

**Asylum-seeking peoples' experiences of  
Narrative Exposure Therapy**

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**Thesis declaration form**

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

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Date: July 2018

## Overview

Refugees and asylum-seeking people who have experienced multiple and prolonged traumatic events have specialised needs for psychological therapy. This thesis investigates the acceptability, process and outcome of interventions provided to this population by mental health services in host countries.

This thesis is in three parts. Part 1 is a systematic literature review and meta-synthesis investigating refugee and asylum-seeking peoples' views of the barriers and facilitators to formal help-seeking for mental health difficulties. Seventeen qualitative studies were reviewed and synthesised. Findings suggest that help-seeking and accessing mental health services was influenced by the individual's beliefs about the causes of distress, social and cultural perceptions of mental health, and service and treatment related factors. However, quality of the studies varied, and facilitators to help-seeking and the views of young refugee and asylum-seeking people were not well elaborated.

Part 2 presents a qualitative study exploring 11 asylum-seeking peoples' views of the effectiveness and acceptability of Narrative Exposure Therapy. Therapy was experienced as a challenging process, which was tolerated in part through building a trusting therapeutic relationship. Following therapy participants reported being better able to manage intrusive re-experiencing of past traumatic events, alongside improved interpersonal relationships and increased activity levels. The challenges of completing therapy with people with uncertain asylum status are considered in light of the findings.

Part 3 is a reflective and critical discussion of conducting the empirical study. Several challenges faced in conducting the interviews are addressed, as well as issues of epistemological and personal reflexivity.

## **Impact statement**

The number of people displaced worldwide due to conflicts and human rights violations continues to rise. People are at increased risk of witnessing and enduring traumatic events and challenging circumstances before, during and after forced migration. This places them at greater risk of developing mental health difficulties and experiencing heightened levels of distress which have a detrimental impact on quality of life.

The meta-synthesis and qualitative study presented in this thesis have implications both for how mental health services can be made more accessible and relevant to refugee and asylum-seeking people in host countries, as well as the acceptability of offering Narrative Exposure Therapy as a psychological intervention following repeated or prolonged traumatic events. Both sets of findings potentially offer unique contributions to existing knowledge as previous research has not investigated these questions in this way.

Findings from the systematic literature review and meta-synthesis hold relevance for services and organisations set up to support the mental health needs of refugee and asylum-seeking people across the lifespan. The recommendations highlight the importance of involving refugee and asylum-seeking communities in shaping and evaluating services. If services implemented changes based on the findings and recommendations the numbers of refugee and asylum-seeking people who access services and seek support for their mental health may increase: potentially decreasing their distress, promoting recovery and improving their quality of life. Researchers working within this field may be interested in the highlighting of gaps in the literature relating to facilitators to accessing services and young asylum-seeking peoples' views.

The qualitative study indicates that Narrative Exposure Therapy (NET) was viewed as an acceptable intervention by the asylum-seeking people interviewed. Benefits experienced following therapy included reducing the negative impact of their past

traumatic experiences, as well as wider improvements in social relationships and increased activity levels. This suggests that some asylum-seeking people experience trauma-focused interventions as beneficial despite lacking the security of refugee status. These findings are of potential benefit to refugee and asylum-seeking people, as well as mental health services and clinicians. Further research is needed to ascertain how many sessions would constitute an adequate dose of NET, which could be investigated by academics working in the field.

Both papers will be disseminated through publication in a peer-reviewed journal. The findings from the qualitative study have been shared with a service user forum at the charity where the research was conducted, as well as with clinicians in a specialised NHS mental health team for forced migrants. Following these meetings an accessible one-page summary has been created which will be shared with refugee support organisations, refugee service user groups such as Survivors Speak OUT, and NHS adult mental health services.

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Finally, I would like to thank all the participants who agreed to share their experiences with me.

## **Part 1: Literature Review**

Refugee and asylum seekers' perceptions of barriers and facilitators to accessing mental health services: a systematic review and thematic synthesis of qualitative studies

## Abstract

**Aims:** This review synthesised qualitative studies exploring refugee and asylum-seeking peoples' perceptions of the barriers and facilitators to help-seeking for mental health and to accessing mental health services.

**Methods:** A systematic review of qualitative research was completed using the PsychINFO, CINAHL, Web of Science and Medline databases. Thematic synthesis was used to analyse the findings. The methodological quality of the studies was appraised using the Critical Appraisal Skills Programme. A sensitivity analysis was carried out to assess the contribution of the weakest studies.

**Results:** The meta-synthesis yielded five overarching analytic themes constructed from 17 studies. Findings suggest that formal help-seeking is influenced by personal beliefs about the causes and suitable sources of support for distress, the perception of the wider society of help-seeking, and ideas about what interventions services offer and how effective these might be. Younger people were particularly concerned about family and peers' perceptions and some preferred to be self-reliant.

**Conclusions:** The findings suggest several recommendations to support accessibility to mental health services for refugees and asylum-seeking people, although research exploring facilitators and young people's perspectives is limited. Services can be made more accessible by consulting with refugee and asylum-seeking communities and providing relevant information to empower people to make informed choices about seeking help for their distress.

## Introduction

Refugee and asylum-seeking adults and children have often experienced multiple traumatic events pre-migration (Ai, Peterson, & Ubelhor, 2002; Jahangiri, Tabatabaie, & Safi Keykaleh, 2017). This exposure acts as a risk factor for the development of a range of mental health difficulties, including post-traumatic stress disorder (PTSD), depression, anxiety, and substance misuse (Horyniak, Melo, Farrell, Ojeda, & Strathdee, 2016; Nose, Turrini et al., 2017; Posselt, Galletly, de Crespigny, & Procter, 2013; Priebe et al., 2013; Reed, Fazel, Jones, Panter-Brick, & Stein, 2012; Steel et al. 2009). This may be further compounded by post-migration experiences including racism in the host country, unemployment, detention, uncertainty about immigration status and separation from friends and family (Kirmayer et al., 2011; Lindencrona, Ekblad, & Hauff, 2008; Porter & Haslam, 2005; Robjant, Hassan & Katona, 2009; Schock, Böttche, Rosner, Wenk-Ansohn, & Knaevelsrud, 2016). Therefore, refugees and asylum-seeking people may be at higher risk of developing trauma-related mental health problems than the native population of the host country (Fazel, Wheeler, & Danesh, 2005; Norredam, Garcia-Lopez, Keiding & Krasnik, 2009; Shawyer, Enticott, Block, Cheng & Meadows, 2017).

Estimated prevalence rates of PTSD and other common mental health problems in refugees and asylum-seeking people range widely. This variation is impacted by differences in measurement methodologies, heterogeneity of the samples surveyed and different cultural constructions of distress and mental health (Hollifield et al., 2002; Nose, Turrini et al., 2017). A systematic review conducted by Fazel et al. (2005) estimated a prevalence rate of 11% for PTSD in refugee children, with a range of 7–17%. A separate systematic review and meta-regression reported unadjusted prevalence rates in adult refugees of 30.8% for depression and 30.6% for PTSD (Steel et al., 2009), which is higher than epidemiological estimates of PTSD (Atwoli, Stein, Koenen, & McLaughlin, 2015). Furthermore, there is

evidence to suggest that PTSD symptoms in refugees persist over time and are still present years after re-settlement in a host country (Bogic, Njoku, & Priebe, 2015). PTSD can have debilitating effects on quality of life and is associated with a significant risk of suicide, particularly in the presence of co-morbid depression and higher levels of re-experiencing and avoidance symptoms (Ferrada-Noli, Asberg, Ormstad, Lundin & Sundom, 1998; Panagioti, Gooding & Tarrier, 2009; Selaman, Chartrand, Bolton & Sareen, 2014).

Much of the research conducted with refugees and asylum-seeking people has focused specifically on prevalence rates and interventions for PTSD (Thompson, Vidgen & Roberts, 2018). However, there has been ongoing debate as to the validity of applying western diagnostic categories to non-western cultures, as well as whether PTSD adequately describes the complex psychological, physical and social problems of refugee and asylum-seeking people (Alarcón et al., 2009; Mezey & Robbins, 2001; Nguyen, 2011; Summerfield, 2001). Some have argued that reducing refugee and asylum-seeking people's experiences to a diagnosis of PTSD risks medicalising a natural response to repeated trauma and making invisible the negative impact on wellbeing of post-migration factors such as poverty, racism, poor housing and social exclusion (Patel, Williams & Kellezi, 2016). It is therefore important to evaluate services and interventions offered in western host countries to ensure that refugee and asylum-seeking people view them as meaningful, appropriate and effective in meeting their needs.

Despite growing evidence for psychological interventions for refugee or asylum-seeking adults and children (Gwozdziwycz, & Mehl-Madrone, 2013; Nose, Ballette et al., 2017; Tribe, Sendt, & Tracy, 2017), there is evidence for low rates of mental health service utilisation by these populations (Colucci, Szwarc, Minas, Paxton, & Guerra, 2014; Gerritsen et al., 2006; McCrone et al., 2005). Understanding the factors that act as either barriers or facilitators to help-seeking and accessing mental health services is therefore important in

ensuring that services are viewed as relevant, effective and appropriate by refugees and asylum-seeking people.

Barriers and facilitators may be internal, such as fear of being judged or hope for change, or external, for example lack of available interpreters or services being advertised through community outreach initiatives. Once identified, these factors can be specifically addressed to improve services in lines with the needs and requirements of refugee and asylum-seeking people. Accessing mental health services is defined in this review as engaging with facilities which provide treatments delivered by trained professionals: for example, psychologists, psychotherapists or psychiatrists. There are a variety of definitions of help-seeking (Rickwood & Thomas, 2012). In this review help-seeking for mental health problems is understood as attempting to find external support when suffering emotional distress. This review focuses on formal help-seeking from trained professionals, rather than informal help-seeking from friends, family or community.

Previous research has explored barriers and facilitators to help-seeking and accessing mental health services for this population. Reviews considering how to improve access to mental health care for immigrants and refugees have highlighted barriers including different conceptions of mental health problems to the host country, lack of awareness of services available, concerns about confidentiality, communication difficulties, stigma and uncertainty about political status undermining the ability to engage in psychological interventions (Giacco, Laxham & Priebe, 2018; Thomson, Chaze, George & Gurgue, 2015). Qualitative and quantitative studies exploring service providers' perspectives have identified similar factors as well as lack of acknowledgment of difficulties, fear of authorities and lack of trust, and negative experiences and perceptions of services (Bartolomei, et al., 2016; Franks, Gawn, & Bowden, 2007). Quantitative research has investigated factors associated with refugees' service use such as levels of psychological

distress and quality of life (Laban, Gernaat, Komproe & De Jong, 2007; Slewa-Younan, Radulovic, Lujic, Hasan & Raphael, 2014; Weine et al., 2000), mental health literacy (May, Rapee, Caello, Momartin, & Aroche, 2014; Slewa-Younan et al., 2014), and the relationship between acculturation and help-seeking attitudes (Thieko, Florin & Ng, 2015).

Colucci et al. (2014) systematically reviewed mental health service use by young refugees and noted similar barriers to access as identified in the adult refugee literature. They draw attention to an additional factor: that similarly to the general child population, guardians and family members' may seek help on the child's behalf even when the child does not consider they need help (Gronholm et al., 2015; Yeh & Weisz, 2001). Therefore, refugee and asylum-seeking children's carers' beliefs about mental health, knowledge of available services and ability to identify emotional difficulties may also present barriers or facilitators to help-seeking (De Anstiss, Ziaian, Procter, Warland, & Baghurst, 2009). Service provider perspectives reported similar barriers to the adult literature and further echoed the importance of engaging the young person's family (Colucci, Minas, Szwarc, Guerra & Paxton, 2015; Posselt, Procter, de Crespigny & Galletly, 2015). Quantitative studies have also investigated whether levels of psychological distress are associated with access of mental health services by refugee children (Bean, Eurelings-Bontekoe, Mooijaart, & Spinhoven, 2006; Geltman, Grant-Knight, Ellis & Landgraf, 2008; Sanchez-Cao, Kramer, & Hodes, 2012), including comparisons of accompanied and unaccompanied minors (Michelson & Sclare, 2009).

However, it is not clear whether quantitative studies and explorations of service providers' perceptions reflect the complex and diverse experiences of refugee and asylum-seeking people. A review of factors associated with mental health service use after a traumatic event reported that people from ethnic minority groups were less likely to seek treatment compared to Caucasian groups (Gavrilovic, Schützwohl, Fazel & Priebe, 2005).

