a further area for development. Therapists need to ensure they have robust clinical supervision in place and clinical supervisors need to be alert to the risk of vicarious and secondary trauma with a plan of how to respond to this (Maguire and Taylor, 2019). A collaborative and supportive workforce who are familiar with the warning signs of vicarious traumatisation will help to address this issue if it arises. The early warning signs can include changes in interpersonal relationships, a loss of compassion, irritability and anger, difficulty completing paperwork, not taking annual leave, and disengagement from colleagues (Yassen, 1995). A varied caseload and access to debriefing to enable discussions around difficult cases is important, as is the awareness of the therapist as a 'whole person', understanding they carry their own life stresses on top of their work stress (Trippany et al, 2004). The trauma-

informed supervisor also needs access to the same level of support as those they are supervising (Knight, 2018). The high incidence of psychological trauma in the wider population suggests that, statistically, there is likely to be trauma experience within clinical staff teams too. Ensuring a trauma-informed approach is extended to the workforce is also important. Allowing therapists to select the level of involvement they would like to engage with, from trauma-informed to trauma specialist, may be helpful in safeguarding staff. Compassionate consideration should be given to staff who are avoidant of engaging in routine enquiry, and a plan of how to deal with this sensitively, is important.

## 8.7 Implications for future research

A larger study across the whole of the UK with higher participant numbers would allow for greater comparisons and offer more generalisable findings. A replication of the survey with larger numbers, using a power calculation to avoid type one and type two errors when comparing patients with and without a trauma history or PTSD symptoms, would be beneficial. This would allow for filtering of the sample and greater statistical testing. Exploration of the treatment resistance and repeated re-referrals for treatment was not possible in this study due to the low numbers. This could be addressed in a larger study to test the hypothesis that PTSD symptoms add to treatment resistance. Greater numbers in the focus groups would also be beneficial, particularly the therapist group. Given that trauma-informed care has become more widely acknowledged and further guidance has been published, it is possible that opinions, beliefs, and clinical practice may have shifted since the onset of this study. It now forms part of pre-registration mental health nurse education (Young et al 2019). Indeed, trauma-informed care has become a relatively well-known phrase with the publication of the NHS Education for Scotland and the Scottish Government (2017) framework: Transforming Psychological Trauma - A Knowledge and Skills Framework for the Scottish Workforce. Further studies into how this framework has been adopted across ED services and the opportunity for qualitative studies of the patients views of the changes would be fruitful. In the short term, patient outcomes and patients' satisfaction will indicate the success of the trauma-informed approach. It could be hypothesised that longitudinal studies should start to demonstrate a reduction in re-referrals for therapy if addressing the underlying trauma and PTSD symptoms is part of the treatment solution for this patient group.

Within this ED patient group there are a small sub-group of patients who fall into a category labelled 'SEED' (severe and enduring eating disorder). However, there is no recognised criteria for this label in terms of the length of illness or severity of symptoms. Longstanding anorexia nervosa is generally categorised by >10 years of consistent illness, evidence of failing to respond to at least one recognised therapeutic intervention, low motivation for recovery, and severe impairment across several domains in life (Bamford and Mountford, 2012). These patients often present with very low weight (BMI <13) and carry the highest physical risks and poorest prognoses, and the illness is apparently intractable. The aim of therapy for these patients is no longer a goal of recovery but simply to find a reasonable quality of life, and treatment is often labelled palliative at this stage. Impaired decision making may or may not be present as a result of living with a starved brain and, for this reason, may be excluded from research into eating disorders. Further research into the prevalence of complex trauma and PTSD symptoms within this patient group would be beneficial to the knowledge base around barriers to recovery for these patients.

#### 8.7 Conclusion

This mixed method study with four distinct phases gathered data on interpretations of trauma-informed care from the perspective of professional key informants through interviews, and two focus groups with service users and ED therapists. A survey was also conducted to explore the prevalence of complex trauma in ED patients and to examine whether exposure to psychological trauma or symptoms of PTSD increase the severity of ED symptoms. Whilst the study recruited small numbers to each phase of the research, some key themes emerged in each phase of the study which met the research aims of understanding interpretations of trauma-informed care from the perspective of key informants, service users and ED therapists. Whilst these findings may not be generalisable, they have helped to illustrate different perspectives regarding trauma-informed care and highlighted the importance of adopting this approach with an ED outpatient setting. Complex trauma is prevalent in the ED population, with an indication that half of these patients also experience symptoms of PTSD.

It is widely acknowledged that there has been a culture of avoidance in broaching or discussing trauma by mental health professionals and one of the objectives of trauma-informed care is to address this issue. The assessment process needs to be standardised and the onus of assessing for trauma lies firmly with the therapist to ask the appropriate questions

and take the onus off the patient to volunteer this. The information should be built into a formulation to aid the patient's understanding of their illness and for planning treatment. This should be a collaborative process with the patient. The use of a validated tool (such as the ACE questionnaire) to screen for complex trauma and routine enquiry, ensuring small-t traumas are not overlooked would also aid this process.

The therapeutic relationship plays a pivotal role in therapy and complex trauma is often associated with anxious or avoidant attachment styles, creating additional barriers to forming and maintain a therapeutic alliance. Important elements in promoting a strong alliance included collaboration, transparency, warmth, and validation. Treatment endings are a very difficult part of therapy for many patients and much preparation is needed in this area.

The trend towards cost effective protocol-driven, manualised therapy has been criticised as being at odds with a trauma-informed approach, as it eliminates patient choice and is diagnosis-driven, rather than being patient centred. Relational pathways and formulation driven CBT are potential alternatives to this. Consideration should be given to the adoption of phase-based interventions and deficits in trauma-specific interventions need to be addressed through structured training and, where referral on to other services is necessary, there needs to be greater emphasis on joined-up working. The language used and the therapeutic environment also need to be considered. The principle of the four r's (realisation, recognising, responding, and resisting re-traumatisation) should be imbedded into treatment. A trauma-informed approach also needs to be contemplated for staff who choose not to train in interventions for complex trauma and PTSD to protect themselves against re-traumatisation. Regular clinical supervision should be compulsory across the service to guard against the occupational hazard of vicarious and secondary trauma. Greater resources will be necessary to adapt ED services to be fully trauma-informed and to be offering trauma-specific treatment.

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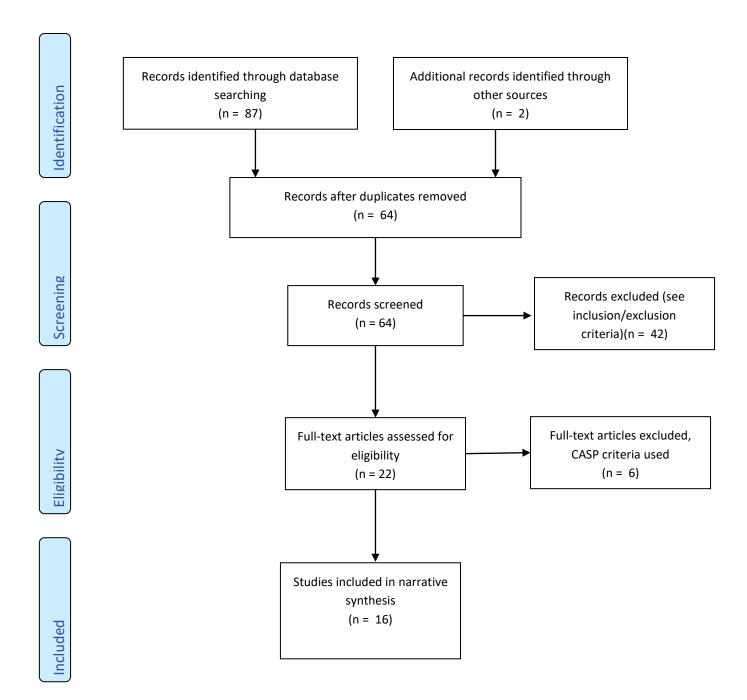
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# Appendix 1: Prisma flow diagram



# **PRISMA 2009 Flow Diagram**



# Appendix 2: Ethics committee approval letter

PH/SN

27 May 2016

Ms L Hulse Nurse Therapist Psychotherapy Greenfields House New Craigs Inverness IV3 8NP



Web: 1-0p /fews str. ac.sk/heathacteriorativesascovethics/

Professor Pat Hoddinott Chair School Research Ethics Committee

The Faculty of Health Sciences and Sport

Stating Fict ILA.
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Dear Laura

Complex Trauma Presentations in Eating Disorder Patients Across Scotland and Perceptions of Trauma Informed Care SREC 15/16 – Paper No.59 – Version 2

Thank you for responding to the SREC communication dated 12 May 2016, and enclosing the revised documents:

- Covering Letter
- IRAS Draft V2 May 2016
- Phase 1 Consent Form V2 May 2016
- Phase 1 Cover letter for Key Informants V2 May 2016
- Phase 1 Key Informants Participation Information Sheet V2 May 2016
- Phase 2 Consent Form V2 May 2016
- Phase 2 Cover letter or service users V2 May 2016
- Phase 2 Service User Participant Information Sheet V2 May 2016
- Phase 3 Consent Form V2 May 2016
- Phase 3 Cover Letter for Eating Disorder Service Users V2 May 2016
- Phase 3 Eating Disorder Patients Participant Information Sheet V2 May 2016
- Phase 4 Consent Form V2 May 2016
- Phase 4 Cover Letter for Eating Disorder Therapists V2 May 2016
- Phase 4 Eating Disorder Therapists Participant Information Sheet V2 May 2016

I am pleased to approve this study by Chair's Action, and wish you and your team all the best. However, I suggest that the title of the research on the consent form matches the title on the Participant Information Leaflet. This pertains to Phase 2.