The authors suggested that qualitative research exploring attitudes towards mental health service use and conception of mental health difficulties was necessary to contextualise these findings. Qualitative research exploring refugee and asylum-seeking peoples' views may allow for a more multi-faceted investigation of barriers and facilitators. Western host countries' psychological services may be constructed around a conceptual understanding of mental distress which differs from the one held by people the services are offered to. This conceptual difference may also affect the focus of research exploring barriers and facilitators designed by Western researchers. Qualitative methods allow for an exploration of different understandings of mental distress and the possibility of alternative explanations (Weine, Durrani & Polutnik, 2014). This methodology also amplifies refugee and asylum-seeking peoples' voices, allowing their views to influence the services designed to support them.

Meta-synthesis aims to review and summarise existing qualitative studies addressing a research question to allow for a more comprehensive understanding than single studies can provide (Timulak, 2009). A meta-synthesis of studies exploring refugee and asylum-seeking peoples' perceptions of help-seeking and accessing mental health services would allow a fuller analysis of the influencing factors and could provide a contextual background to the reported low rates of mental health service utilisation.

This review primarily aimed to systematically review and synthesise the qualitative literature exploring the perceptions of refugee and asylum-seeking people on help-seeking for mental health problems and accessing mental health services. A secondary aim was to formulate the synthesis findings in relation to factors which act as barriers and facilitators to these processes. A third aim was to create recommendations to guide service providers in the construction and delivery of services.

## **Method**

### **Epistemological position**

Within the field of meta-synthesis there are a range of different methodological approaches which are in part influenced by differing epistemological positions. These differences in epistemological background influence search strategy, data extraction, method of synthesising and interpretation of findings. The methodology used in this review was informed by thematic synthesis (Thomas & Harden, 2008); an approach to synthesis which reflects a “critical realist” or “subtle realist” position. This position proposes that the findings of original studies can be extracted and reflect a truth about the external world, while recognising that the findings are filtered through the researchers’ own assumptions, experience and theories (Barnett-Page & Thomas, 2009; Sandelowski, 2012). This position was chosen as appropriate for the review question and aims and is also consistent with the researcher’s own epistemological position.

### **Protocol**

Following PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (Shamseer, et al., 2015), a protocol was established to guide the search, selection, quality appraisal and synthesis of studies, and a data extraction form was developed. The protocol was registered (CRD42018094456) at PROSPERO (International Prospective Register of Systematic Reviews) and can be accessed at [www.crd.york.ac.uk/prospERO/display\\_record.php?RecordID=94456](http://www.crd.york.ac.uk/prospERO/display_record.php?RecordID=94456).

### **Data collection**

#### **Inclusion and exclusion criteria.**

Criteria for including studies:

- 1) participants were refugees or asylum seekers aged 12 or older

- 2) investigated factors relating to accessing mental health services and or help-seeking for mental health difficulties
- 3) conducted in host countries in community settings
- 4) used a qualitative method of data collection e.g. interviews, focus groups
- 5) published in a peer-reviewed journal before January 2018 in English.

Studies were excluded if they reported:

- 1) research focused on help-seeking or access to physical health services, including perinatal services
- 2) perspectives of others e.g. professionals, community leaders, parents
- 3) data from participants who were internally displaced or not forced migrants
- 4) reviews or case studies.

#### **Search strategy.**

As discussed, search strategies vary across meta-synthesis approaches. This review employed a comprehensive search strategy with the aim of identifying as many relevant papers to the review topic as possible in line with a more 'realist' approach (Barnett-Page & Thomas, 2009). Other meta-synthesis methods suggest a more iterative approach involving searching for concepts relevant to the review topic and stopping once theoretical saturation is reached in the analysis (Timulak, 2009).

Systematic searches were conducted in four databases representing psychology, nursing and allied health, sciences and psychiatry: PsychINFO, CINAHL, Web of Science and Medline. Databases were searched to include papers published from the start of the database up to and including December 2017. The last searches were performed on 2<sup>nd</sup> January 2018. The search terms used were related to the key concepts of the review

question; help-seeking/access, mental health, psychological intervention, and refugee/asylum-seeking people (see Table 1). Synonyms were identified through examining previous reviews, relevant articles, and in consultation with a specialist librarian. The searches were limited to the English language and peer reviewed journals. To identify additional relevant studies hand searches were completed of the reference lists and citations of the included papers, as well as relevant reviews.

Table 1. *Search terms.*

| Help-seeking /access | AND | Mental health | AND | Psychological intervention | AND | Refugee/ asylum seeking | AND |
|----------------------|-----|---------------|-----|----------------------------|-----|-------------------------|-----|
| help                 |     | mental        |     | psycholog*                 |     | migra*                  |     |
| OR                   |     | health        |     | OR                         |     | OR                      |     |
| help-seeking         |     | OR            |     | therap*                    |     | immigra*                |     |
| OR                   |     | trauma        |     | OR                         |     | OR                      |     |
| information          |     | OR            |     | treatment*                 |     | Refugee*                |     |
| OR                   |     | PTSD          |     | OR                         |     | OR                      |     |
| advice seek*         |     | OR            |     | intervention*              |     | transient               |     |
| OR                   |     | post-         |     | OR                         |     | OR                      |     |
| access*              |     | traumatic     |     | psychotherap*              |     | asylum*                 |     |
| OR                   |     | stress        |     | OR                         |     | OR                      |     |
| utili*               |     |               |     | counsel*                   |     | torture*                |     |
|                      |     |               |     | OR                         |     | OR                      |     |
|                      |     |               |     | clinic                     |     | evacuee*                |     |
|                      |     |               |     |                            |     | OR                      |     |
|                      |     |               |     |                            |     | displaced               |     |
|                      |     |               |     |                            |     | person*                 |     |
|                      |     |               |     |                            |     | OR                      |     |
|                      |     |               |     |                            |     | displaced               |     |
|                      |     |               |     |                            |     | people                  |     |
|                      |     |               |     |                            |     | OR                      |     |
|                      |     |               |     |                            |     | asylum-                 |     |
|                      |     |               |     |                            |     | seek*                   |     |
|                      |     |               |     |                            |     | OR                      |     |
|                      |     |               |     |                            |     | political               |     |
|                      |     |               |     |                            |     | asylum                  |     |

### **Study selection.**

The combined search results from the databases identified 2928 articles after removing duplicates. Titles and abstracts were then screened and articles not meeting the inclusion criteria were removed, leaving 101 articles. The full texts of these articles were assessed for eligibility, resulting in the identification of 12 articles. A further five articles were identified through manual searches leading to 17 studies included in the meta-synthesis (see Figure 1 for PRISMA flow diagram: Moher, Liberati, Tetzlaff, Altman, 2009). To check adherence to the inclusion and exclusion criteria a second researcher independently reviewed a random selection of 25% of the full text articles (n= 25). There was strong inter-rater agreement, Cohen's kappa = .840 (95% CI .690 to 0.990). Disagreements were discussed until consensus was achieved.

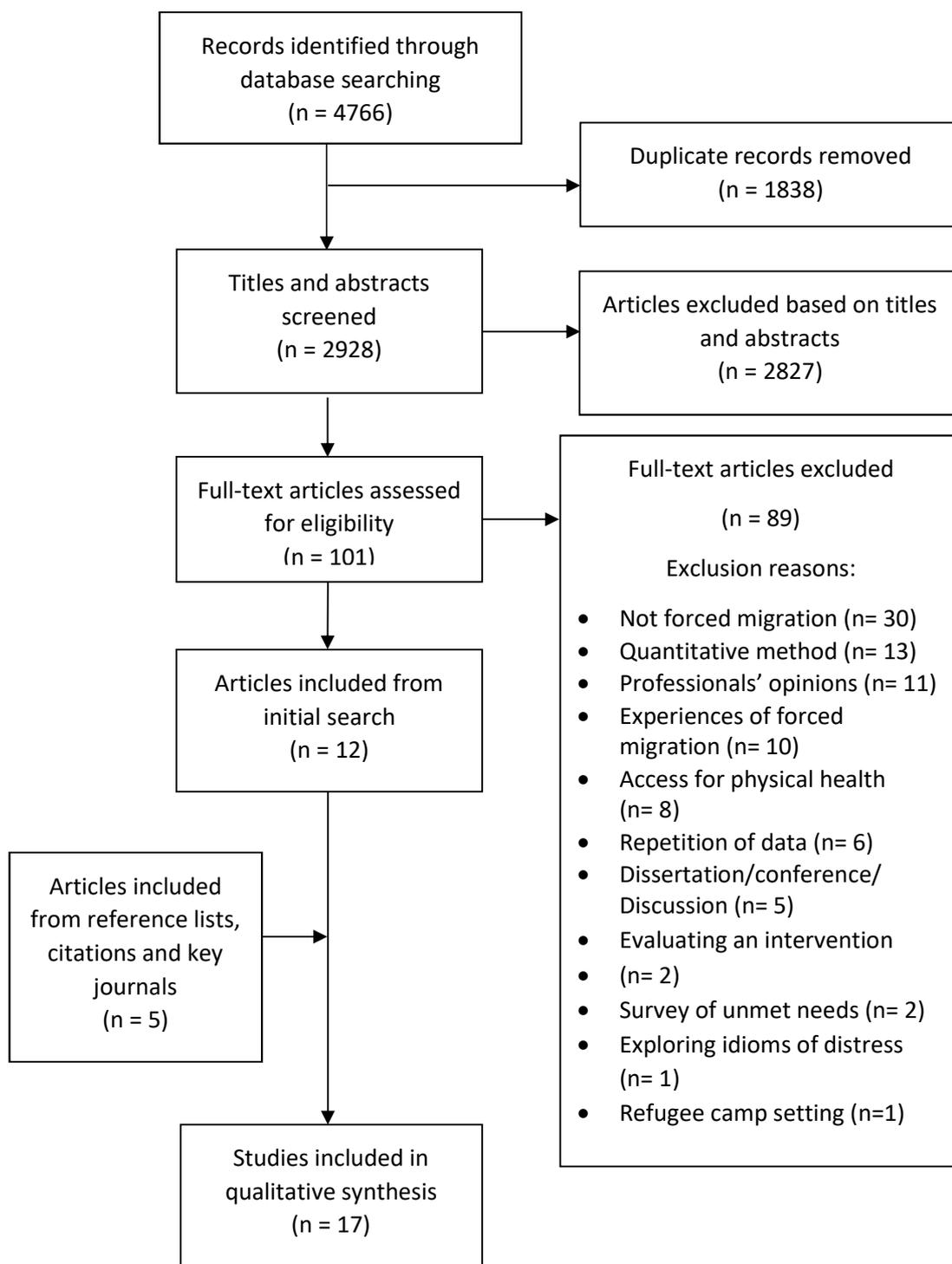


Figure 1. PRISMA flow diagram

### **Data extraction.**

Data was extracted from the included studies via a data extraction sheet created for this study following PRISMA guidelines (Shamseer, et al., 2015). As mentioned, there are various positions on what constitutes data to be extracted from the original studies within meta-synthesis (Noyes et al., 2018). For this review all data under the headings “results” or “findings” were treated as data including any tables or figures in keeping with a realist approach (Barnett-Page & Thomas, 2009; Sandelowski, 2012). All data relevant to the review questions was synthesised, despite how it was labelled or described in the original studies. The data was extracted electronically and imported into NVivo (NVivo Qualitative Data Analysis Software, 2017).

### **Analysis**

#### **Quality appraisal.**

The appraisal of the included studies was guided by the 10-item Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist (CASP, 2017) (See Appendix A) a tool which has been used in similar qualitative reviews (Coleman, Stevelink, Hatch, Denny, & Greenberg, 2017). The CASP checklist assesses several methodological considerations including the research aims, appropriateness of using a qualitative method, design, recruitment, data collection, analysis and description of findings, as well as a consideration of the wider value of the research.

In accordance with established methodological guidelines for conducting systematic reviews, studies were not excluded from the synthesis based on the quality appraisal (Centre for Reviews and Dissemination (CRD), 2009; Noyes et al., 2018). The reliability and validity of the CASP checklist has also not been assessed and there is ongoing debate in the field as to the place of quality appraisal within qualitative research (Barnett-Page & Thomas, 2009; Dixon-Woods, Shaw, Agarwal & Smith, 2004; Dixon-Woods et al.,

2007). The CASP checklist was instead used to identify weaker quality studies and a sensitivity analysis was conducted to explore the impact of methodological quality on the results of the synthesis (CRD, 2009; Shamseer, et al., 2015). The sensitivity analysis involved removing data from the themes that originated from the weakest studies as identified through the quality appraisal. The results were compared to the original themes to evaluate how removing the contributions from the studies of lower quality changed the structure and content of the themes.

To check reliability a second researcher independently appraised the quality of a selection of 25% of the studies (n= 5). Inter-rater agreement was moderate, Cohen's Kappa = .600 (95% CI .443 to 0.757). Disagreements were discussed until consensus was achieved.

#### **Meta-synthesis approach.**

The meta-synthesis was carried out following a combination of thematic analysis (Braun & Clarke, 2006) and thematic synthesis (Thomas & Harden, 2008). In line with Thomas and Harden's (2008) approach, initially a descriptive analysis was completed keeping close to the findings of the studies, before moving on to develop analytical themes in response to the review question. This second more interpretative stage was undertaken with the aim of extending the synthesis beyond summarising the original findings.

In the descriptive phase the data from each study was first coded line by line. As subsequent studies were coded existing codes were used or new codes were created as necessary. Secondly, data relevant to each code was collected together, re-read and compared for consistency in coding, allowing the creation of preliminary themes which described similar codes across studies. Thirdly, each paper was re-read to ensure that all relevant data had been coded and to search for data that contradicted the preliminary themes. Lastly, themes were refined and arranged into a hierarchy to show connections and relationships between them. In the analytic stage the descriptive themes were

reviewed again by re-reading all data coded under each theme and analytic themes describing potential barriers and facilitators to accessing mental health services and help-seeking were generated. Associated recommendations for policy and practice for each analytic theme were derived to increase the applicability to practice of the review. Where participants in the original studies had made suggestions for improvements to services these were incorporated into the recommendations.

### **Researcher's background and preconceptions**

The researcher is a white, British, female trainee clinical psychologist with some experience of working with refugees and asylum seekers within research and clinical practice. She identified her hypotheses before starting the thematic synthesis, including that barriers to accessing mental health services might include practical structural barriers such as waiting times and language, as well as internal barriers including avoidance of discussing traumatic past experiences. The researcher recognises the wider debate around the validity of psychiatric diagnoses such as PTSD and their applicability to non-Western communities, as well as the role the concept of diagnosis has in shaping not only which interventions are offered but how services are structured and who services are offered to (Alarcón et al., 2009; Mezey & Robbins, 2001; Nguyen, 2011; Summerfield, 2001). Having being trained within a western model of psychology, the researcher tried to pay particular attention to data which presented an alternative view of helpful sources of support including spiritual and community resources, to try to counter any bias on her part. The researcher also tried to look for data that might contradict her preconceptions that the main internal barrier would be reluctance to discussing traumatic experiences.

### **Methodological credibility checks**

During the analysis reflective notes were kept by the researcher as part of a proactive effort to "bracket" and remain aware of the influence of their existing ideas and

preconceptions (Fischer, 2009; Timulak, 2009). Once the initial phase of the descriptive analysis was complete the resulting themes were discussed and revised under guidance of the research supervisor, and this process was repeated during the generation of the analytic themes and recommendations for policy and practice (Levitt, Morrow, Wertz, Motulsky, & Ponterotto, 2017). Triangulation of the final themes was conducted by consulting existing literature, including quantitative studies of factors relating to access to mental health service (Timulak, 2009). The relationship between the themes in this review and previous research are presented in the discussion below.

### **Confidence in meta-synthesis findings**

In line with GRADE-CERQual guidance (Confidence in the Evidence from Reviews of Qualitative Research) (Lewin et al., 2015) steps were taken to facilitate transparency in the methodology of the review and increase confidence in the synthesis findings. The methodological limitations of the original studies were appraised using CASP (2017) (Table 3) and the characteristics of the included studies are presented to provide information about the relevance of included studies to the review question (Table 2). In addition, a table was created to show the contribution of studies to each theme to enable assessment of the adequacy of data supporting the final themes (see Appendix B) (Shamseer et al., 2015).

## **Results**

### **Study characteristics**

The characteristics of the 17 qualitative studies included in the synthesis are summarised below and presented in Table 2.

#### **Study aims.**

The included studies explored the participants' perceptions of mental health problems and their causes, ideas about informal and formal help for mental health

problems and use of mental health services. Three articles directly addressed barriers to accessing mental health services, all of which focused on young refugees (De Anstiss & Ziaian, 2010; Posselt, McDonald, Procter, de Crespigny, & Galletly, 2017; Valibhoy, Szwarc, & Kaplan, 2017). Some studies also considered broader topics, which were not included in the synthesis, such as comparisons to views of other populations (Kokanvoic, Dowrick, Butler, Herrman, & Gunn, 2008) or service provider perspectives (Posselt et al., 2017). Four studies also contained a quantitative element which was not included in this review (Bernardes et al., 2011; Ellis et al., 2010; Markova & Sandal, 2016; Posselt et al., 2017).

### **Participants.**

The total number of participants across all studies was 508, with individual study sample sizes ranging from five to 111. In studies which stated the gender of participants, the average percentage of female participants reported ranged from six percent to 60, apart from two papers which included only one gender (Omar, Kuay & Tuncer, 2017; Whittaker, Hardy, Lewis & Bunchan, 2005). Where reported, participants' ages ranged from 12 to 65, with five studies including participants under the age of 18 (Ellis et al., 2010; De Anstiss & Ziaian, 2010; Fazel, Garcia, & Stein, 2016; Majumder, O'Reilly, Karim, & Vostanis, 2015; Posselt et al. 2017). Three of these studies reported the percentage of participants who had sought asylum as unaccompanied minors; 13% (Posselt et al., 2017), 32% (Fazel et al., 2016) and 100% (Majumder et al., 2015).

Most studies included participants who had originated from a range of different countries, although five studies focused solely on Somali people (Bettman, Penney, Clarkson Freeman, & Lecy, 2015; Carroll, 2004; Ellis et al., 2010; Markova & Sandal, 2016; Whittaker et al., 2005).

### **Setting and contact with mental health services.**

The studies were conducted mainly in English speaking Western countries; five in the UK, five in Australia, four in the USA, and one each in Switzerland, Norway and Canada. Eleven studies reported on whether participants had had experience accessing mental health services.

### **Data collection and analysis.**

Nine studies used individual interviews to collect data, four used focus groups, and four used a combination of focus groups and individual interviews. The studies used a variety of methodologies for analysis including thematic analysis, framework analysis, grounded theory and interpretative phenomenological analysis.

### **Quality appraisal**

The studies were reviewed against the 10 items on the CASP checklist (see Table 3).

### **Research aims and design.**

All studies complied with the first two items on the CASP checklist; outlining clear research aims for which a qualitative methodology was appropriate. Sixteen studies were assessed to meet the third criterion as they included some justification of the research design and description of the qualitative methods chosen. One study did not outline the qualitative analysis methodology used (Behnia, 2004).

Table 2. *Study Characteristics*

| Study                    | Aims  | Sample Characteristics                             | Country of origin of participants | Contact with mental health services   | Data collection method   | Data analysis method   |
|--------------------------|---|--|-----------------------------------|---|--|--|
| Behnia (2004)            | To discuss factors that impact refugees' use of mental health services as well as the functions and benefits of community peer groups   | N= 36<br>Adult refugees                            | Bosnia<br>Cambodia<br>El Salvador | 8/36 using mental health services at time of interview  | Individual semi-structured interviews                                      | Not reported   |
| Canada                   |   | Age range:<br>78% between 20-49<br>Majority female | Iran<br>Somalia                   | 25% had approached a mental health professional at some time in host country  |  |  |
| Bernardes et al., (2011) | To explore asylum seekers' subjective experiences of the asylum process and its potential impact on their mental health as well as participants' suggestions for tackling mental health needs | N= 8<br>Adult asylum seekers                       | Not reported                      | Recruitment from a health clinic and mental health team   | Individual semi-structured interviews                                      | Free association narrative interview method (Holloway & Jefferson, 2000) & Thematic Analysis |
| UK                       |   | Ages not reported<br>10% female                    |                                   |   |  |  |
| Bettman et al., (2015)   | To explore how Somali and Somali Bantu refugees perceive, describe, and explain mental illness, and explore their beliefs about treatment for mental illness                                  | N= 20<br>Adult refugees                            | Somalia                           | Recruitment targeted people who were openly communicative about having experiences with physical and/or mental health care both in their home country and USA | Individual semi-structured interviews (n=12) & Four Joint interviews (n=8) | Grounded Theory  |
| USA                      |   | Ages not reported<br>50% female                    |                                   |   |  |  |

|                            |  |  |   |  |                                       |                   |
|----------------------------|--|--|---|--|---------------------------------------|-------------------|
| Carroll (2004)             | To study how mental health difficulties are understood, expressed, and treated among Somali refugees and how these factors influence use of mental health services | N= 17<br>Adult refugees                                  | Somalia   | 2/17 diagnosed with depression                             | Individual semi-structured interviews | Grounded Theory   |
| USA                        |  | Age range: 21-45<br>53% female                           |   | 1/17 diagnosed with depression & PTSD                      |                                       |                   |
| De Anstiss & Ziaian (2010) | To explore rates and patterns of service utilisation across service sectors, use of informal supports, and actual and perceived barriers to services               | N= 85<br>Adolescent refugees                             | Afghanistan<br>Bosnia<br>Iran<br>Iraq<br>Liberia<br>Serbia<br>Sudan | Most had no mental health service experience or exposure   | Focus groups                          | Thematic analysis |
| Australia                  |  | % UAM not reported<br><br>Age range: 13-17<br>48% female |   |  |                                       |                   |
| Ellis et al., (2010)       | To examine the utility of the Gateway Provider Model in understanding service utilization and pathways to help for Somali refugee adolescents.                     | N= 30<br>Adolescents refugees                            | Somalia   | 5/30 screened positive for PTSD                            | Individual interviews (n=14)          | Thematic Analysis |
| USA                        |  | % UAM not reported<br><br>Ages and genders not reported  |   | 2/30 sought services for emotional or behavioural problems | & 3 focus groups (n=16)               |                   |

|                                       |  |  |  |   |  |                    |
|---------------------------------------|--|--|--|---|--|--------------------|
| Fazel (2016)<br>UK                    | To explore refugee and asylum seeking young people's experiences of school-based mental health services  | N= 40<br>Adolescent refugees and asylum seekers<br><br>32% UAM<br><br>Age range: 15-24<br>28% female | 20 different countries   | All recently discharged from a mental health team   | Individual semi-structured interviews                  | Framework Analysis |
| Kokanvoic et al., (2008)<br>Australia | To explore lay concepts of distress from Anglo Australian, Ethiopian and Somali communities in Australia; to assess similarities and differences in views about depression, its causes and consequences, and how it should be managed or treated                           | N= 30<br>Adult refugees<br><br>Age range and genders not reported                                    | Somalia<br>Ethiopia  | Not reported  | 3 Focus groups & Individual semi-structured interviews | Thematic Analysis  |
| Maier & Straub (2011)<br>Switzerland  | To explore what kind of help/treatment traumatised migrants expect from the local health care system; what kind of help/treatments they have already made use of; whether they have prior knowledge of psychotherapy and whether they consider it an appropriate treatment | N= 13<br>Adult refugees & asylum seekers<br><br>Age range: 22 to 53<br>38% female                    | Bosnia<br>Kosovo<br>Turkey<br>Iran<br>Afghanistan<br>Cameroon<br>Sudan<br>Chechnya | All had accessed mental health services<br><br>11/13 diagnosed with PTSD<br>2/13 diagnosed with adjustment disorder | Individual semi-structured interviews                  | "Content Analysis" |

|                         |   |  |   |  |                                       |                                  |
|-------------------------|---|--|---|--|---------------------------------------|----------------------------------|
| Majumder et al. (2015)  | To explore the views and perceptions that unaccompanied minors hold about mental health and services  | N= 15<br>Adolescent refugees & asylum seekers<br><br>100% UAM<br><br>Age range: 15-18<br>6% female | Afghanistan<br>Iran<br>Somalia<br>Eritrea | All had seen a mental health service<br><br>8/15 diagnosed with PTSD<br>6/15 diagnosed with depression | Individual semi-structured interviews | Thematic analysis                |
| UK                      |   |  |   |  |                                       |                                  |
| Markova & Sandal (2016) | To gain an understanding of how Somali refugees make sense of depression and prefer to cope with mental health problems   | N= 10<br>Adult refugees<br><br>Age range: 25-60<br><br>60% female                                  | Somalia                                   | Not reported   | 2 Focus groups                        | Template Analysis (King, 2007)   |
| Norway                  |   |  |   |  |                                       |                                  |
| Omar et al. (2017)      | To examine Horn of Africa Muslim men's understanding, experiences and views on the causes of emotional difficulties, barriers to seeking help, access to mainstream mental health services and traditional African treatments | N= 36<br>Adult refugees<br><br>Age range between 18-29 and 50-60<br>0% female                      | Somalia<br>Eritrea<br>Dijbouti            | Not reported   | 5 Focus groups                        | Ethnographic & Thematic Analysis |
| Australia               |   |  |   |  |                                       |                                  |