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May I also remind you of the need to inform SREC prior to making any amendments to this protocol, of any changes to the duration of the project and provide notification of study completion. A site file of all documents related to the research should be maintained throughout the life of the project, and kept up to date at all times. The site file template can be found on the SREC page of the School's website.

# http://www.stir.ac.uk/health-sciences/research/ethics/

Please bear in mind that your study could be audited for adherence to research governance and research ethics protocols.

Ref: SREC 15/16 - Paper No.59 - Version 2 Please quote this number on all correspondence

Yours sincerely

DR JOSIE EVANS

(Depute Chair)

Faculty of Health Sciences & Sport Research Ethics Committee

# **Appendix 3: Peer review**

Complex trauma presentation in eating disorder patients across Scotland and perceptions of trauma-informed care

Many thanks for request to externally peer review the above named proposed study. I am aware the study has been approved by the University of Stirling and North of Scotland REC. I have reviewed the following study documents:

- IRAS copy
- Letters of invitation for phases 1, 2, 3 and 4
- Patient information sheets for phases 1, 2, 3 and 4
- Consent forms for phases 1, 2, 3 and 4
- Interview schedule and focus group questions
- Questionnaires: EDE-Q, ACE and IES-r
- Data collection form

This is a particularly interesting and clinically relevant study. I have several comments that the investigator and team may wish to consider with regards the study.

- 1. The issue of consent and capacity are always at the forefront when conducting research with those that could be considered 'vulnerable'. I wonder if more specific information regarding what presentations constitute a lack of capacity to consent. This would be useful for those recruiting and consenting participants?
- 2. Leading on from the above, the documentation identifies that for Phase 2 & 3 the direct care team will assess capacity to consent, however it is not clear from the information provided how this process will be undertaken. This is particularly the case for Phase 3 where administrators are identified as those who will distribute study information documentation to service users. Perhaps, a flow chart of the exact process would provide clarity.
- 3. There are clear procedures in place for safeguarding of service user participants. I wonder if further clarity regarding procedures if a service user becomes upset during the focus groups is needed i.e. will focus groups be halted, would the individual leave, what would the protocol be for supporting the existing service users? What would happen if personal information is divulged (I note that the type of questions to be used would not encourage divulging of personal information, however this might not be 100% water tight).
- 4. Should the Personality Disorder group leader consent the service users in Phase 2? I would consider their role is as gatekeeper and that consenting should be undertaken by the researcher, once the potential participant has provided verbal consent to be approached by the researcher who can then gain fully informed consent.
- 5. I also wonder if the consenting process for Phase 3 is rigorous? I wonder if there may be opportunity for potential participants to be consented by the researcher?
- 6. Is there any scope for participants to be reimbursed for any travel to participate in the study?

- 7. A general comment regarding the Service user documentation. We must always be mindful of our use of research terminology and language that may not be familiar to the general population.
- 8. Worth reminding service users at the end of the focus groups where they can seek information and support if they wish concerning any issues raised during the focus groups.

I hope these comments may considered useful and wish the investigator well with the proposed study.

Dr Aisha Holloway

Senior Lecturer, CNO Clinical Academic Research Fellow

**Nursing Studies** 

The University of Edinburgh

# Appendix 4: focus group and interview questions



## Phase 1

# Interview Questions for Key Informants

# Introduction:

"My name is Laura Hulse and I will be conducting the interview today. I will ask you several open questions. Your personal opinions and views are very important. There are no right or wrong answers. Please feel welcome to express yourself freely during the discussion. This conversation will be audio recorded for the purpose of the research only. No names or personal information will be included in any written reports. The discussion will last for about one hour. Please switch off your mobile phones. Please give everyone the chance to express their opinion during the conversation. Have you any questions before we begin?"

- 1. How are Eating Disorder services across Scotland responding to psychological trauma?
- 2. Are there any new developments happening locally, nationally, or internationally regarding the integration of trauma-informed care into eating disorder services that you are aware of?
- 3. Have you any examples of good practice regarding trauma-informed care?
- 4. Where do you see trauma specific treatment (e.g. Prolonged exposure, EMDR) sitting in ED services (should this be offered internally or externally)?
- 5. Do you know of any other experts in this field?

<sup>&</sup>quot;Thank you for your time today"



# Phase 2

# Focus group questions for Personality Disorder Service User group

## Introduction:

"My name is Laura Hulse and I will be conducting the discussion today and will take notes. I will ask you several open questions. Your personal opinions and views are very important. There are no right or wrong answers. Please feel welcome to express yourself freely during the discussion. This conversation will be audio recorded for the purpose of the research only. No names or personal information will be included in any written reports. The discussion will last for about 90 minutes. Please switch off your mobile phones. Please give everyone the chance to express their opinion during the conversation. Has anybody any questions before we begin?"

Trauma-informed care is an initiative which encourages mental health services to have an awareness of the link between psychological trauma and mental illness. This includes asking the right questions at assessment and being able to support you if you disclose a traumatic event. For some services, this will include offering specialist treatment for trauma. Other services may need to refer you on to another service where they have specially trained professionals."

- 1. We'll start with an ice breaker; can everybody introduce themselves and then tell me the name of a celebrity you admire and why?
- 2. What are the advantages and disadvantages of being asked about your trauma history when you first come into contact with mental health services?
- 3. What made it possible for you to discuss trauma openly with a mental health professional?
- 4. If you have received specialist trauma treatment (for example, EMDR or prolonged exposure), what were the important factors when considering readiness to start that work?
- 5. How do you think tier three services (for example, Eating Disorder or Substance Misuse services) should care for patients who have experienced psychological trauma?
  - a. Should specialist trauma therapy be included in the treatment? (*if not already answered*)
  - b. What are the advantages of including trauma therapy in tier three treatment? (*if not already answered*).

- c. What are the disadvantages of including trauma therapy in tier three treatment? (*if not already answered*).
- 6. Are there any other comments you'd like to make about trauma-informed care?

"Thank you for your time today"





## Phase 4

# Focus group questions for eating disorder therapists

# Introduction:

"My name is Laura Hulse and I will be conducting the discussion today and will take notes. I will ask you several open questions. Your personal opinions and views are very important. There are no right or wrong answers. Please feel welcome to express yourself freely during the discussion. This conversation will be audio recorded for the purpose of the research only. No names or personal information will be included in any written reports. The discussion will last for about 90 minutes. Please switch off your mobile phones. Please give everyone the chance to express their opinion during the conversation. Has anybody any questions before we begin?"

- 1. Can you introduce yourself and state your job title?
- 2. How comfortable are you asking patients about their psychological trauma history?
- 3. How do you currently assess for psychological trauma in therapy?
- 4. What is trauma-informed care?
- 5. How can eating disorder services across Scotland adopt a trauma-informed approach?
- 6. What are the potential barriers to adopting a trauma-informed approach?
- 7. Have you had any specific trauma training?
- 8. What are the advantages and disadvantages of offering trauma specific treatment (e.g. EMDR, prolonged exposure) within eating disorder services?
- 9. Are there any other comments you'd like to add about trauma-informed care?

<sup>&</sup>quot;Thank you for your time today".

# Appendix 5: Participant information sheet example

Participant information sheet - phase 1 key informants version 2.1 September 2016

PHASE I – Key informants





Contact

(research student):

Laura Huise Highland Eating Disorder Service

Psychotherapy Services Greenfields House New Craigs Hospital 6-16 Leachkin Road

Inverness IV3 8NP

Phone 01463 253 667

Ermail:

laura.huise@nhs.net

Contact

(<u>independent</u> contact):

Mbald Will Lead Nurse New Craigs Hospital NHS Highland

Phone 01463 704000

Ext 2508

Contact (supervisor):

Dr Tessa Parkes University of Stirling

Phone 01786 466357

Email: f.s.parkes@stir.ac.uk

# Phase 1: Participant Information Sheet for Key Informants

#### Study title:

Complex trauma presentations in eating disorder patients across Scotland and perceptions of trauma informed care

You are being invited to take part in a research study. Please take time to read through this information sheet and to discuss it with others if <u>necessary</u> before deciding whether you wish to take part. If you would like any additional information or need to clarify anything, please contact me. Thank you for reading this.

### What is the purpose of the study?

The aim of this phase of the study is to determine how <u>Eating Disorder</u> services across Scotland are currently delivering care to patients who have been exposed to psychological trauma. Comparisons will be made between Scotland and the rest of the UK and internationally, whilst considering any new developments in the field. This forms part of a larger study which is aiming to understand complex trauma in eating disorder patients, from both the perspective of the service users and from service providers.

#### Why have I been chosen?

You have been identified as an expert in the field of <u>Eating Disorders</u> and have experience in Eating Disorder service provision or policy development.

Do I have to take part?

Page 1 of 2

No. It is up to you whether you choose to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form once you have had time to read this form, reflect on the implications and ask questions. If you decide to take part, you are still free to withdraw at any time and without giving a reason. Should you withdraw from the study, information already obtained will be retained for use in the research.

#### What is involved?

If you choose to participate you will be contacted by Laura Huise who will arrange a suitable time for a telephone interview. The interview will last up to 60 minutes and will be audio recorded so that the researcher does not need to take notes and has an accurate record of the discussions. The questions will be focussed on Eating Disorder Service provision and how trauma informed care is being adopted. Any new developments nationally or internationally will be discussed.

## Are there any disadvantages to participating?

There will be a demand on your time, but it is not anticipated there will be any other disadvantage from participating in this research.

#### How is this research helpful?

You will be providing valuable input into the study with an overall aim of shaping future service provision for individuals with a history of complex trauma.

#### What if there is a problem?

If you have any concerns regarding this research, you can contact Laura Huise, or if you would prefer to speak to somebody independently about this, please approach **Madd** Will, the Lead Nurse for mental health at NHS Highland (see contact details above).

## What will happen to the results of the study?

The results of this study may be published in an academic journal after the research has been completed. If you would like a copy of the findings at the end of the research, you can provide an email address on the consent form.

# Will my information be kept confidential?

All the information collected will be treated as strictly confidential in accordance with the Data Protection Act 1998. The audio recordings and written record of your interview will be kept for 10 years and will not show your name. Any identifiable information, such as names and places, will be removed from the transcripts. The information collected will be used for the study only. Only selected members of the study team will have access to your information. The researcher will take all reasonable steps to protect your privacy.

# Who is organising and funding the research?

This research is being undertaken as part of a Clinical Doctorate in Nursing, which is being completed through the University of Stirling and NHS Highland.

#### Who has reviewed this study?

This study has been reviewed by the North of Scotland Research Ethics Committee.

Thank you for considering taking part in this study.





# Invitation to participate in a study exploring complex trauma and trauma informed care

Dear (name),

I am a Clinical Doctorate student currently studying at the University of Stirling. My study title is "Complex trauma presentations in eating disorder patients across Scotland and perceptions of trauma informed care". I am contacting you to invite you to take part in the first phase of my study which is a scoping exercise to understand how Eating Disorder Services across Scotland are currently delivering care to patients with a psychological trauma history and how this compares to the rest of the UK and internationally.

I am going to conduct short telephone interviews with key informants in the field of <u>Eating</u>.

<u>Disorders</u> to develop a picture of current Eating Disorder service delivery across Scotland and will be also be interested in areas of development. This interview will take no longer than 60 minutes and can be conducted at a time to suit you.

I have attached a copy of the participant information sheet which has further details, but please do not hesitate to contact me if you have any additional questions.

I will contact you again by email in one week's time to find out if you would like to participate. Alternatively, you can email me back: laura.hulse@nhs.net or telephone me on: 01463 253 667.

Thank you for taking the time to read this. Your contribution to the project would be much appreciated.

Kind regards

Laura Huise

Page 1 of 1

# **Appendix 7: Consent form example**

Consent from Phase 1 Key Informants version 1.1 30 July 2016





Highland Eating Disorder Bervioe Psychotherapy Services Greenfields House New Craigs Hospital 8-18 Leachkin Road IVS SNP Enquiries to: Laura Huise Jaura.huise@nhs.net

# Consent Form: Phase 1 - Key Informants

#### Study title:

Complex trauma presentations in eating disorder patients across Scotland and perceptions of trauma informed care

Name of recearcher: Laura Huise

EH.	ease hitial each box to indicate consent;	Initials
1.	I confirm that I have read and understand the information sheet dated for the above study.	
2.	I have had the opportunity to consider the information, ask questions and have had these answered satisfactority.	
3.	I understand that my participation is voluntary and that I am free withdraw at any time without giving any reason.	to
4.	I consent to my conversation being audio recorded.	
5.	I consent to anonymised quotes being used in the publication or presentation of this study.	
6.	I agree to take part in the above study.	
Participant's name (in CAPITAL 8):		
Pa	articipant's signature:	
Re	esearcher's signature: Date:	
		Page 1 of 2

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Consent form Phase 1 Key Informants version 1.1 30 July 2016

If you would like a copy of the results forwarding to you at the end of the study, please provide an email address. This will not be used for any other purposes and there is no requirement as part of the study for you to provide your contact details:

.....

## Independent Contact:

Mhairi Will Lead Nurse New Craigs Hospital 6-16 Leachkin Road Inverness IV3 8NP Phone 01463 704000 ext 2508

# Supervisor contact:

Dr Tessa Parkes University of Stirling

Phone 01786 466357

Email: t.s.parkes@stir.ac.uk

# Appendix 8: Eating Disorder Evaluation Questionnaire (EDE-Q)

Appendix in Fairburn C.G. Cognitive Behavior Therapy and Eating Disorders. Guilford Press, New York, 2008.

# - APPENDIX II -

# EATING DISORDER EXAMINATION QUESTIONNAIRE (EDE-Q 6.0)

# Copyright 2008 by Christopher G Fairburn and Sarah Beglin

#### INTRODUCTION

The EDE-Q (Fairburn and Beglin, 1994) is a self-report version of the Eating Disorder Examination (EDE), the well-established investigator-based interview (Fairburn and Cooper, 1993). It is scored in the same way as the EDE. Its performance has been compared with that of the EDE and other instruments in numerous studies (see Peterson & Mitchell, 2005): in some respects it performs well, but in others it does not. Community norms are available for adults (see page \*\*\* and Mond et al, 2006) and adolescents (Carter, Stewart and Fairburn, 2001).

# RECOMMENDED READING

- Carter, J. C., Stewart, D. A., & Fairburn, C. G. (2001). Eating Disorder Examination Questionnaire: Norms for adolescent girls. Behaviour Research and Therapy, 39, 625-632.
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# EATING QUESTIONNAIRE

Instructions: The following questions are concerned with the past four weeks (28 days) only. Please read each question carefully. Please answer all the questions. Thank you.

Questions 1 to 12: Please circle the appropriate number on the right. Remember that the questions only refer to the past four weeks (28 days) only.

	On how many of the past 28 days	No days	1-5 days		13-15 days			Every day
1	Have you been deliberately <u>trying</u> to limit the amount of food you eat to influence your shape or weight (whether or not you have succeeded)?	0	1	2	3	4	5	6
2	Have you gone for long periods of time (8 waking hours or more) without eating anything at all in order to influence your shape or weight?	0	1	2	3	4	5	6
	Have you tried to exclude from your diet any foods that you like in order to influence your shape or weight (whether or not you have succeeded)?	0	1	2	3	4	5	6
	Have you <u>tried</u> to follow definite rules regarding your eating (for example, a calorie limit) in order to influence your shape or weight (whether or not you have succeeded)?	0	1	2	3	4	5	6
5	Have you had a definite desire to have an <u>empty</u> stomach with the aim of influencing your shape or weight?	0	1	2	3	4	5	6
6	Have you had a definite desire to have a totally flat stomach?	0	1	2	3	4	5	6
7	Has thinking about <u>food</u> , <u>eating or calories</u> made it very difficult to concentrate on things you are interested in (for example, working, following a conversation, or reading)?	0	1	2	3	4	5	6
8	Has thinking about shape or weight made it very difficult to concentrate on things you are interested in (for example, working, following a conversation, or reading)?	0	1	2	3	4	5	6
9	Have you had a definite fear of losing control over eating?	0	1	2	3	4	5	6
10	Have you had a definite fear that you might gain weight?	0	1	2	3	4	5	6
11	Have you felt fat?	0	1	2	3	4	5	6
12	Have you had a strong desire to lose weight?	0	1	2	3	4	5	6

# Questions 13-18: Please fill in the appropriate number in the boxes on the right. Remember that the questions only refer to the past four weeks (28 days).

Over the past four weeks (28 days) ......

13 Over the past 28 days, how many times have you eaten what other people would regard as an unusually large amount of food (given the circumstances)?	
14 On how many of these times did you have a sense of having lost control over your eating (at the time that you were eating)?	
15 Over the past 28 days, on how many <u>DAYS</u> have such episodes of overeating occurred (i.e., you have eaten an unusually large amount of food <u>and</u> have had a sense of loss of control at the time)?	
16 Over the past 28 days, how many <u>times</u> have you made yourself sick (vomit) as a means of controlling your shape or weight?	
17 Over the past 28 days, how many <u>times</u> have you taken laxatives as a means of controlling your shape or weight?	
18 Over the past 28 days, how many <u>times</u> have you exercised in a "driven" or "compulsive" way as a means of controlling your weight, shape or amount of fat, or to burn off calories?	

Questions 19 to 21: Please circle the appropriate number. <u>Please note that for these questions the term "binge eating" means</u> eating what others would regard as an unusually large amount of food for the circumstances, accompanied by a sense of having lost control over eating.

19 Over the past 28 days, on how many days have you eaten in secret (ie, furtively)?	No days	1-5 days	6-12 days	13-15 days	16-22 days		Every day
Do not count episodes of binge eating	0	1	2	3	4	5	6
20 On what proportion of the times that you have eaten have you felt guilty (felt that you've done wrong) because of its effect on your shape or weight? Do not count episodes of binge eating	of the	of the times	than half	times	More than half	Most of the time	Every time
21 Over the past 28 days, how concerned have you been about other people seeing you eat?	Not at		Slightl	-	derately	-	arkedly
Do not count episodes of binge eating	0	1	2	3	4	5	6

Questions 22 to 28: Please circle the appropriate number on the right. Remember that the questions only refer to the past four weeks (28 days).