|                                    |  |  |  |  |                                       |                           |
|------------------------------------|--|--|--|--|---------------------------------------|---------------------------|
| Palmer & Ward (2007)<br>UK         | To explore the challenges of accessing mental health services by refugee and asylum-seeking populations  | N= 21<br>Adult refugees & asylum seekers<br><br>Age range:<br>21-65<br>48% female                                  | Azerbaijan<br>Bosnia<br>Congo<br>Ethiopia<br>Iran<br>Iraq<br>Kosovo<br>Kurdish<br>Russia<br>Rwanda<br>Somalia<br>Ukraine | 15/21 were accessing mental health services at the time of interview | Individual semi-structured interviews | Framework Method          |
| Posselt et al. (2017)<br>Australia | To determine the barriers and facilitators to effective, culturally responsive service provision for young people of refugee background living with comorbid mental health and alcohol and other drug problems | N= 15<br>Adolescent & Young adult refugees<br><br>13% UAM<br><br>Age range:<br>12-25<br>average 17.7<br>60% female | Afghanistan<br>Congo<br>Liberia<br>Burundi<br>Bhutan   | 4/15 recruited through their MH or AOD worker                        | Individual semi-structured interviews | Thematic Analysis         |
| Shannon et al., (2015)<br>USA      | To explore reasons refugees find it difficult to discuss the mental health effects of political violence and how this relates to health service utilization  | N= 111<br>Adult refugees<br><br>Mean age range:<br>27-45<br>43% female   | Burma<br>Bhutan<br>Somalia<br>Ethiopia   | Not reported   | 13 Focus groups                       | “Thematic categorisation” |

|                         |   |   |   |  |  |                   |
|-------------------------|---|---|---|--|--|-------------------|
| Valibhoy et al. (2017)  | To examine barriers to accessing mental health services, from the perspective of young people of refugee background who have been service users | N= 16<br>Adult refugees<br><br>% UAM not reported<br><br>Age range: 18-25<br>56% Female                 | Iraq<br>Iran<br>Afghanistan<br>Sudan<br>DR Congo<br>Ethiopia<br>Tanzania<br>Cote d'Ivoire<br>Pakistan | 8/16 currently accessing mental health services<br><br>8/16 had previously accessed mental health services | Individual interviews                                    | Thematic Analysis |
| Whittaker et al. (2005) | To explore individual and collective understandings of psychological well-being among young Somali asylum seeker or refugee women.              | N=5<br>Adult refugees & asylum seekers<br><br>% UAM not reported<br><br>Age Range: 17-25<br>100% female | Somalia   | Not reported   | 3 Focus groups & 5 Individual semi-structured interviews | IPA               |

UAM= unaccompanied minors; IPA= Interpretative Phenomenological Analysis

### **Recruitment.**

Studies were marked as meeting the fourth criterion if they described the recruitment strategy and the participant characteristics which guided the sampling. Thirteen studies were assessed as adequate, although overall the studies lacked full information about exclusion criteria. Ellis et al. (2010) outlined the inclusion criteria for participants to the wider quantitative study but not how participants were selected for qualitative interviews. One study outlined only the characteristics which guided the sampling (Behnia, 2004), and two studies included participant demographics but did not adequately explain the recruitment process (Majumder et al., 2015; Shannon, Wieling, Simmelink-McCleary, & Becher, 2015). Of additional note, two studies explained the researcher may have already known the participants due to working at the centre participants were recruited from (Carroll, 2004; Palmer & Ward, 2007), and Posselt et al. (2017) described four of the participants being encouraged to participate by mental health professionals.

The checklist further suggests considering if studies have described the numbers of participants who chose not to take part and their reasons; only three studies partially reported this information (Bernardes et al., 2011; Carroll, 2004; Palmer & Ward, 2007).

### **Data collection.**

For the fifth checklist item, studies were assessed as having described the data collection adequately if they explicitly reported the method, form and setting of the data collection. Most studies used either interviews or focus-groups with semi-structured interview guides, except Markova and Sandal's (2016) study in which a clinical vignette describing a person with symptoms of depression was read aloud and then participants were asked related questions to prompt discussion. The checklist also suggests considering if the studies discuss saturation of the data. As only five studies reported this information

(De Anstiss & Ziaian, 2010; Ellis et al., 2010; Majumder et al.,2015; Omar et al., 2017; Valibhoy et al.,2017), if a study met all three points above it was marked as adequate, which resulted in fourteen studies meeting this criterion. Two studies described how the data were collected and the form, but not the data collection setting (Majumder et al.,2015; Markova & Sandal, 2016). Palmer and Ward (2007) did not state how data were collected or the setting.

#### **Researchers' reflections on their role in the research.**

Only three studies met the sixth checklist item, which considers if researchers have discussed their role and bias in the research design, recruitment and analysis (Carroll, 2004; Omar et al., 2017; Whittaker et al., 2005). Three studies included some limited reference to the researchers' background, reactions to the interviews, or potential bias in the design of the study (Bernardes et al., 2011; Markova and Sandal, 2016; Palmer & Ward, 2007). Three studies described using principles of participatory action research and consulting community members on the objectives, interview schedules, recruitment and findings (Ellis et al., 2010; Posselt et al., 2017; Shannon et al., 2015).

#### **Ethical issues.**

Studies were assessed to have met the seventh question on the checklist if the researchers had adequately described issues of consent and seeking approval from an ethics committee. Eleven studies met this criterion. Two studies described only the process of gaining consent (Behnia, 2004; Palmer & Ward, 2007), three only referred to approval from an ethics committee (Ellis et al., 2010; Kokanvoic et al.,2008; Majumder et al., 2015) and one did not include either information (De Anstiss & Ziaian, 2010).

### **Analysis and description of findings.**

The last three checklist items assess whether the analysis was sufficiently rigorous, the clarity of the findings and the value of the research.

Eleven studies were assessed as having sufficiently analysed the data as they described the analysis process, provided sufficient data to support findings, referred to any contradictory data and described at least one credibility check. However, there was variation in the quality of detail provided. Whittaker et al. (2005) outlined the steps of the analysis and described six steps taken to increase credibility and validity including respondent validation, independent assessment of transcripts and triangulation, whereas Valibhoy et al. (2017) briefly state which data analysis method was used and described collaboration over the categorisation of themes without reference to the number of researchers involved or how consensus was reached.

Two studies referred to pre-existing frameworks in the analysis; Ellis et al. (2010) used the Gateway Provider Model (Stiffman, Pescosolido & Cabassa, 2004) as a way of understanding service use and pathways to help and Markova and Sandal (2016) created *a priori* categories to analyse the data derived from a pre-existing model of causal beliefs and coping strategies (Hagmayer & Engelmann, 2014).

Findings were rated as being clearly stated if they referred to the original research question, the description went beyond simply summarising what participants had said and there was some comment on the findings as a whole. Fifteen studies met this criterion; two studies did not offer much interpretation of the findings or elaborate further than summarising what participants had said (Behnia, 2004; Palmer & Ward, 2007). Overall the studies tended to be more descriptive than interpretative and lacked comprehensive discussion of the interaction between themes. Three studies provided a richer description of themes (De Anstiss & Ziaian, 2010; Majumder et al., 2015; Whittaker et al., 2005).

All the studies were assessed as being valuable and showed evidence of discussing findings in relation to policy, practice or previous research. However not all studies discussed the generalisability of the findings or new areas for research.

### **Sensitivity analysis**

The four weakest studies were removed from the synthesis to assess their contributions to the analysis (Behnia, 2004; Ellis et al., 2010; Majumder et al., 2015; Palmer & Ward, 2007). After removing the studies two sub-themes were then only supported by one study each: schools can be a trusted environment and increasing accessibility. These themes should therefore be interpreted with caution. Otherwise the themes remained unchanged, suggesting that these four studies did not contribute significantly to the overall themes and recommendations.

The studies which made the least overall contributions to the themes either did not set out to answer directly the question of the review or were mixed-method designs (Carroll, 2004; Ellis et al., 2010; Kokanovic et al., 2008; Markova & Sandal, 2016; Omar et al., 2017).

Table 3. Quality assessment of included studies using the CASP Qualitative Research Checklist (Critical Appraisal Skills Programme, 2014)

| CASP criterion   | Behnia (2004) | Bernardes et al. (2011) | Bettman et al. (2015) | Carroll (2004) | De Anstiss & Ziaian (2010) | Ellis et al. (2010) | Fazel (2016) | Kokanvoic et al. (2008) | Maier & Straub (2011) | Majumder et al. (2015) | Markova & Sandal (2016) | Omar et al. (2017) | Palmer & Ward (2007) | Posselt et al. (2017) | Shannon et al. (2015) | Valibhoy et al. (2017) | Whittaker et al. (2005) |
|--|---------------|-------------------------|-----------------------|----------------|----------------------------|---------------------|--------------|-------------------------|-----------------------|------------------------|-------------------------|--------------------|----------------------|-----------------------|-----------------------|------------------------|-------------------------|
| 1) Clear statement of the aims?                        | ✓             | ✓                       | ✓                     | ✓              | ✓                          | ✓                   | ✓            | ✓                       | ✓                     | ✓                      | ✓                       | ✓                  | ✓                    | ✓                     | ✓                     | ✓                      | ✓                       |
| 2) Qualitative methodology appropriate?                | ✓             | ✓                       | ✓                     | ✓              | ✓                          | ✓                   | ✓            | ✓                       | ✓                     | ✓                      | ✓                       | ✓                  | ✓                    | ✓                     | ✓                     | ✓                      | ✓                       |
| 3) Design appropriate to the aims?                     | X             | ✓                       | ✓                     | ✓              | ✓                          | ✓                   | ✓            | ✓                       | ✓                     | ✓                      | ✓                       | ✓                  | ✓                    | ✓                     | ✓                     | ✓                      | ✓                       |
| 4) Recruitment strategy appropriate to the aims?       | X             | ✓                       | ✓                     | ✓              | ✓                          | X                   | ✓            | ✓                       | ✓                     | X                      | ✓                       | ✓                  | ✓                    | ✓                     | X                     | ✓                      | ✓                       |
| 5) Data collected method addressed the research issue? | ✓             | ✓                       | ✓                     | ✓              | ✓                          | ✓                   | ✓            | ✓                       | ✓                     | X                      | X                       | ✓                  | X                    | ✓                     | ✓                     | ✓                      | ✓                       |

|   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 6) Relationship between researcher & participants considered? | X | X | X | ✓ | X | X | X | X | X | X | X | ✓ | X | X | X | X | ✓ |
| 7) Ethical issues considered?                                 | X | ✓ | ✓ | ✓ | X | X | ✓ | X | ✓ | X | ✓ | ✓ | X | ✓ | ✓ | ✓ | ✓ |
| 8) Data analysis sufficiently rigorous?                       | X | ✓ | ✓ | ✓ | ✓ | X | ✓ | ✓ | X | ✓ | X | X | X | ✓ | ✓ | ✓ | ✓ |
| 9) Clear statement of the findings?                           | X | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | X | ✓ | ✓ | ✓ | ✓ |
| 10) How valuable is the research?                             | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |

✓ = met criterion X = did not meet criterion

## **Meta-synthesis**

The findings from the 17 studies were synthesised and five overarching analytic themes were constructed. Table 4 outlines a summary of the themes and subthemes. The first theme, individuals' conceptions of their difficulties, contains four subthemes that outline the relationship between conception of mental health difficulties and the sources of support sought. The second theme, beliefs about the social meaning and consequences of mental health difficulties, contains four subthemes which further illustrate the ways participants described people with mental health difficulties and the response of their communities towards these people. The third theme, existing knowledge and expectations of services, is made up of nine subthemes which outline the level of familiarity with the idea of mental health services and the beliefs participants held as to whether such services could meet their perceived needs. The fourth theme outlines participants trust in services and beliefs about professionals. The final theme outlines the aspects of service delivery which limit or facilitate refugee and asylum-seeking peoples' access to mental health services.