Over the past 28 days	Not at all		Slightly		Moderate -ly		Markedly
22 Has your weight influenced how you think about (judge) yourself as a person?	0	1	2	3	4	5	6
23 Has your <u>shape</u> influenced how you think about (judge) yourself as a person?	0	1	2	3	4	5	6
24 How much would it have upset you if you had been asked to weigh yourself once a week (no more, or less, often) for the next four weeks?	0	1	2	3	4	5	6
25 How dissatisfied have you been with your weight?	0	1	2	3	4	5	6
26 How dissatisfied have you been with your <u>shape</u> ?	0	1	2	3	4	5	6
27 How uncomfortable have you felt seeing your body (for example, seeing your shape in the mirror, in a shop window reflection, while undressing or taking a bath or shower)?	0	1	2	3	4	5	6
28 How uncomfortable have you felt about others seeing your shape or figure (for example, in communal changing rooms, when swimming, or wearing tight clothes)?	0	1	2	3	4	5	6
What is your weight at present? (Please give yo	What is your weight at present? (Please give your best estimate.)						
What is your height? (Please give your best estimate.)							
If female: Over the past three-to-four months have you missed any menstrual periods?							
If so, how many?							
Have you been taking the "pill"?							
TH	ANK YO	OU					

# Appendix 9: Adverse Childhood Experiences (ACE) Questionnaire

# Adverse Childhood Experience (ACE) Questionnaire Finding your ACE Score with 10 24 06

While you were growing up, during your first 18 years of life: 1. Did a parent or other adult in the household often .... Swear at you, insult you, put you down, or humiliate you? Act in a way that made you afraid that you might be physically hurt? Yes No If yes enter I 2. Did a parent or other adult in the household often ... Push, grab, slap, or throw something at you? Ever hit you so hard that you had marks or were injured? Yes No If yes enter I 3. Did an adult or person at least 5 years older than you ever .... Touch or fondle you or have you touch their body in a sexual way? Try to or actually have oral, anal, or vaginal sex with you? Yes No If yes enter I 4. Did you often feel that .. No one in your family loved you or thought you were important or special? Your family didn't look out for each other, feel close to each other, or support each other? Yes No If yes enter i You didn't have enough to eat, had to wear dirty clothes, and had no one to protect you? Your parents were too drank or high to take care of you or take you to the doctor if you needed it? Yes No If yes enter I 6. Were your purents ever separated or dispeced? If yes enter 1 \_\_ Yes No 7. Was your mother or stepmother: Often pushed, grabbed, slapped, or had something thrown at her? Sometimes or often kicked, bitten, hit with a fist, or hit with something hard? Ever repeatedly hit over at least a few minutes or threatened with a gan or knife? If yes enter I 8. Did you live with anyone who was a problem drinker or alcoholic or who used street drugs? If yes enter I 9. Was a household member depressed or mentally ill or did a household member attempt suicide? If yes enter 1 10. Did a household member go to prison? If yes enter 1

Now add up your "Yes" answers: \_\_\_\_\_ This is your ACE Score

# **Impact of Event Scale - Revised (IES-R)**

# (Weiss & Marmar, 1997)

**Devised By:** The IES-R was developed by Daniel S. Weiss and Charles R. Marmar in 1997 to parallel the DSM-IV criteria for PTSD. The original IES was developed prior to the adoption of Posttraumatic Stress Disorder as a legitimate diagnosis in the DSM-III published in 1980, and only tap 2 of the 4 criteria set out for PTSD in the DSM-IV: intrusion and avoidance (Weiss & Marmar, 1997). IES-R was intended to tap hyperarousal cluster of symptoms, the 4th criterion for PTSD.

**Type of Instrument:** The IES-R is similar to IES in that it is a self-report measure designed to assess current subjective distress for any specific life event. The IES-R has 22 items, 7 items having being added to the original 15-item IES (Weiss & Marmar, 1997). The 7 items comprise 6 that tap hyperarousal symptoms such as: anger and irritability, heightened startle response, difficulty concentrating, hypervigilance; and 1 new intrusion item that taps the dissociative-like re-experiencing when experiencing true flash-back. The hyperarousal subscale and the new intrusion item along with the existing intrusion and avoidance subscales parallel the DSM-IV criteria for PTSD.

The 7 items were randomly interspersed with the existing 7 intrusion and 8 avoidance items. The only modification to the IES items was the bifurcation of the item "I had trouble falling asleep or staying asleep" into "I had trouble falling asleep" (assigned to the hyperarousal subscale), and "I had trouble staying asleep" (retained in the intrusion subscale).

Respondents are asked to rate each item in the IES-R on a scale of 0 (not at all), 1 (a little bit), 2 (moderately), 3 (quite a bit) and 4 (extremely) according to the past 7 days.

**Reliability:** In their study of 4 different population samples, Weiss and Marmar (1997) reported that the internal consistency of the 3 subscales was found to be very high, with intrusion alphas ranging from .87 to .92, avoidance alphas ranging from .84 to .86, and hyperarousal alphas ranging from .79 to .90 (Briere, 1997).

Split-half/Cronbach's Alpha: NA

**Test-Retest Reliability:** Test-retest data were available for 2 of the samples in the Weiss and Marmar (1997) study. Data from sample 1 (n = 429) yielded the following test-retest correlation co-efficients for the subscales: intrusion = .57, avoidance = .51, hyperarousal = .59. From sample 2 (n = 197) the correlation coefficients were considerably higher: intrusion = .94, avoidance = .89, hyperarousal = .92. It is believed that the shorter interval between assessments and the greater recency of the traumatic event for Sample 2 contributed to the higher coefficients of stability.

**Alternate Form Reliability: NA** 

**Inter-rater Reliability: NA** 

Validity:

**Criterion (or Predictive) Validity:** Weiss and Marmar noted that the hyperarousal subscale has good predictive validity with regard to trauma (Briere, 1997). The intrusion and avoidance subscales, which are original IES components, have been shown to detect change in repondents' clinical status over time and detect relevant differences in the response to traumatic events of varying severity (Weiss and Marmar, 1997, Horowitz et al, 1979).

**Content Validity:** Not available for the hyperarousal subscale. The intrusion and avoidance subscales which are originally IES items had high endorsements of up to 85% (Horowitz, et al 1979).

Construct Validity: Weiss and Marmar (1997) utilised the item-to-subscale correlation with that item removed from the subscale generated by the standard alpha coefficient analyses. These were then compared to the cross-subscale Pearson correlations. The results showed that only 1 item ("I had trouble falling asleep") showed a stronger relationship between it and a different subscale. The corrected correlation of this item with its assigned hyperarousal subscale was .71, and its correlation with the intrusion subscale was .79. Nineteen items showed a correlation with their assigned subscale that was higher than with the other subscales; and 2 items ("I had trouble staying asleep" and "I avoided letting myself get upset when I though about it or was reminded of it") showed a correlation that was equal.

The explanations given by Weiss and Marmar (1997) for these results are that the 2 sleep items are very highly correlated, driving a relationship between them in terms of intrusion and hyperarousal; and as to the equal relationship of the avoidance item with the avoidance and intrusion subscales, this may have occurred because the presentation of the thought or the reminder invokes intrusion, and the not dealing with it invokes avoidance.

**Convergent Validity: NA** 

**Discriminant Validity: NA** 

# **Scoring Method:**

Avoidance Subscale: Mean of items 5, 7, 8 11, 12, 13, 17, 22

Intrusions Subscale: Mean of items 1, 2, 3, 6, 9, 14, 16, 20

Hyperarousal subscale: Mean of items 4, 10, 15, 18, 19, 21

IES-R score: Sum of the above 3 clinical scales.

For valid comparisons with scores from the IES, use just the sum of the Avoidance and Intrusion subscales.

Norms: NA

# **References:**

Briere, J. (1997). <u>Psychological assessment of adult posttraumatic states.</u> Washington D.C.: American Psychological Association.

Horowitz, M., Wilner, M., and Alvarez, W. (1979). Impact of Event Scale: A measure of subjective stress. Psychosomatic Medicine, 41, 209-218.

Weiss, D. & Marmar, C. (1997). The Impact of Event Scale -Revised. In J. Wilson & T. Keane (Eds), <u>Assessing psychological trauma and PTSD.</u> New York: Guildford.

# The Impact of Event Scale - Revised

Below is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS with respect to \_\_\_\_\_\_\_, how much were you distressed or bothered by these difficulties?

	Not at all	A little bit	Moderately	Quite a bit	Extremely
Any reminder brought back feelings about it	0	1	2	3	4
I had trouble staying asleep	0	1	2	3	4
Other things kept making me think about it	0	1	2	3	4
I felt irritable and angry	0	1	2	3	4
I avoided letting myself get upset when I thought about it or was reminded of it	0	1	2	3	4
I thought about it when I didn't mean to	0	1	2	3	4
I felt as if it hadn't happened or wasn't real	0	1	2	3	4
I stayed away from reminders about it	0	1	2	3	4
Pictures about it popped into my mind	0	1	2	3	4
I was jumpy and easily startled	0	1	2	3	4
I tried not to think about it	0	1	2	3	4

I was aware that I still had a lot of feelings about it, but I didn't deal with them	0	1	2	3	4
My feelings about it were kind of numb	0	1	2	3	4
I found myself acting or feeling as though I was back at that time	0	1	2	3	4
I had trouble falling asleep	0	1	2	3	4
I had waves of strong feelings about it	0	1	2	3	4
I tried to remove it from my memory	0	1	2	3	4
I had trouble concentrating	0	1	2	3	4
Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart	0	1	2	3	4
I had dreams about it	0	1	2	3	4
I felt watchful or on-guard	0	1	2	3	4
I tried not to talk about it	0	1	2	3	4

# **Scoring:**

Avoidance Subscale = mean of items 5, 7, 8, 11, 12, 13, 17, 22 Intrusion Subscale = mean of items 1, 2, 3, 6, 9, 14, 16, 20 Hyperarousal Subscale = mean of items 4, 10, 15, 18, 19, 21

Above written by: Ms. Estela Hutchings & Dr. Grant J. Devilly

# Appendix 11: Data collection sheet

Data collection form version 1.1 March 2016





Laura Hulse Highland Eating Disorder Service Psychotherapy Greenfields House New Craigs Hospital Leachkin Road Inverness IV3 8NP

# Data collection sheets for Eating Disorder Therapists

# Study Title:

Complex trauma presentations in eating disorder patients across Scotland and perceptions of trauma informed care: evaluative research by Laura Hulse as part completion of a Clinical Doctorate (University of Stirling)

Therapists, for those patients who have consented to engage in this study, please complete the details on this form and then return the form to your service administrator, along with the completed consent form attached.

Thank you

Data collection form version 1.1 March 2016

# Patient data

Service (pleas	e circle): Highland	Gramp	pian	Tayside	Cullen Centre
Aga:		Gende	er:	Male Eemale_E	
BMI:					
ED diagnosis:	AN (or atypical)				
	BN (or atypical)				
	EDNOS				
Previously tre	ated for an Eating Di	conder?	Yes		
18)	68	ink	No		
Co-morbid me	ental health diagnosis	2			

# ACE scores

ACE	Answer:
questions	
1	Yes/no
2	Yes/no
3	Yes/no
4	Yes/no
5	Yes/no
6.	Yes/no
7	Yes/no
8	Yes/no
9	Yes/no
10	Yes/no

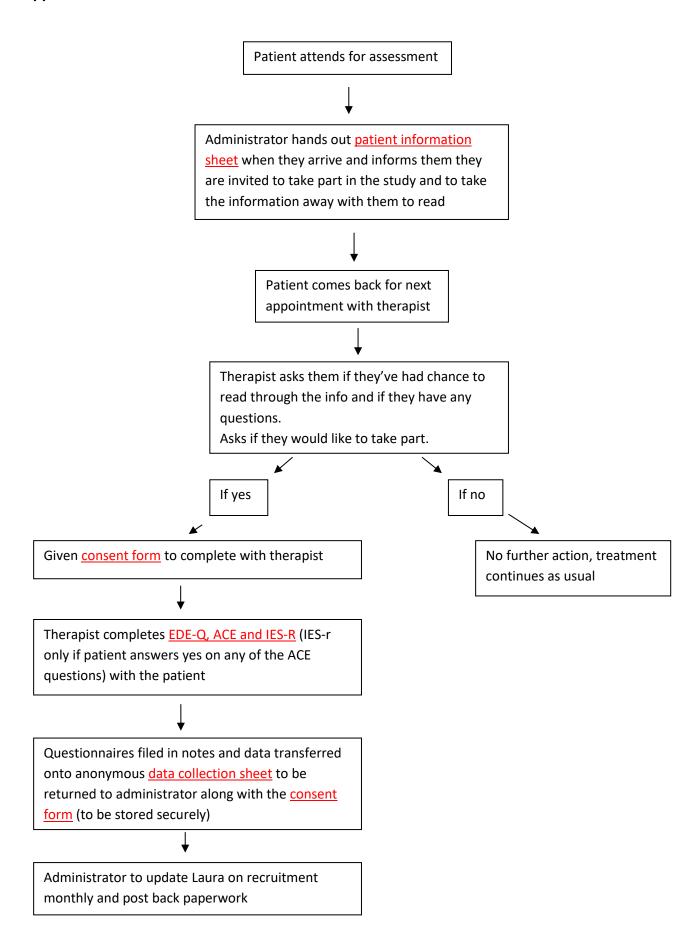
# IES-R (to be completed if the patient answered ges to any questions in ACE)

Security of the second	scores
intrusion	
Avoidance	-335
Hyperarousal	38
Total score	-36

EDE-Q	
	Global EDE-
es-loggraphics concernor	Q score:
EDE-Q Total scores	Section in the second

Page 2 of 2

Appendix 12: flow chart for data collection



Appendix 13	COREQ checklist	
Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist		
No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Laura Hulse (interviews and two focus groups)
2.	Credentials	RMN, BSc, PgDip
3.	Occupation	Cognitive Behavioural Psychotherapist / Registered Mental Health Nurse
4.	Gender	Female
5.	Experience and training	Clinical Doctorate student
Relationship with participants		
6.	Relationship established	Phase one: no relationship, Phase two: no relationship, phase four: participants known to the interviewer through a Managed Clinical Network but not direct colleagues
7.	Participant knowledge of the interviewer	Participants were given prior information regarding the purpose of the study and the credentials of the interviewer through a participant information sheet prior to consenting to engaging in the researcher. A short introduction was also given at the start of the interviews and focus groups to recap this.

8.	Interviewer characteristics	History of working with personality disorders and phase-based interventions and using routine enquiry for taking trauma history. Trained in trauma-specific treatment for PTSD. Working in a trauma-informed way within PD service. ED service colleagues have mixed awareness of trauma-informed care and mixed attitudes re: best place to treat ED patients with trauma / PTSD.
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	Mixed methods, pragmatism
Participant selection		
10.	Sampling	Phase one: purposive plus snowballing; phase two: convenience sampling; phase four: convenience sampling
11.	Method of approach	Phase one: email; phase two: face to face; phase four: email
12.	Sample size	phase one: six participants: phase two: two participants; phase four: four participants
13.	Non-participation	Phase one: none; phase two: one participant did not attend the focus group after giving consent (no reason given and no follow up to explore why as the consent form advised they could withdraw from the study at any given point); phase four: none
Setting		
14.	Setting of data collection	Phase one: over the telephone; phase two: meeting room (non-clinical area) within the hospital; phase four: meeting room in Tayside hospital (chosen by the participants)
15.	Presence of non- participants	Phase two focus group: Kate Clark as an independent observer

16.	Description of sample	Phase one: experts in the field of eating disorders or psychological trauma or involved in the development of related polices / treatment guidelines; phase two: service users with a lived experience of complex trauma who had completed the stabilisation phase of treatment; phase four: eating disorder therapists across the managed clinical network (MCN) for eating disorders (interviewers own team not recruited)
Data collection		
17.	Interview guide	all phases were conducted using semi- structured interview schedules, no pilot testing of the focus groups took place. A "dry run" of the research questions was undertaken with Dr Tessa Parkes (supervisor) prior to undertaking the interviews and some prompts for further probing were suggested.
18.	Repeat interviews	no
19.	Audio/visual recording	audio recording with consent
20.	Field notes	yes, field notes were made by the interviewer at each phase
21.	Duration	phase one: 60 minutes; phase two: 90 minutes; phase four: 90 minutes
22.	Data saturation	Yes
23.	Transcripts returned	No
Domain 3: analysis and findings		
Data analysis		
24.	Number of data coders	One
25.	Description of the coding tree	Yes
26.	Derivation of themes	Themes were derived from the data across all phases
27.	Software	QSR NVivo (version 11)
28.	Participant checking	No
Reporting		
29.	Quotations presented	Yes

30.	Data and findings consistent	Yes
31.	Clarity of major themes	Yes
32.	Clarity of minor themes	Yes

# Appendix 14: Draft article for publication

# **Draft Article for Publication**

# Journal - Eating Disorders: The Journal of Treatment & Prevention

### TITLE PAGE

# COMPLEX TRAUMA PRESENTATIONS IN EATING DISORDER PATIENTS ACROSS SCOTLAND AND PERCEPTIONS OF TRAUMA-INFORMED CARE

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### **ABSTRACT**

Introduction: Understanding the role trauma and post-traumatic stress disorder has in the severity of eating disorders (ED) is important for achieving the best outcomes for those accessing treatment yet there is a lack of guidance for ED services across Scotland regarding best practice. Trauma-informed care sets out to make services more accessible to those with a trauma history, offering guidance on establishing a safe environment and adapting therapeutic approaches to accommodate the needs of service users who have experienced trauma.

Study aim: The aim of this study was to explore prevalence rates of complex trauma in ED patients in Scotland and to understand the impact of exposure to psychological trauma or symptoms of PTSD on the severity of ED symptoms.

*Methods*: A survey was used to collect data on prevalence rates of trauma and PTSD and their association with ED symptoms using the validated eating disorder evaluation questionnaire (EDE-Q), adverse childhood experiences (ACE) questionnaire, impact of events scale-revised (IES-r) questionnaire, along with body mass index (BMI).

Setting: Two adult outpatient eating disorder services in Scotland.

*Participants*: Eating disorder outpatients over the age of 18 (n=44).

Findings: Complex trauma, as measured by adverse childhood experiences (ACEs), was found to be common in ED patients, with 82% of patients having experienced at least one adverse childhood experience. 50% of participants with a trauma history reported PTSD symptomology. There was a moderate association between higher PTSD symptoms and a greater severity of ED symptoms, but no significant relationship between complex trauma and eating disorder symptom severity. PTSD appeared to be a

prevalent presentation, with 41% of the total sample population reporting active PTSD symptomology at the point of completing the survey.

Conclusions: There was a high prevalence of complex trauma in ED outpatients, and half of those patients also had active symptoms of PTSD. This strengthens the argument for adapting ED services to be fully trauma-informed and to consider offering trauma-specific treatment.

# **KEY WORDS**

Complex trauma, trauma-informed care, adverse childhood experiences, post-traumatic stress disorder, anorexia nervosa, bulimia nervosa, binge eating disorder, eating disorders, Scotland.