Table 4: *Overarching analytic themes, barrier and facilitator subthemes*

| Analytic theme   | Barriers to help-seeking   | Facilitators to help-seeking   |
|--|--|--|
| 1. Individuals' conception of their difficulties                                   | Socio-political and spiritual conception leads to community and spiritual support      |  |
|  | Young people prefer to seek support from friends                                       |  |
| 2. Beliefs about the social meaning and consequences of mental health difficulties | Lack of familiarity with Western conception of mental health                           | Familiarity with Western conception of mental health                         |
|  | Mental health difficulties mean you are "crazy"  |  |
|  | Fear of community gossip and rejection leads to denial and concealment of difficulties | Community will care for you<br>Talking to professionals protects from gossip |
| 3. Existing knowledge and expectations of services                                 | Lack of knowledge of services  | Services available in country of origin                                      |
|  | Services are not culturally appropriate  |  |
|  | Fears of hospitalisation and forced medication   |  |
|  | Discrimination against refugees  |  |
|  | Talking about the past has negative consequences                                       | Services can help distress   |
| 4. Trust in services and beliefs about professionals                               | Practical concerns take priority   | Professionals engaging with practical concerns builds trust                  |
|  | Impact of political oppression   | Schools can be a trusted environment   |
|  | Professionals do not care or understand  | Feeling safe and understood  |
| 5. Service delivery  | Concerns about confidentiality   | Considering the cultural background of professionals                         |
|  | Service related barriers   | Increasing accessibility   |

Note: subthemes on the same level of the table are part of a continuum

## **1. Individuals' conception of their difficulties**

### **Socio-political and spiritual conception leads to community and spiritual support.**

Participants across all studies reported a range of socio-political causes for their emotional difficulties including family tension, changes to social role after migration, loss and traumatic experiences. The impact of traumatic experiences, such as war, were described by some participants as a shared social experience, rather than in individual terms. Additionally, participants in eight studies specifically linked the cause of their emotional difficulties to the socio-political context of the host country and post-migration stressors, including discrimination, isolation, poverty, worry about family who remained behind and the uncertainty of their asylum status (Behnia, 2004; Bernardes et al., 2011; De Anstiss & Ziaian, 2010; Fazel, 2016; Kokanvoic et al., 2008; Maier & Straub, 2011; Palmer & Ward, 2007; Valibhoy et al., 2017).

Thirteen studies described community and spiritual sources of support for emotional distress including family, wider community, herbal remedies, and religion (Behnia, 2004; Bernardes et al., 2011; Bettman et al., 2015; Carroll, 2004; De Anstiss & Ziaian, 2010; Ellis et al., 2010; Kokanvoic et al., 2008; Maier & Straub, 2011; Markova & Sandal, 2016; Omar et al., 2017; Palmer & Ward, 2007; Valibhoy et al., 2017; Whittaker et al., 2005). The family were described as starting point of support and took on the role of assessing difficulties and deciding what form of help to seek (Bettman et al., 2015; Ellis et al., 2010; Markova & Sandal, 2016). However, other participants expressed that talking to other refugees was not always helpful (Behnia 2004; Bernardes et al., 2011; Palmer & Ward, 2007; Shannon et al., 2015).

Ideas about religious and spiritual causes of mental health difficulties appeared to be specific to certain nationalities; four studies involving only Somalian people identified casual beliefs about God, Jinn or Zar possession (Bettman et al., 2015; Carroll, 2004;

Markova & Sandal, 2016; Whittaker, et al., 2005), while one study discussed Liberian and Sudanese youths' ideas about witchcraft (De Anstiss & Ziaian, 2010). If the person was thought to be distressed because of a Jinn or witchcraft then help was sought from religious leaders or witchdoctors (Bettman et al., 2015; De Anstiss & Ziaian, 2010; Carroll, 2004; Markova & Sandal, 2016; Whittaker et al., 2005).

#### **Young people prefer to seek support from friends.**

For young refugees and asylum-seekers three studies mentioned friends as the preferred source of help (De Anstiss & Ziaian, 2010; Ellis et al., 2010; Valibhoy et al., 2017), although fears of being negatively perceived and friends telling the wider community about their difficulties were identified (De Anstiss & Ziaian, 2010; Ellis et al. 2010; Fazel, 2016; Whittaker et al, 2005). Reasons for avoiding speaking to parents included the cultural norm being less discussion of emotional problems with parents, parents being distressed themselves and parents not being able to relate to younger people's difficulties (De Anstiss & Ziaian, 2010; Ellis et al., 2010).

#### **Lack of familiarity with Western conception of mental health.**

Nine studies referred to participants lacking familiarity with a Western conception of mental health, especially a biomedical understanding (Carroll, 2004; De Anstiss & Ziaian, 2010; Ellis et al., 2010; Kokanvoic et al., 2008; Majumder et al., 2015; Markova & Sandal, 2016; Posselt et al., 2017; Shannon et al., 2015; Valibhoy et al., 2017). Three studies further explained that terms such as mental health, depression, and stress were not meaningful as they did not easily translate into the participants' understanding of distress (De Anstiss & Ziaian, 2010; Kokanvoic et al., 2008; Palmer & Ward, 2007).

### **Facilitator: Familiarity with Western conception of mental health.**

Evidence from seven studies suggested some familiarity with a Western conception of mental health, including a biomedical model and terms such as “worry” and “depression” (Bettman et al, 2015; Carroll, 2004; Ellis et al., 2010; Kokanvoic et al., 2008; Maier & Straub, 2011, Majumder et al.,2015, Markova & Sandal, 2016). Kokanvoic et al. (2008) and Maier & Straub (2011) linked this to participants with higher levels of education. Three studies mentioned generational differences, suggesting that younger refugees were more open to Western understandings of mental health and interventions (Omar et al., 2017; Valibhoy et al., 2017; Whittaker et al., 2005).

Participants in ten studies identified therapy and mental health services as a helpful source of support, or as an alternative if initial community support did not improve the problem (Behnia, 2004; Bernardes et al.; 2011; Carroll, 2004; Fazel, 2016; Maier & Straub, 2011; Majumder et al., 2015; Markova & Sandel, 2016; Palmer & Ward, 2017; Vailbhoy et al., 2017; Whittaker et al., 2015). It may be that these ideas were more represented by participants who had previously accessed mental health services.

In six studies participants expressed positive views of medication (Bettman et al., 2015; Carroll, 2004; Maier & Straub, 2011; Majumder et al., 2015; Markova & Sandal, 2016; Palmer & Ward, 2017); although some participants felt medication alone was not enough (Maier & Straub, 2011) and Majumder et al. (2015) raised concerns that young refugees were taking medication without understanding its purpose.

If individuals’ conceptions of their emotional difficulties is that psychological or biological factors are causing their distress, then their conceptions may be more similar to the Western conception of mental health difficulties, which many services are constructed around and seeking help from a mental health service may seem more valid and appropriate.

## **2. Beliefs about the social meaning and consequences of mental health difficulties.**

### **Mental health difficulties mean you are “crazy”.**

Participants in nine studies labelled people with mental health difficulties as “crazy” and “mad”, describing them talking nonsense, running naked in the streets, screaming and hitting or killing others (Bettman, et al., 2015; Carroll, 2004; De Anstiss & Ziaian, 2010; Ellis et al., 2010; Majumder et al., 2015; Omar et al., 2017; Palmer & Ward, 2007; Shannon et al., 2015; Valibhoy et al., 2017). Some participants felt that due to the danger they posed to themselves and others, “crazy” people should be restrained, kept at home by the family, sent to hospital or exorcised by religious leaders. Additionally, participants did not always identify as needing mental health services as they were perceived as reserved for “crazy” people and therefore accessing them was felt to be socially stigmatised (Behnia, 2004; Bernardes, 2011; De Anstiss & Ziaian, 2010; Ellis et al., 2010; Fazel, 2016; Maier & Straub, 2011; Majumder et al., 2015; Posselt et al., 2017; Valibhoy et al., 2017).

### **Fear of community gossip and rejection leads to denial and concealment.**

Participants further explained that if they were to access services they feared members of their community would find out, gossip about them and tell others they are “crazy” (De Anstiss & Ziaian, 2010; Ellis et al., 2010; Fazel, 2016; Palmer & Ward, 2007; Posselt et al., 2017; Valibhoy et al., 2017). Due to negative perceptions of mental distress gossip was perceived by many to damage a person’s and their family’s reputation and could result in social exclusion (De Anstiss & Ziaian, 2010; Majumder et al., 2015; Shannon et al., 2015; Valibhoy et al., 2017). Young refugees were particularly concerned about being negatively perceived by peers and family members finding out or being contacted by services (De Anstiss & Ziaian, 2010; Fazel, 2016; Posselt et al., 2017; Valibhoy et al., 2017).

Participants described concealing mental health difficulties as the norm within their communities, and some denied during the interviews that they themselves experienced any

difficulties (De Anstiss & Ziaian, 2010; Ellis et al., 2010; Fazel, 2016; Majumder et al., 2015; Omar et al., 2017; Palmer & Ward, 2007; Shannon et al., 2015; Whittaker et al., 2005). Some participants also highlighted restrictions based on gender; women are supposed to be strong and not discuss certain issues (Shannon et al., 2015; Whittaker et al., 2005) and men don't talk about emotions (Valibhoy et al., 2017). Younger people stressed the importance of self-reliance and stoicism rather than open discussion of difficulties (Ellis et al., 2010; Valibhoy et al., 2017; Whittaker et al., 2005).

Therefore, the combination of mental health difficulties being understood as a person being "crazy", the fear that if others know about any difficulties they will tell the wider community and that person will be isolated and their reputation degraded leads people to conceal their mental health difficulties and reduces the likelihood of them seeking help.

**Facilitator: Community will care for you.**

Conversely, some participants in the study conducted by Bettman et al. (2015) did describe helpful responses from the community towards "crazy" people.

**Facilitator: Talking to professionals protects from gossip.**

Additionally, a few participants in two studies reported that fear of gossip meant they would prefer to talk to professionals rather than friends and family (Carroll, 2004; Whittaker et al., 2015).

### **3. Existing knowledge and expectations of services**

**Lack of knowledge of services.**

In ten studies participants spoke about not being aware of available mental health services, not knowing how to access them, and not being familiar with services they offered or the role of mental health professionals (Behnia, 2004; Bettman et al, 2015; De Anstiss &

Ziaian, 2010; Maier & Straub, 2011; Majumder et al., 2015; Markova & Sandal, 2016; Posselt et al., 2017; Shannon et al., 2015; Valibhoy et al., 2017; Whittaker et al., 2005).

**Facilitator: Services available in country of origin.**

Participants in two studies were familiar with the idea of mental health services because of provision in their countries of origin (Bettman et al., 2015; Maier & Straub, 2011).

**Services are not culturally appropriate.**

Nine studies provided evidence that seeking support from unknown people, including mental health professionals, was not something participants would do because it was viewed as not normal and services were not culturally appropriate (Behnia, 2004; Bettman et al., 2015; De Anstiss & Ziaian, 2010; Ellis et al., 2010; Kokanvoic et al., 2008; Omar et al., 2017; Posselt et al., 2017; Valibhoy et al., 2017; Whittaker et al., 2005). Unfortunately, the meaning of “culturally appropriate” in the context of these studies was not well elaborated. Posselt et al. (2017) reported some refugees highlighting that services hold a Western conception of mental health which clashes with other cultures’ beliefs.

**Fears of hospitalisation and forced medication.**

Connected to the perception that mental health services are only for “crazy people”, in six studies participants described fears that accessing mental health services would result in hospitalisation and or being medicated against their will (Bettman et al., 2015; Maier & Staub, 2011; Majumder et al., 2015; Omar et al, 2017; Shannon et al., 2015; Valibhoy et al., 2017).

### **Discrimination against refugees.**

Other participants felt discrimination against refugees affected access to services and therefore made them sceptical that services could meet their needs (Bernardes et al., 2011; Posselt et al., 2017; Whittaker et al., 2005).

### **Talking about the past has negative consequences.**

Participants in six studies described believing that nothing can help, predicting or having experience of talking about past difficulties making them feel worse and not wanting to talk about the past because it was too difficult and painful to express (De Anstiss & Ziaian, 2010; Fazel, 2016; Maier & Straub, 2011; Palmer & Ward, 2007; Shannon et al., 2015; Valibhoy et al., 2017).

### **Facilitator: Services can help distress.**

However, others felt that services could help them to recover, even if they were not always clear what the process of recovery would involve (Behnia, 2004; Bernardes et al., 2011; Carroll, 2004; Maier & Straub, 2011; Majumder et al., 2015; Markova & Sandal, 2016; Palmer & Ward, 2007; Whittaker et al., 2005).

### **Practical concerns take priority.**

From participants' descriptions of their needs there seemed to be a gap between the help they perceived they needed and that offered by services. In nine studies participants described wanting practical support and solutions for the post-migration stressors which were contributing to their distress including support to find work, improve housing and resolve asylum claims (Behnia, 2004; Bernardes et al., 2011, Fazel, 2016, Kokanovic et al., 2008; Maier & Straub, 2011; Omar et al., 2017, Palmer & Ward, 2007; Posselt et al., 2017; Valibhoy et al., 2017). Therefore, they felt that just talking and therapy would not change

anything (Behnia, 2004; Bernardes et al., 2011; Omar et al., 2017; Palmer & Ward, 2007; Valibhoy et al.,2017; Whittaker et al., 2005).