### INTRODUCTION

Adverse childhood experiences (ACEs) were originally studied over 20 years ago to explore the link between adversities in childhood and the long-term impact these had on health and risk-taking behaviours into adulthood (Felliti et al, 1998). Adversity was measured across ten domains including: physical, sexual, and emotional abuse; physical and emotional neglect; exposure to adult incarceration, mental illness, substance abuse, violence in the household, and parental separation or divorce. These adversities have been shown to have a significant impact on both the physical and mental health of an individual, as well as the health-related behaviours that a person engages in (Centers for Disease Control and Prevention (CDC Kaiser-Permanente, 2014)). Four or more ACEs are associated with high-risk alcohol use, unintended teenage pregnancy, substance misuse, perpetrating violence, being the victim of violence, and custodial sentences (Public Health Wales, 2015).

ACE is now a well-recognised term and many further studies have been conducted over the years which corroborate the original findings, with ACEs thought to contribute to approximately a third of all mental health and behavioural disorders (Green et al., 2010; McLaughlin, 2017). Over the years, ACE has become a common term and tool when discussing childhood trauma, despite the ten domains identified by Felliti et al (1998) missing other common traumas such as bullying, racial discrimination, poverty, exposure to community violence and separation from immigrant parents (Cronholm et al, 2015). This common usage has sparked some debate regarding the breadth of the definition of ACEs (Portwood et al, 2021) and a suggestion that when capturing complex trauma, ACEs are referred to alongside childhood trauma as 'traumatic and adverse childhood experiences (TRACES+)' (Weems et al, 2021). Adverse childhood

experiences are subjective and not all of these experiences would be identified as traumatic through the eyes of the individual experiencing them. ACEs are not intended to be diagnostic, merely an indication of increased risk for physical and mental health issues later in life.

The scoring of ACEs is a simple summing procedure, adding up the total from the ten domains that an individual has been exposed to. This treats all the domains as equal, despite research demonstrating trauma is most damaging when it is severe and repeated over a longer duration (Hughes et al, 2017). Throughout this study, the terms complex trauma, ACE and type two trauma (Terr, 1991) were used to capture a broader sense of exposure to psychological trauma and adversity. A narrative review of the literature demonstrated a strong link between complex trauma and the development of ED, most commonly bulimia nervosa (Brewerton, 2007). Complex trauma, or type two trauma, is a term which refers to traumatic experiences which happen repeatedly, as opposed to a single event; it is usually of an invasive, interpersonal nature and has a wide-ranging, long-term impact (Complex Trauma Treatment Network, 2016). Often these are events that are experienced during childhood, such as sexual abuse, physical or emotional abuse, physical or emotional neglect, or bullying.

There are many other examples of exposure to complex trauma including natural disasters, intimate partner violence, traumatic grief, trafficking, medical trauma, and terrorism (Greeson et al, 2014). The term complex trauma can also be used to describe the long-term, wide-ranging effects of these traumatic events and the learned adaptations that survivors develop as a means of coping and functioning on a day-to-day basis (National Child Traumatic Stress Network, 2017; Mantovani and Smith, 2021). Psychological trauma generates stress hormones such as cortisol and

catecholamines and these neuronal hormones have been shown to influence the developing brain which does not reach maturity until early adulthood (Teicher et al, 2002). These neurodevelopmental deficits negatively impact a child's social, emotional, cognitive, and affective functioning (Soloman and Heide, 2005) and are associated with a later diagnosis of personality disorders and post-traumatic stress disorder (PTSD) for some (Scannapieco & Connell-Carrick, 2005).

PTSD affects approximately one third of people who have been exposed to traumatic

events (National Institute for Health and Care Excellence, NICE, 2018) and a much larger number of people will experience subthreshold PTSD. Subthreshold or subclinical PTSD can be defined as the presence of some PTSD symptoms (avoidance, intrusions, hyperarousal) but not meeting the full criteria for diagnosis (Cukor et al, 2010). Subthreshold PTSD can cause significant impairment in social and family functioning and is associated with depression, suicidal ideation and psychiatric comorbidities (Marshall et al, 2001). Exposure to psychological trauma and PTSD are associated with a greater incidence and severity of an eating disorder (Mitchell et al, 2012; Brewerton and Brady, 2014). When PTSD is present alongside an eating disorder (ED) this has also been associated with greater ED comorbidity (Lipschitz et al, 1996). The exact mechanisms for the link with PTSD and ED aetiology are not clear. Exposure to childhood sexual abuse may directly impact on perceptions of body image (Sacks et al, 2001) and early trauma is also associated with the development of a self-critical view (Dunkley et al, 2010). These could encourage engagement in ED behaviours to pursue an ideal sense of self or, conversely, to become less attractive to perpetrators by minimising gender-specific physical characteristics. Emotional dysregulation has been shown to be a common factor in both ED and PTSD presentations (Corstorphine et al, 2007), as are alexithymia and dissociation (Mazzeo et al, 2002), and ED behaviours are

thought to be a method of attempting to emotionally regulate. Psychiatric co-morbidity in ED patients is associated with poor engagement in treatment and treatment resistance (Agras, 2000), and full recovery from an ED is dependent on the satisfactory treatment of all the comorbidity and this includes PTSD symptoms (Brewerton, 2007).

Subthreshold PTSD would not be identified on standard screening tools and is linked with eating disorder symptoms which highlights the importance of a detailed assessment of trauma in ED patients, sensitive enough to pick up on subthreshold PTSD symptoms, (Cukor et al, 2010). Eating disorders present high levels of physical risk, with anorexia nervosa having the greatest mortality rate of all mental illnesses (Arcelus et al, 2011). Long term follow-up studies demonstrate a considerable number of former ED patients will continue to meet the full diagnostic criteria for an ED decades later (Fichter et al, 2017) so understanding the aetiology of the disease and exploring barriers for recovery is an important area for research. Whilst there is a wealth of evidence supporting the link between trauma and poor mental health, there is very little literature regarding trauma-specific treatment in ED patients. Trauma-informed care was a relatively new topic at the start of this research and there was no gold standard to consider regarding the delivery of trauma interventions for ED patients.

The concept of exposure to a traumatic event is now widely recognised as a contributing factor to the development of a variety of mental health conditions and several guidelines and recommendations have been published to encourage mental health services to adopt a trauma-informed approach to patients entering services (NICE, 2004; World Health Organization, 1992; NHS Education for Scotland, 2017). Trauma-informed care aims to provide an environment which feels safe and fosters trust for those who have experienced psychological trauma, requiring a compassionate and sensitive approach from healthcare providers (SAMHSA, 2014). Increasing awareness

of psychological trauma can aid clinicians to respond to the individual's needs, possibly signposting them on to the appropriate services (NHS Education for Scotland, 2017).

Trauma-informed approaches are intended to have a positive influence on both staff and service users, yet there is limited evidence that exists on the implementation of trauma-informed approaches across ED outpatient services. There are two main benefits that a trauma-informed workforce offers an individual with a trauma history. Firstly it offers a new experience of relationships, building trust through safety, choice, and collaboration, as opposed to coercion, control and betrayal. These repeated positive exposures to healthy supportive relationships help to extinguish the link between trauma and abusive relationships which is an important part of recovery. Secondly it addresses the potential barriers to entering treatment, seeking to provide an environment which will not risk retraumatising the individual through the triggering of traumatic memories (NHS Education for Scotland, 2017).

The aim of the study was to explore the presence of complex trauma in ED patients across Scotland. Trauma-informed care was a fledging subject at the onset of the study and pre-dated much of the guidance that is now available for professionals. There was a lack of direction for ED services in how to best treat patients presenting with a trauma history and the problems that often arise as a result of being exposed to adverse childhood experiences.

### **METHODS**

A quantitative approach was adopted which involved surveying patients accessing specialist outpatient ED treatment in two sites across Scotland, examining the

prevalence of complex trauma histories and, within this group, the prevalence of PTSD symptoms.

### Data collection

A quantitative observational approach using a cross-sectional survey design gathered data from patients attending for assessment for outpatient ED treatment to answer the following two research questions: 1) how prevalent is complex trauma in ED patients, and 2) does exposure to psychological trauma or symptoms of PTSD increase the severity of ED symptoms? In order to aid analysis, the questions were broken down further into the following parts: (i) how common are post-traumatic stress disorder symptoms in patients with complex trauma? (ii) do higher adverse childhood experiences result in a greater severity of eating disorder symptoms? and (iii) do post-traumatic stress disorder symptoms have an impact on the severity of eating disorder symptoms?

The survey included questions regarding the outpatient ED treatment site, participant demographics (age and gender), ED diagnosis, body mass index (BMI), co-morbid diagnoses and the number of any previous episodes of treatment, and the use of three validated questionnaires to measure complex trauma, PTSD and ED severity. ED severity was measured through the global scores of the Eating Disorder Evaluation Questionnaire (EDE-Q) (Fairburn and Beglin, 1994). This is a 36-item screening tool used to evaluate ED symptoms and has subscales scored across the four core clinical dimensions of EDs: eating concern, body shape concern, weight concern, and restraint. It has a global score ranging from 0 to 6, with higher numbers denoting a higher severity of eating disorder symptoms and behaviours. Scoring assesses the frequency of

behaviours over a 28-day period as well as scoring the severity of eating disorder attitudes and beliefs. Berg et al (2012) undertook a systematic review of the literature exploring the psychometric properties of the EDE-Q and found data to support the test-retest reliability of the EDE-Q subscale scores and in terms of validity, the overall data supported the EDE-Qs ability to differentiate between cases and non-cases of EDs. The EDE-Q was chosen as it is a tool which is already in use in clinical practice and is widely considered to be a reliable screening tool in research (Mond et al, 2004).

Participants completed two additional questionnaires administered by their therapist gathering data on complex trauma and PTSD. The Adverse Childhood Experiences (ACE) scale (Felitti, et al., 1998) is a ten-item self-report questionnaire designed to capture the common subtypes of traumatic events occurring before the age of 18. Each question requires a yes or no answer, with a yes response scoring: 1, and no scoring: 0. Any score of one or above would indicate there is a history of trauma. The ACE questionnaire is widely used in clinical practice and is recommended by the Centre for Disease Control and Prevention (CDC) as a tool for screening for psychological trauma and predicting the lifetime risks associated with this (mental and physical health probems and social difficulties) (Redding, 2016).

Zanotti et al (2018) conducted an examination into the test-retest reliability of the ACE questionnaire and found a modest test-retest coefficient r = 0.71, p < 0.001. They recruited 141 student athletes and adminstered the questionnaire 12 months apart and found a higher stability coefficient in the items relating to househould dysfunction, r = 0.65, p < 0.001 compared with the items relating to abuse and neglect, r = 0.52, p < 0.001. The variation in responses over time can be possibly attributed to the nature of the questions within the questionnaire, subjective interpretations of what constitutes as abuse and neglect can vary within in an individual over time, whereas the household

dysfuntion questions generally use more objective descriptions. Adversities also often co-occur (Lacey and Minnis, 2020). Validated interview-based questionnaires have been cited as the gold standard for assessing retrospective accounts of adverse childhood events (Bifulco et al, 1994). However, the use of an interview-based questionnaire was not feasible within the realms of this study. The ACE questionnaire was chosen as it is a simple questionnaire which captures the broad areas of childhood trauma and is free to use in research. The survey data was collected by the patient's therapist as part of the routine assessment process.

Participants who indicated a trauma history were then invited to complete the Impact of Events Scale-revised (IES-r, Horowitz et al, 1979). This is one of the most commonly used questionnaires for assessing the presence of symptoms of post-traumatic stress disorder (PTSD) (Weiss, 2004). It is a 22 item self-report questionnaire which assesses for common symptoms of PTSD over a seven-day period using a five-point Likert scale with each answer ranging from a score of 0 ('not at all') to 4 ('extremely'), yielding a total score ranging from 0 to 88. These symptoms are grouped into sub-categories of hyperarousal, intrusions, and avoidance. The groupings are based on Horowitz's (1976) emotional processing model of trauma which identifies the alternating states an individual will experience between intrusive thoughts and feelings, and the use of avoidance strategies until the memories have been psychologically assimilated. Scores greater than 33 are indicative of the presence of PTSD and higher scores indicate greater symptom severity.

Beck et al (2008) studied the psychometric properties of the IES-r and deemed it to be a sound measure of post-traumatic phenomena for both clinical and research purposes.

Briere (1997) reports the internal consistency of the three subscales to be very high, with intrusion ranging from 0.87 to 0.92, hyperarousal ranging from 0.79 to 0.90 and

avoidance ranging from 0.84 to 0.86. The IES-r tool was chosen because it is easy to administer and score and is commonly used in clinical practice. These two additional questionnaires took approximately 15 minutes to complete together. The original data collection period was fixed at 12 months, but an agreement was made to extend this due to the data collection being limited to two sites.

Extending this period needed careful consideration to ensure the sample was not likely to have changed over the period of time since recruitment started. The sample could be at risk of changing for multiple reasons, for example, changes to the referral criteria could suddenly exclude certain patients from entering treatment or introduce a previously unknown cluster of participants to the service. Increased media coverage of a particular ED diagnosis could prompt patients to approach their GP with symptoms they hadn't recognised as an eating disorder and this would amplify referrals for a particular diagnosis, skewing the numbers over that period. Also, as more staff became increasingly aware of trauma-informed care, they may start to adapt their style of assessment and broach the topic of trauma differently. Participants may also become more familiar with trauma terminology through media exposure of trauma or their experience of treatment in other services who have already adopted a trauma-informed approach. This may increase their readiness to share their history, inflating the number of patients with a trauma history who volunteer to participate in the study.

In the short term, the supervisory team felt there was not likely to be a huge cultural shift and, should that have happened, this would have introduced the option to either cease data collection at that stage or to identify all those who were recruited after that stage and to make comparisons between the two groups. Neither of these were necessary. It was also felt that the quantitative data being collected (ACE, IESr, EDEq, BMI, age, gender, ED diagnosis and previous episodes of treatment) should not be

impacted upon greatly by any improvements in trauma-informed care. The data collection period ran from March 2017 to August 2019.

# **Participants**

The sample consisted of 44 patients, of whom 98% (n=43) were women. Men are typically assumed to make up 25% of those affected by eating disorders (Royal College of Psychiatrists' Section of Eating Disorders, 2012), yet the number of men presenting for therapy across these two outpatient services is significantly lower with clinicians reporting less than 10% of annual referrals being men. This suggests men are underrepresented in this sample. Participants were recruited from two large Scottish Health Boards. Two-thirds (68%; n=30) of participants were recruited from one outpatient eating disorder service and 32% (n=14) from another outpatient eating disorder service. Their ages ranged from 18 to 59 years and the mean age was 28. BMI (body mass index) values ranged from 15.7 to 40.4. The mean BMI was 23.6 and mode was 17.4. Within the field of eating disorders across the UK, a healthy BMI in an adult is deemed to be between 20 to 25 (WHO, 2000). At the time of data collection, a BMI below 17.5 was the cut-off for a diagnosis of anorexia nervosa (Diagnostic and Statistical Manual of Mental disorders: DSM-IV, American Psychiatric Association, 2013). BMIs below 20 deem an individual to be underweight, whilst a BMI of 25-30 is classed as overweight, and above 30 is obese. BMI data was missing for four participants and there was no indication from the data collection sheet why the therapist had not recorded this data. It is possible it was an error when completing the form, it is also possible the patient's weight had not been recorded at that stage of assessment.

The ED diagnosis was made by the patient's therapist and was based on the criteria from the Diagnostic and Statistical Manual of Mental disorders: DSM-IV (American Psychiatric Association, 2013). Bulimia nervosa was the most common diagnosis with 43% (n=19) of patients meeting the criteria for this or atypical bulimia nervosa. This diagnosis is used when a patient closely corresponds to the diagnostic criteria but not all that is specified. Just over a third (39%: n=17) had a diagnosis of anorexia nervosa or atypical anorexia nervosa. This label is used primarily when a patient's BMI is above the diagnostic threshold. 18% (n=8) had a diagnosis of EDNOS (eating disorder not otherwise specified). A third of patients (36%; n=16) had previously been treated for an eating disorder and 64% (n=28) of patients were presenting for their first treatment episode.

# Data analysis

The quantitative data from the data collection forms was entered into and analysed with IBM SPSS (Statistical Package for the Social Sciences) software (version 27). Missing data was given a value of 99 to avoid being included in the results. This is discussed further in the results section.

Frequency analysis was used to:

 understand how common PTSD symptoms (IES-r scores) are in the patients who present with complex trauma (ACE scores).

A Spearman's r test of correlation was used to:

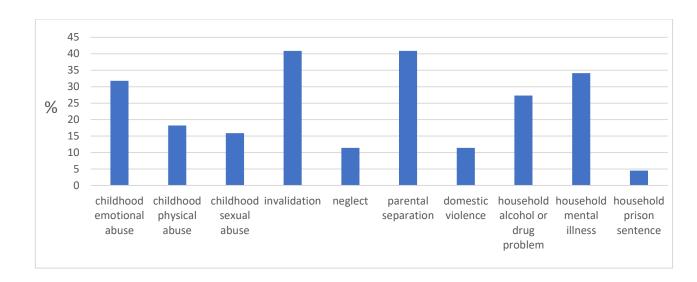
• examine the relationship between a history of complex trauma (ACE scores) and the severity of ED symptoms (Global EDE-Q scores).

 examine the association between PTSD symptoms (IES-r scores) and the severity of ED symptoms (EDE-Q global scores).

### **RESULTS**

The majority of patients had experienced at least one adverse childhood experience (82%, n=36) with 18% (n=8) declaring no trauma history, as measured through the ACE questionnaire (Felitti et al, 1998). The maximum number of ACEs experienced by any individual was 8 and this accounted for only 2% (n=1) of the participants. The experience of a single ACE event was the most frequently reported, with 27% (n=12) reporting this. The average number of reported traumatic events for those in the group with a trauma history was 3.6. The most common forms of trauma reported were invalidation (41%; n=18) and parental separation (41%; n=18). Next most common were household mental illness (34%; n=15) and emotional abuse (32%; n=14), followed by physical abuse (18%; n=8) and sexual abuse (16%; n=7). Neglect was reported by 11% (n=5) and domestic violence was also experienced by 11% (n=5) of patients. A household member going to prison was experienced the least with only 5% (n=2) of patients reporting this. Figure 1.1 illustrates the proportion of participants who had reported experiencing each of the traumatic events assessed in the ACE questionnaire.