**Facilitator: Professionals engaging with practical concerns builds trust.**

In support of the importance of addressing refugees' perceived priorities, even if they fall outside the usual remit of a professional's role, two studies which interviewed young people described how mental health professionals engaging with their practical concerns and taking a holistic approach had helped to build trust and improve the therapeutic relationship (Fazel,2016; Posselt et al, 2017).

**4. Trust in services and beliefs about professionals**

**Impact of political oppression.**

Participants described not trusting services, a few linking this to experiences of political oppression when not trusting organisations had a protective function. Some also feared the result of talking to services would be deportation or placing family in countries of origin at risk, leading them to feel it was unsafe to access services (Behnia, 2004; Majumder et al.,2015; Posselt et al., 2017; Shannon et al., 2015; Vaibhoy et al., 2017).

**Facilitator: School can be a trusted environment.**

However, some young refugees explained that school was familiar and felt safe, school counsellors were viewed as more acceptable sources of help than external mental health services which might not be trustworthy, and that trusted teachers could support in accessing school-based services (Ellis et al., 2010; Fazel, 2016).

**Professionals do not care or understand.**

Another barrier to accessing mental health services was the perception of professionals by some as not caring or listening, lacking expertise, and not understanding

their difficulties and therefore offering unhelpful advice, especially as professionals were often from a different cultural background (Behnia, 2004; Bernardes et al., 2011; De Anstiss & Ziaian, 2010; Majumder et al., 2015; Posselt et al., 2017; Shannon et al., 2015; Valibhoy et al., 2017).

**Facilitator: Feeling safe and understood.**

Others described professionals listening, trying to understand and showing care (Behnia, 2004; Bernardes et al., 2011; Fazel, 2016). Younger refugees related feeling safe to being able to trust the professional (De Anstiss & Ziaian, 2010; Majumder et al., 2015; Valibhoy et al., 2017), and a few requested that professionals be educated about their cultures to aid feeling understood (Posselt et al., 2017; Whittaker, et al., 2005).

**Concerns about confidentiality.**

Participants described concern that information shared with services would not remain confidential, also expressing mistrust of some culture professionals, including translators, connecting to the fear of community gossip (Bernardes et al., 2011; De Anstiss & Ziaian, 2010; Palmer & Ward, 2007; Posselt et al., 2017; Shannon et al., 2015; Valibhoy et al., 2017).

**Facilitator: Considering the cultural background of professionals.**

However, others requested more staff from their own communities (Kokanvoic et al., 2008; Palmer & Ward, 2007) while some felt that trustworthiness was more important than background (De Anstiss & Ziaian, 2010). This suggests that staffing services with professionals from a range of cultural backgrounds may increase access to services.

## **5. Service delivery**

### **Service related barriers.**

Participants in six studies described service-related barriers to access including lack of interpreters, complex referral pathways and criteria, long waiting times, high costs and location of services (Bernardes et al., 2011; Bettman et al., 2015; Palmer & Ward, 2007; Posselt et al., 2017; Valibhoy et al., 2017; Whittaker et al., 2005).

### **Facilitator: Increasing accessibility.**

Participants suggested increasing availability of translators, translating letters and questionnaires, employing more people from their communities and offering appointments outside of the clinic (Palmer & Ward, 2007; Posselt et al., 2017).

## **Discussion**

This review synthesised findings from 17 qualitative studies relating to refugee and asylum-seeking peoples' views on help-seeking for mental health problems and accessing mental health services. Five overarching themes were constructed, with related subthemes comprising either barriers or facilitators to help-seeking for mental health problems and accessing mental health services. The results of this review offer some contextual information relating to the low reported rates of mental health service utilisation by refugee and asylum-seeking people (Colucci et al., 2014; Gerritsen et al., 2006; McCrone et al., 2005).

### **Barriers and facilitators for adults and children**

#### **Barriers**

Previous reviews have reported similar barriers to help-seeking and accessing mental health services as identified in this review, including holding different beliefs about

mental health difficulties to the host country, stigma, lack of knowledge of the health care services, lack of trust in public sector services and language differences (Colucci et al., 2014; De Anstiss, et al., 2009; Giacco, et al., 2018; Thomson, et al., 2015). Studies exploring key informant and service providers' perspectives of barriers to access for this population have described similar factors to the reviews above, as well as additional barriers including lack of acknowledgment of difficulties, low prioritisation of mental health difficulties and previous negative experiences of services, which were also present in the current review (Colucci et al., 2015; Franks et al., 2007; Posselt, et al., 2015). This suggests that service providers have an awareness of the barriers which need to be addressed to increase accessibility to services for this population. However, two themes present in this review are not well represented in the previous literature; that services are not culturally appropriate and that some refugees and asylum-seeking people feel that services discriminate against them. Based on the methodological descriptions provided in the reviewed studies it was not possible to ascertain if these views were based on participants' perceptions or experiences of accessing mental health services.

The current findings are also comparable to previous research indicating low rates of treatment seeking following traumatic events in the general population, as well as within ethnic minority communities (Gavrilovic et al., 2005; Koenen et al., 2017). A recent review of quantitative and qualitative studies of the barriers and facilitators to the use of mental health services in adult trauma survivors identified comparable barriers to this review: for example, a preference for avoiding talking about the past and not attributing experiences to having a mental health difficulty (Kantor, Knefel & Lueger-Schuster, 2017). However, as the studies reviewed included samples of both military and general populations it may be that concerns regarding confidentiality, stigma, and mistrust of services have a different origin than for refugees and asylum-seeking people. It is important to be able to identify

specific barriers for refugees and asylum-seeking people in order to make services more accessible to these populations.

Clement et al., (2015) reviewed the impact of mental health related stigma and concluded that it has a small to moderate sized negative effect on help-seeking in the general population, but that certain populations were disproportionately affected, including ethnic minorities and youth. The studies reviewed which included ethnic minority and youth samples more frequently reported barriers relating to concerns that their family would be stigmatised, mental health difficulties being viewed as not normal, a preference for non-disclosure and seeking support from family. This supports themes identified in this review suggesting that negative beliefs about the social meaning and consequences of mental health difficulties act as a barrier to seeking help from services.

### **Facilitators**

Although facilitators to help-seeking and accessing services were identified, several of these facilitators were present in only a few studies. It may be that support for these views came from participants who had already accessed services and had a positive experience. As only some of the included studies reported on participants current or past use of mental health services it was not possible to ascertain the impact of experience on participants' views.

Existing research into facilitators to help-seeking and accessing mental health services is limited. Previous reviews have suggested increasingly the availability of translators, dedicating time to establish a trusting working relationship, training in cultural competence for mental health professionals, increasing the cultural diversity of staff and increasing "mental health literacy" through psychoeducational interventions (May et al., 2014; Giacco, et al., 2018; Slewa-Younan et al., 2014; Thomson, et al., 2015). However, the concept of providing a psychoeducational intervention to increase "mental health literacy"

presupposes that western models of distress and mental health, including diagnoses such as PTSD, can be straightforwardly applied to other cultures (Alarcón et al., 2009; Nguyen, 2011; Summerfield, 2001).

### **Specific child related barriers and facilitators**

#### **Barriers**

Although this review presented combined findings for both adult and child refugee and asylum-seeking people some specific child related barriers and facilitators were identified. However, both the barrier and facilitators reported should be treated with caution as two out of the five studies included in the meta-synthesis focusing on young refugee and asylum-seeking people were appraised as weak studies and removed during the sensitivity analysis.

Barriers included that young people preferred to seek support from friends, were particularly concerned about being perceived negatively by peers and family being contacted by services, leading some to have a preference for coping by being self-reliant and stoic. Fears of family being contacted by services being identified as a barrier to seeking-help appeared to contrast with previously reported views of service providers who suggested that working with families was an important part of engaging young people in services (Colucci et al., 2015). Concerns about the negative perceptions of friends and family were echoed in the review conducted by Clement et al. (2015) of the relationship between stigma and help-seeking in the general population as outlined above. Similarly a review of the perceived barriers and facilitators to mental health help-seeking in young people in the general population identified stigma, limited knowledge about mental health difficulties, concerns about confidentiality and trust, and a preference for self-reliance as barriers to seeking help (Gulliver, Griffiths, & Christensen, 2010). This suggests that these barriers may be common across young people rather than specific to refugees and asylum-

seeking young people. Alternatively, it may be that the concerns about family being contacted by services discussed by refugees and asylum-seeking youth in the studies included in this review are not solely related to stigma and are influenced by specific cultural beliefs. However, it is difficult to draw conclusions as research specific to refugee and asylum-seeking youth is sparse and existing studies report findings from culturally heterogeneous samples.

### **Facilitators**

Refugee and asylum-seeking young people also identified several facilitators to accessing services including professionals helping to address wider practical problems including asylum-related needs, being seen by professionals at school as it is a trusted environment and requesting professionals are educated about their cultures.

There is some discrepancy between the facilitators in this review and the reported views of service providers. The study by Colucci et al. (2015) reported that service providers suggested that matching young people to professionals of a similar background would aid engagement with services. The findings from this review suggest that although refugee and asylum-seeking youth would like professionals to be educated about their culture, this does not mean they have to be of the same cultural background. Due to concerns about confidentiality and worries about family finding out about their mental health difficulties, trustworthiness of the professional was the most salient factor for some young people. This suggests that the solution is not as simple as increasing staff from certain cultural backgrounds, but rather increasing the cultural diversity of professionals to enable young people to have a choice of worker.

### **Limitations**

There were several limitations to the current review. Although a comprehensive search strategy was used it is unlikely that every relevant article was identified, particularly

as there is great variability in the way that qualitative research is described in titles, abstracts and keywords (Timulak, 2009). Additionally, due to the limited number of qualitative studies directly exploring refugee and asylum-seeking peoples' perspectives or experiences of help-seeking for mental health difficulties and accessing mental health services, the studies included in the review varied in terms of research aims, the amount of data relevant to the review and the characteristics of the participants included. As a result of the heterogenous samples it was not possible to consider the contribution to the themes of factors such as country of origin, gender, type of mental health difficulty, unaccompanied as compared to accompanied minors or previous experiences of accessing mental health services. Caution should therefore be used when generalising the findings of this review to other refugee and asylum-seeking populations, especially as all the studies were conducted in Western countries. Furthermore, although attempts were made to assess the quality of the included studies using the CASP (2017), this tool had not been validated (Dixon-Woods et al., 2004; Dixon-Woods et al., 2007). There is ongoing debate as to the place of quality appraisal within meta-synthesis and it could be argued that tools such as the CASP involve an assessment of the way in which the study has been reported, rather than a reflection of the quality of the findings (Carroll & Booth, 2014; Mays & Pope, 2000). Given these limitations, studies were not excluded on the basis of the CASP appraisal and a sensitivity analysis was conducted. Although removing the weakest rated studies did not significantly affect the final themes the included studies varied widely in quality. The findings of this review were therefore limited as the studies rarely provided a rich description of participant's views and experiences and provided very limited information relating to facilitators.

## **Clinical recommendations**

The results of this review suggest several clinical recommendations. It is important to consider if existing services are providing sufficient and appropriate support to meet the all needs of refugee and asylum-seeking people, and not just focusing on interventions based in western models of distress and culturally bound ideas about what form help should take. Therefore, it is important to consider complementary or alternative options to psychological support. This might include the creation of more advice centres or multi-disciplinary teams that can offer support with practical concerns around housing, finances and the asylum process in order to counteract the significant negative impact on mental health of post-migration stressors (Carswell, Blackburn & Barker, 2011; Chen, Hall, Ling, & Renzaho, 2017). It might also involve community-level interventions, such as lending support to community groups or organisations, or policy-level interventions which call attention to the psychological impact of post-migration stressors such as detention, separation from family and poverty.

Within existing services which receive referrals for this population individual clinicians should be aware that refugees and asylum-seeking people may have different conceptions and understandings of their difficulties which will affect their views on which interventions can help and support them. Extra attention may need to be paid to explaining the rationale for psychological interventions and clear acknowledgments made of the limits of these interventions. Professionals should conduct holistic assessments which include practical as well as psychological concerns. More time may need to be given to developing a trusting and safe relationship and professionals should be aware that lack of trust in authorities may have served a protective and adaptive function in the past. Particular care should be taken in explaining the role of the service, the professional and the limits to confidentiality. When working with young refugee and asylum-seeking people professionals

should remain alert to potential concerns that young people may have about family's and peers' reactions to them accessing services, as well as respecting young people's desires to be autonomous.

Mental health services could be made more accessible by employing staff from a range of cultural backgrounds in order to be able to offer a choice of worker, as well as increasing the availability of professional interpreters. All staff should be trained in relevant therapeutic skills and specific socio-political problems faced by these populations to increase their cultural competency. Services would benefit from working in partnership with service users and community leaders to evaluate services and implement and review changes based on their feedback. This is particularly important given findings in this review that services are viewed as not culturally appropriate and discriminatory. Through joint working with refugee and asylum-seeking communities' knowledge about services can be increased through providing information about western conceptions of mental health, psychological interventions and referral criteria and pathways. This would allow people to make an informed choice about whether or not to engage with services and may tackle some of the perceived stigma around mental health difficulties. For young refugees and asylum-seekers another way to reduce the impact of the stigma of accessing services might be to consider the location and offer appointments outside of hospital or clinical environments.

### **Research implications**

The results of this review suggests some partial explanations for the reported low rates of mental health services utilisation by refugee and asylum-seeking people (Colucci et al., 2014; Gerritsen et al., 2006; McCrone et al., 2005). However, more research is needed to better understand this finding and ensure that services are appropriate and accessible. Firstly, studies exploring peoples' pathways into services may identify points at which to

target interventions, as well as community organisations and leaders services can consult and work alongside to ensure services are culturally appropriate and relevant. Secondly, more research is needed to explore facilitators, as well as barriers, to help-seeking and accessing services. Thirdly, the findings of this review suggest that not all refugees and asylum-seeking people wish to engage with mental health services therefore another potential area of research is factors which enable resilience and recovery without the need of services. Finally, research focused on young refugee and asylum-seeking people's experiences and views of help-seeking and accessing services is particularly limited and does not allow for comparisons of accompanied or unaccompanied minors.

In order to increase services accessibility and acceptability refugees and asylum-seeking people should be consulted at all stages of the research process. One way this can be achieved is through using participatory action research frameworks (Ellis, Kia-Keating, Yusuf, Lincoln & Nur, 2007; Löfman, Pelkonen, & Pietilä, 2004; Meyer, 2000). Ultimately it is only through listening to refugee and asylum-seeking peoples' voices and understanding their views and opinions that services will be better able to adapt to effectively serve these populations.

## References

- Ai, A., Peterson, C., & Uebelhor, D. (2002). War-related trauma and symptoms of post-traumatic stress disorder among adult Kosovar refugees. *Journal of Traumatic Stress, 15*, 157-160.
- Alarcón, R., Becker, A., Lewis-Fernández, R., Like, R., Desai, P., Foulks, E., ... Primm, A. (2009). Issues for DSM-V: the role of culture in psychiatric diagnosis. *The Journal of Nervous and Mental Disease, 197*, 559-660.

- Atwoli, L., Stein, D., Koenen, K., & Mclaughlin, K. (2015). Epidemiology of post-traumatic stress disorder: prevalence, correlates and consequences. *Current Opinion in Psychiatry, 28*, 307-311.
- Barnett-Page, E., & Thomas, J. (2009). Methods for the synthesis of qualitative research: a critical review. *BMC Medical Research Methodology, 9*, DOI:10.1186/1471-2288-9-59.
- Bartolomei, J., Baeriswyl-Cottin, R., Framorando, D., Kasina, F., Premand, N., Eytan, A., & Khazaal, Y. (2016). What are the barriers to access to mental healthcare and the primary needs of asylum seekers? A survey of mental health caregivers and primary care workers. *BMC Psychiatry, 16*, 336.
- Bean, T., Eurelings-Bontekoe, E., Mooijaart, A., & Spinhoven, P. (2006). Factors associated with mental health service need and utilization among unaccompanied refugee adolescents. *Administration and Policy in Mental Health and Mental Health Services Research, 33*, 342–355.
- Behnia, B. (2004). Refugees' convoy of social support; community peer groups and mental health services. *International Journal of Mental Health, 32*, 6-19.
- Bernardes, D., Wright, J., Edwards, C., Tomkins, H., Difo, D., & Livingstone, A. (2011). Asylum seekers' perspectives on their mental health and views on health and social services: contributions for service provision using a mixed-methods approach. *International Journal of Migration, Health and Social Care, 6*, 3-19.
- Bettman, J., Penney, D., Clarkson Freeman, P., & Lecy, N. (2015). Somali refugees' perceptions of mental illness. *Social Work in Health Care, 54*, 738-757.

- Bogic, M., Njoku, A., & Priebe, S. (2015). Long-term mental health of war-refugees: a systematic literature review. *BMC International Health and Human Rights*, *15*, DOI: 10.1186/s12914-015-0064-9.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*, 77–101.
- Carroll, J. (2004). Murug, Waali, and Gini; expressions of distress in refugees from Somalia. *Primary Care Companion to the Journal of Clinical Psychiatry*, *6*, 119-125.
- Carroll, C. & Booth, A. (2014). Quality assessment of qualitative evidence for systematic review and synthesis: Is it meaningful, and if so, how should it be performed? *Research Synthesis Methods*, *6*, 149-154.
- Carswell, K., Blackburn, P., & Barker, C. (2011). The relationship between trauma, post-migration problems and the psychological well-being of refugees and asylum seekers. *The International Journal of Social Psychiatry*, *57*, 107-119.
- Centre for Reviews and Dissemination. (2009). *Systematic Reviews: The Centre for Reviews and Disseminations' guidance for undertaking reviews in health care*. Retrieved on 1<sup>st</sup> June 2018 from <https://www.york.ac.uk/crd/guidance/>.
- Chen, Hall, Ling, & Renzaho. (2017). Pre-migration and post-migration factors associated with mental health in humanitarian migrants in Australia and the moderation effects of post-migration stressors: findings from the first wave data of the BNLA cohort study. *Lancet Psychiatry*, *4*, 218-229.
- Clement, S., Schauman, O., Graham, T., Maggioni, F., Evans-Lacko, S., Bezborodovs, N., ... Thornicroft, G. (2015). What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. *Psychological Medicine*, *45*, 11-27.

- Coleman, S., Stevelink, S., Hatch, S., Denny, J., & Greenberg, N. (2017). Stigma-related barriers and facilitators to help-seeking for mental health issues in the armed forces: a systematic review and thematic synthesis of qualitative literature. *Psychological Medicine, 47*, 1880-1892.
- Colucci, E., Szwarc, J., Minas, H., Paxton, G., & Guerra, C. (2014). The utilisation of mental health services by children and young people from a refugee background: a systematic literature review. *International Journal of Culture and Mental Health, 7*, 86-108.
- Colucci, E., Minas, H., Szwarc, J., Guerra, C., & Paxton, G. (2015). In or out? Barriers and facilitators to refugee-background young people accessing mental health services. *Transcultural Psychiatry, 52*, 766-790.
- Critical Appraisal Skills Programme (CASP). (2017). *Qualitative Research Checklist: 10 questions to help you make sense of qualitative research*. National CASP Collaboration for Qualitative Methodologies. Oxford: Public Health Research Unit.
- De Anstiss, H., Ziaian, T., Procter, N., Warland, J., & Baghurst, P. (2009). Help-seeking for mental health problems in young refugees: a review of the literature with implications for policy, practice, and research. *Transcultural Psychiatry, 46*, 584-607.
- De Anstiss, H., & Ziaian, T. (2010). Mental health help-seeking and refugee adolescents: qualitative findings from a mixed-methods investigation. *Australian Psychologist, 45*, 29-37.
- Dixon-Woods, M., Shaw, R., Agarwal, S., & Smith, J. (2004). The problem of appraising qualitative research. *Quality and Safety in Health Care, 13*, 223-225.

- Dixon-Woods, M., Sutton, A., Shaw, R., Miller, T., Smith, J., Young, B., ... Jones, D. (2007). Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods. *Journal of Health Services Research and Policy, 12*, 42-47.
- Ellis, B., Kia-Keating, M., Yusuf, S., Lincoln, A., & Nur, A. (2007). Ethical research in refugee communities and the use of community participatory methods. *Transcultural Psychiatry, 44*, 459-481.
- Ellis, B., Lincoln, A., Charney, M., Ford-Paz, R., Benson, M., & Strunin, L. (2010). Mental health service utilization of Somali adolescents: religion, community and school as gateways to healing. *Transcultural Psychiatry, 47*, 789-811.
- Fazel, M., Wheeler, J., & Danesh, J. (2005). Prevalence of serious mental disorder in 7000 refugees resettled in Western countries: a systematic review. *The Lancet, 363*, 1309-1314.
- Fazel, M., Garcia, J., & Stein, A. (2016). The right location? Experiences of refugee adolescents seen by school-based mental health services. *Clinical Child Psychology and Psychiatry, 21*, 368-380.
- Ferrada-Noli, M., Asberg, M., Ormstad, K., Lundin, T., & Sundbom, E. (1998). Suicidal behavior after severe trauma. Part 1: PTSD diagnoses, psychiatric comorbidity, and assessments of suicidal behaviour. *Journal of Traumatic Stress, 11*, 103-112.
- Fischer, C. (2009) Bracketing in qualitative research: conceptual and practical matters. *Psychotherapy Research, 19*, 583-590.
- Franks, W., Gawn, N., & Bowden, G. (2007). Barriers to access to mental health services for migrant workers, refugees and asylum seekers. *Journal of Public Mental Health, 6*, 33-41.

- Gavrilovic, J., Schützwohl, M., Fazel, M., & Priebe, S. (2005). Who seeks treatment after a traumatic event and who does not? A review of findings on mental health service utilisation. *Journal of Traumatic Stress, 18*, 595-605.
- Geltman, P., Grant-Knight, W., Ellis, H., & Landgraf, J. (2008). The “lost boys” of Sudan: use of health services and functional health outcomes of unaccompanied refugee minors resettled in the U.S. *Journal of Immigrant and Minority Health, 10*, 389-396.
- Gerritsen, A., Bramsen, I., Devillé, W., Van Willigen, L., Hovens, J., & Van Der Ploeg, H. (2006). Use of health care services by Afghan, Iranian, and Somali refugees and asylum seekers living in The Netherlands. *European Journal of Public Health, 16*, 394-399.
- Giacco, D., Laxhman, N., & Priebe, S. (2018). Prevalence of and risk factors for mental disorders in refugees. *Seminars in Cell and Developmental Biology, 77*, 144-152.
- Gronholm, P., Ford, T., Roberts, R., Thornicroft, G., Laurens, K., & Evans-Lacko, S. (2015). Mental health service use by young people: the role of caregiver characteristics. *PLoS ONE, 10*, DOI:10.1371/journal.pone.0120004.
- Gulliver, A., Griffiths, K., & Christensen, H. (2010). Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review. *BMC Psychiatry, 10*, DOI: 10.1186/1471-244X-10-113.
- Gwozdziwycz, N., & Mehl-Madrona, L. (2013). Meta-analysis of the use of Narrative Exposure Therapy for the effects of trauma among refugee populations. *The Permanente journal, 17*, 70-76.
- Hagmayer, Y., & Engelmann, N. (2014). Causal beliefs about depression in different cultural groups-what do cognitive psychological theories of causal learning and reasoning predict? *Frontiers in Psychology, 5*, DOI: org/10.3389/fpsyg.2014.01303.

- Hollifield, M., Warner, T., Lian, N., Krakow, B., Jenkins, J., Kesler, J., ... Westermeyer, J. (2002). Measuring trauma and health status in refugees; a critical review. *Journal of the American Medical Association, 288*, 611-621.
- Horyniak, D., Melo, J., Farrell, R., Ojeda, V., & Strathdee, S. (2016). Epidemiology of substance use among forced migrants: a global systematic review. *PLoS ONE, 11*, DOI: 10.1371/journal.pone.0159134
- Jahangiri, K., Tabatabaie, S., & Safi Keykaleh, M. (2017). Mental health challenges in immigrant and refugee children and adolescents: a systematic review. *Health in Emergencies and Disasters Quarterly, 3*, 3-10.
- Kantor, V., Knefel, M., & Lueger-Schuster, B. (2017). Perceived barriers and facilitators of mental health service utilization in adult trauma survivors: A systematic review. *Clinical Psychology Review, 52*, 52-68.
- Kirmayer, L., Narasiah, L., Munoz, M., Rashid, M., Ryder, A., Guzder, J., ... Pottie, K. (2011). Common mental health problems in immigrants and refugees: general approach in primary care. *Canadian Medical Association Journal, 183*, 959-967.
- Koenen, K., Ratanatharathorn, L., McLaughlin, K., Bromet, E., Stein, D., Karam, E., ... Kessler, R. (2017). Post-traumatic stress disorder in the World Mental Health Surveys. *Psychological Medicine, 27*, 2260-2274.
- Kokanovic, R., Dowrick, C., Butler, E., Herrman, H., & Gunn, J. (2008). Lay accounts of depression amongst Anglo-Australian residents and East African refugees. *Social Science and Medicine, 66*, 454-466.
- Laban, C., Gernaat, H., Komproe, I., & Jong, J. (2007). Prevalence and predictors of health service use among Iraqi asylum seekers in the Netherlands. *Social Psychiatry and Psychiatric Epidemiology, 40*, 837-844.