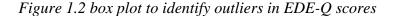
Figure 1.1. Proportion of ACEs by category

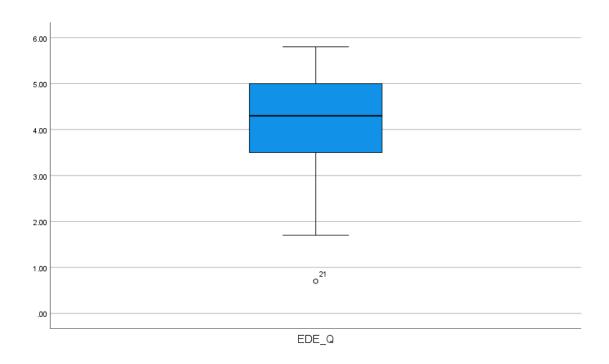


In order to answer research question one: "how common are post-traumatic stress disorder symptoms in patients with complex trauma?" the IES-r questionnaire (Weiss et al, 1997) was administered to the 82% (n=36) of patients who reported a trauma history. Of those 82% who had self-reported complex trauma, 50% (n=18) scored 33 or over on the IES-r questionnaire. Whilst the IES-r is not designed as a diagnostic tool, scores of 33 or above are indicative of the presence of PTSD. The mean total IES-r score was 32.7 (SD=24), median was 33 and mode was 0. The overall prevalence rate for PTSD within the 44 participants who took part in this study was 41% (n=18).

The EDE-Q was to be completed by all 44 participants in the study, but data was missing for two participants (there are no details as to why the data is missing). Of the 96% (n=42) who completed the EDE-Q, global scores ranged from 0.7 to 5.8, with a mean score of 4.1 (SD=1.2), median of 4.3 and mode of 5.2. The subscales were disregarded for the purpose of this research as they added no benefit to the focus of the study. The overall global score was used as the marker for severity, with clinical significance being assumed at a cut-off score of 4 or above. This classifies an individual to be within the clinical range for a diagnosis of an eating disorder (Carter et al, 2001). There was one clear outlier in this data set (see boxplot in Figure 1.2) who recorded a

low EDE-Q score, possibly reflecting the omission of certain sections of the form which would skew the scoring, or possibly a deliberate attempt by the patient to downplay the ED symptoms. Anecdotally within therapy, it is not unusual for patients to admit to under-rating the severity of their eating disorder when first asked about the specific behaviours due to high levels of shame. Unfortunately, the data collection sheet did not provide the scope for therapists to record any additional information that may have given an indication as to why the scoring was low. The outlier was a participant with the lowest BMI (15.7) and they scored below the threshold for an ED diagnosis on the EDE-Q, scoring 0.7. This outlier was removed from the data set for analysis. The mean, median and mode EDE-Q scores were recalculated to reflect the omission of the outlier, with the global score then ranging from 1.7 to 5.8. The mean score was 4.2 (SD=1.1), median 4.3 and mode 5.2. The analysis was run a second time to include the outlier and it did not materially change the results.





To address the research question: "are adverse childhood experiences associated with severity of eating disorder symptoms?" a Spearman's correlation test was applied to explore the association between the total EDE-q scores of the 41 participants and the total number of ACEs recorded in those individuals. A small positive correlation (r=.2) was found but this was not significant (p=.211) (see Table 1.1).

A further Spearman's correlation test was conducted to address research question three "is there a relationship between post-traumatic stress disorder symptoms and the severity of eating disorder symptoms?". This test was employed to explore the association between the EDE-Q scores and the IES-r scores. Of the 36 patients who had completed the IES-r questionnaire, two were removed from the analysis as the EDE-Q data was missing, along with the outlier, leaving 33 patients for the analysis. A moderate significant positive correlation (r=.551, p < .05) was found (see Table 7.1). This indicates that greater PTSD symptoms are related to a greater severity of symptoms of an eating disorder. Whilst this test only indicates there is a relationship between the PTSD and ED symptoms, and is not an indication of causality, it could be speculated that the behaviours exhibited in ED patients escalate with higher symptoms of PTSD, as a means to cope with the psychological distress. One of the subscales within the IES-r questionnaire measures for avoidance, a common symptom of PTSD, and dietary restriction and binge eating behaviours are well documented means of avoiding negative emotions (Haynos et al, 2011). It is not clear from these results whether treating the ED symptoms alone would reduce PTSD symptoms, or conversely, whether removing an individual's means of coping through their dietary restriction or binge eating as part of their ED treatment may escalate PTSD symptoms further. Further research to explore this would strengthen arguments for introducing specialist trauma-focused treatment into ED therapy.

Table 1.1 Spearman's correlation between eating disorder severity and childhood trauma (ACE) and symptoms of PTSD (IES\_r)

		Eating disorder severity (EDE-Q)
ACE	Spearman's rho	.20
	Sig. (2-tailed)	.21
	N	41
IES-r total	Spearman's rho	.55
	Sig. (2-tailed)	.00
	N	33

## DISCUSSION

The results from this study further substantiate the requirements for a trauma-informed approach within the field of eating disorder services. The results demonstrate adverse childhood experience are widespread in this ED outpatient service user group and a number of these patients also presented with PTSD symptoms. The presence of complex trauma, as measured by the presence of ACES was 82% in this sample. This is higher than the findings from the large National Epidemiologic Survey on Alcohol and Related Conditions-III (NESARC-III; Forrest, 2020), quoting a prevalence rate of 60.2% of ACES in participants with EDs. This may reflect the differing sample groups, with this study collating data from patients engaged in outpatient ED therapy, in contrast to the NESARC-III which was a community-based survey which identified the presence of ED through interview. Those engaged in treatment for an ED are most likely to have greater severity of symptoms which would prompt them to seek therapy

and this may explain the higher ACE prevalence in this study, in comparison to the NESARC-III figures.

Assessment of PTSD takes a snapshot in time and measures active symptoms of avoidance, hyperarousal, and intrusions in relations to the traumatic experience. However, PTSD is not the only response to trauma and many responses can fall below the threshold for a PTSD diagnosis with individuals instead presenting with co-morbid chronic mental health issues (e.g., depression, substance misuse, and self-injury) (SAMHSA (2014). Within this study, the experience of psychological trauma alone did not appear to be associated with an increase in ED symptom severity. However, there was a positive correlation between active symptoms of PTSD, with higher PTSD scores being associated with a greater severity of ED symptoms. An awareness of this link suggests there is a place for treatment of PTSD in conjunction with ED treatment as usual, as a greater severity of ED symptomology would significantly affect the quality of life of the individual.

Poor quality of life is a well-recognised issue in patients with anorexia nervosa (Bamford et al, 2015; Sy et al, 2013). It affects physical and reproductive health, can be disabling and disrupts psychosocial functioning (Treasure et al, 2020). It can also place a significant burden on the family (Van Hoeken and Hoek, 2020). It is associated with increased risk, with anorexia nervosa having the greatest mortality rate of all mental illnesses (Arcelus et al, 2011). The impact of prolonged starvation on physical health is part of that risk, and these physical complications can include liver, renal, osteoporosis and cardiac failure. These physical complications also place a burden on primary care services and specialist medical facilities (Birmingham and Treasure, 2010). Long term follow-up studies demonstrate a considerable number of former ED patients will continue to meet the full diagnostic criteria for an ED decades later (Fichter et al, 2017).

This treatment resistance places a strain on ED services as it can lead to lengthier episodes of treatment, with above average numbers of outpatient appointments, and the potential requirement for inpatient treatment, as well as the 'revolving door' pattern of relapse and re-referral. This is costly and creates waiting time implications for services.

### Limitations

A major limitation of this study was recruitment, with low numbers of patients recruited overall and one site withdrawing from the study completely. This also affected the geographical spread of the data which had intended to be a descriptive picture of ED outpatient services across Scotland. With only two sites contributing to the data, it is not possible to generalise the study findings to the whole of Scotland. However, the aim of this study was descriptive to add illustration to a larger wider, mixed methods study. The characteristics of the group were also limited. Whilst it is known that ED is more prevalent in women (Fairburn, 2008), the number of men recruited to this study was not representative of the gender split across the services they were recruited from. Men are typically underrepresented in eating disorder research and this is most likely a result of the stereotypical view of EDs being a female disorder and the stigmatisation this creates for men (Roberts et al, 2018).

Other factors which may skew the findings were the list of exclusion criteria. For ethical reasons, and the difficulty with obtaining informed consent, patients who were detained under the mental health act were omitted from the survey. These patients are likely to have the greatest severity of ED symptoms and as this was one of the variables in this study, not having access to that data limits the wider picture. The patients who volunteered to take part in this study may only represent a specific cohort of ED

patients and may not be representative of the wider population. The study was also specific to adult ED outpatient services, with a minimum cut-off age of 18. The exclusion of inpatient services which would have included patients with a greater severity of eating disorders, and child and adolescent mental health services (CAMHS) may have offered distinct and unique data to the statistics in this study.

# CONCLUSIONS

This was a small study with low numbers but the results suggest complex trauma is common in ED patients, with 82% of patients having experienced at least one adverse childhood experience. However, exposure to psychological trauma alone does not automatically cause PTSD symptoms: only 50% of participants with a trauma history reported PTSD symptomology. There was a moderate association between higher PTSD symptoms and a greater severity of ED symptoms but no significant relationship between complex trauma and eating disorder symptom severity. PTSD appears to be a prevalent presentation, with 41% of the total sample population self-reporting through the questionnaire active PTSD symptomology at the point of engaging with this study. Further research to understand the links between PTSD and ED symptoms is required and this would strengthen arguments for treating PTSD symptoms as part of a phase-based approach for ED treatment. A larger study with greater participant numbers would also enable greater insight into the role complex trauma plays in ED presentations.

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