- Levitt, H., Morrow, S., Wertz, F., Motulsky, S., & Ponterotto, J. (2017). Recommendations for designing and reviewing qualitative research: promoting methodological integrity. *Qualitative Psychology, 4*, 2-22.
- Lewin, S., Glenton, C., Munthe-Kaas, H., Carlsen, B., Colvin, C., Glümezoglu, M., ... Rashidian, A. (2015). Using qualitative evidence in decision making for health and social interventions: an approach to assess confidence in findings from qualitative evidence syntheses (GRADE-CERQual). *PLoS Medicine, 12*, DOI:10.1371/journal.pmed.1001895.
- Lindencrona, F., Ekblad, S., & Hauff, E. (2008) Mental health of recently resettled refugees from the Middle East in Sweden: the impact of pre-resettlement trauma, resettlement stress and capacity to handle stress. *Social Psychiatry and Psychiatric Epidemiology, 43*, 121–131.
- Löfman, P., Pelkonen, M., & Pietilä, A. (2004). Ethical issues in participatory action research. *Scandinavian Journal of Caring Sciences, 18*, 333-340.
- Maier, T., & Straub, M. (2011). “My head is like a bag full of rubbish”: concepts of illness and treatment expectations in traumatised migrants. *Qualitative Health Research, 21*, 233-248.
- Majumder, P., O’Reilly, M., Karim, K., & Vostanis, P. (2015). ‘This doctor, I not trust him, I’m not safe’: the perceptions of mental health and services by unaccompanied refugee adolescents. *International Journal of Social Psychiatry, 61*, 129-136.
- Markova, V., & Sandal, G. (2016). Lay explanatory models of depression and preferred coping strategies among Somali refugees in Norway. A mixed-method study. *Frontiers in Psychology, 7*, DOI: 10.3389/fpsyg.2016.01435.

- May, S., Rapee, R., Caello, M., Momartin, S., & Aroche, J. (2014). Mental health literacy among refugee communities: differences between the Australian lay public and the Iraqi and Sudanese refugee communities. *Social Psychiatry and Psychiatric Epidemiology, 49*, 757-769.
- Mays, N. & Pope., C. (2000). Assessing quality in qualitative research. *British Medical Journal, 320*, 50-52.
- McCrone, P., Bhui, K., Craig, T., Mohamud, S., Warfa, N., Stansfeld, S., ... Curtis, S. (2005). Mental health needs, service use and costs among Somali refugees in the UK. *Acta Psychiatrica Scandinavica, 111*, 351–357.
- Meyer, J. (2000). Using qualitative methods in health related action research. *British Medical Journal, 320*, 178-181.
- Mezey, G., & Robbins, I. (2001). Usefulness and validity of post-traumatic stress disorder as a psychiatric category. *British Medical Journal, 323*, 561-563.
- Michelson, D., & Sclare, I. (2009). Psychological needs, service utilization and provision of care in a specialist mental health clinic for young refugees: a comparative study. *Clinical Child Psychology and Psychiatry, 14*, 273-296.
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D., & The PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med, 6*, DOI:10.1371/journal.pmed1000097.
- Nguyen, L. (2011). The ethics of trauma: re-traumatization in society's approach to the traumatized subject. *International Journal of Group Psychotherapy, 61*, 26-47.
- Norredam, M., Garcia-Lopez, A., Keiding, N., & Krasnik, A. (2009). Risk of mental disorders in refugees and native Danes: a register-based retrospective cohort study. *Social Psychiatry and Psychiatric Epidemiology, 44*, 1023-1029.

- Nose, M., Turrini, G., Imoli, F., Ballette, F., Ostuzzi, G., Cucchi, F., ... Barbui, C. (2017). Prevalence and correlates of psychological distress and psychiatric disorders in asylum seekers and refugees resettled in an Italian Catchment Area. *Journal of Immigrant and Minority Health, 20*, 263-270.
- Nose, M., Ballette, F., Bighelli, I., Turrini, G., Purgato, M., Tol, W., ... Barbui, C. (2017). Psychosocial interventions for post-traumatic stress disorder in refugees and asylum seekers resettled in high-income countries: systematic review and meta-analysis. *PLoS ONE, 12*, DOI:10.1371/journal.pone.0171030.
- Noyes, J., Booth, A., Flemming, K., Garside, R., Harden, A., Lewin, S., ... Thomas, J. (2018). Cochrane Qualitative and Implementation Methods Group guidance series—paper 3: methods for assessing methodological limitations, data extraction and synthesis, and confidence in synthesized qualitative findings. *Journal of Clinical Epidemiology, 97*, 49-58.
- NVivo Qualitative Data Analysis Software. (2017). QSR International Pty Ltd. Version 11. Los Angeles, CA.
- Omar, Y., Kuay, J., & Tuncer, C. (2017). 'Putting your feet in gloves designed for hands': Horn of Africa Muslim men perspectives in emotional wellbeing and access to mental health services in Australia. *International Journal of Culture and Mental Health, 10*, 376-388.
- Palmer, D., & Ward, K. (2007). 'Lost': listening to the voices and mental health needs of forced migrants in London. *Medicine, Conflict and Survival, 23*, 198-212.
- Panagioti, M., Gooding, P., & Tarrier, N. (2009). Post-traumatic stress disorder and suicidal behavior: a narrative review. *Clinical Psychology Review, 29*, 471-482.

- Patel, N., Williams, A., & Kellezi, B. (2016). Reviewing outcomes of psychological interventions with torture survivors: Conceptual, methodological and ethical issues. *Torture, 26*, 1-15.
- Porter, M., & Haslam, N. (2005). Predisplacement and postdisplacement factors associated with mental health of refugees and internally displaced persons: a meta-analysis. *Journal of the American Medical Association, 294*, 602-612.
- Posselt, M., Galletly, C., de Crespigny, C., & Procter, N., (2013). Mental health and drug and alcohol comorbidity in young people of refugee background: a review of the literature. *Mental Health and Substance Use, 7*, 19–30.
- Posselt, M., McDonald, K., Procter, N., de Crespigny, C., & Galletly, C. (2017). Improving the provision of services to young people from refugee backgrounds with comorbid mental health and substance use problems: addressing the barriers. *BMC Public Health, 17*, DOI: 10.1186/s12889-017-4186-y.
- Posselt, M., Procter, N., de Crespigny, C., & Galletly, C. (2015). Merging perspectives: obstacles to recovery for youth from refugee backgrounds with comorbidity. *Australasian Psychiatry, 23*, 293-299.
- Priebe, S., Jankovic Gavriloic, J., Bremner, S., Ajdukovic, D., Franciskovic, T., Galeazzi, G., ... Bogic, M. (2013). Psychological symptoms as long-term consequences of war experiences. *Psychopathology, 46*, 45-54.
- Reed, R., Fazel, M., Jones, L., Panter-Brick, C., & Stein, A. (2012). Mental health of displaced and refugee children resettled in low-income and middle-income countries: risk and protective factors. *The Lancet, 379*, 250-265.

- Rickwood, D., & Thomas, K. (2012). Conceptual measurement framework for help-seeking for mental health problems. *Psychology Research and Behavior Management, 5*, 173–183.
- Robjant, K., Hassan, R., & Katona, C. (2009). Mental health implications of detaining asylum seekers: systematic review. *The British Journal of Psychiatry: The Journal of Mental Science, 194*, 306-312.
- Sanchez-Cao, E., Kramer, T., & Hodes, M. (2012). Psychological distress and mental health service contact of unaccompanied asylum-seeking children. *Child: Care, Health and Development, 39*, 651-659.
- Sandelowski, M. (2012). Metasynthesis of qualitative research. In H. Cooper (Ed.), *APA Handbook of Research Methods in Psychology: Vol. 2. Research Designs* (pp. 19-36). Washington, DC: American Psychological Association.
- Schock, K., Böttche, M., Rosner, R., Wenk-Ansohn, M., & Knaevelsrud, C. (2016). Impact of new traumatic or stressful life events on pre-existing PTSD in traumatized refugees: results of a longitudinal study. *European Journal of Psychotraumatology, 7*, DOI: 10.3402/ejpt.v7.32106.
- Selaman, Z., Chartrand, H., Bolton, J., & Sareen, J. (2014). Which symptoms of post-traumatic stress disorder are associated with suicide attempts? *Journal of Anxiety Disorders, 28*, 246-251.
- Shamseer, L., Moher, D., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., ... Stewart, L. (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: Elaboration and explanation. *British Medical Journal, 349*, DOI: 10.1136/bmj.g7647.

- Shannon, P., Wieling, E., Simmelink-McCleary, J., & Becher, E. (2015). Beyond stigma: barriers to discussing mental health in refugee populations. *Journal of Loss and Trauma, 20*, 281-296.
- Shawyer, F., Enticott, J., Block, A., Cheng, I., & Meadows, G. (2017). The mental health status of refugees and asylum seekers attending a refugee health clinic including comparisons with a matched sample of Australian-born residents. *BMC Psychiatry, 17*, 76-87.
- Slewa-Younan, S., Mond, J., Bussion, E., Mohammad, Y., Uribe Guajardo, M., Smith, M., ... Jorm, A. (2014). Mental health literacy of resettled Iraqi refugees in Australia: knowledge about post-traumatic stress disorder and beliefs about helpfulness of interventions. *BMC Psychiatry, 14*, DOI: 10.1186/s12888-014-0320-x
- Slewa-Younan, S., Radulovic, M., Lujic, S., Hasan, T., & Raphael, B. (2014). Trauma in resettled Iraqi refugees: differences between those seeking psychological treatment versus those not seeking psychological treatment. *Journal of Aggression, Maltreatment & Trauma, 23*, 917-929.
- Steel, Z., Chey, T., Silove, D., Marnane, C., Byrant, R., & Van Ommeren, M. (2009). Association of torture and other potentially traumatic events with mental health outcomes among populations exposed to mass conflict and displacement: a systematic review and meta-analysis. *Journal of the American Medical Association, 302*, 537-549.
- Stiffman, A., Pescosolido, B., & Cabassa, L. (2004). Building a model to understand youth service access: the gateway provider model. *Mental Health Services Research, 6*, 189-198.
- Summerfield, D. (2001). The invention of post-traumatic stress disorder and the social usefulness of a psychiatric category. *British Medical Journal, 322*, 95-98.

- Timulak, L. (2009). Meta-analysis of qualitative studies: A tool for reviewing qualitative research findings in psychotherapy. *Psychotherapy Research, 19*, 591-600.
- Thieko, M., Florin, P., & Ng, C. (2015). Help-seeking attitudes among Cambodian and Laotian refugees: implications for public mental health approaches. *Journal of Immigrant and Minority Health, 17*, 1679-1686.
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology, 8*, DOI: 10.1186/1471-2288-8-45.
- Thompson, C., Vidgen, A., & Roberts, N. (2018). Psychological interventions for post-traumatic stress disorder in refugees and asylum seekers: A systematic review and meta-analysis. *Clinical Psychology Review, 63*, 66-79.
- Thomson, M., Chaze, F., George, U., & Guruge, S. (2015). Improving immigrant populations' access to mental health services in Canada: a review of barriers and recommendations. *Journal of Immigrant and Minority Health, 17*, 1895-1905.
- Tribe, R., Sendt, K., & Tracy, D. (2017). A systematic review of psychosocial interventions for adult refugees and asylum seekers. *Journal of Mental Health*, DOI: 10.1080/09638237.2017.1322182.
- Valibhoy, M., Szwarc, J., & Kaplan, I. (2017). Young service users from refugee backgrounds: their perspectives on barriers to accessing Australian mental health services. *International Journal of Human Rights in Healthcare, 10*, 68-80.
- Weine, S., Razzano, L., Brkic, N., Ramic, A., Miller, K., Smajkic, A., ... Pavkovic, I. (2000). Profiling the trauma related symptoms of Bosnian refugees who have not sought mental health services. *The Journal of Nervous and Mental Disease, 188*, 416-421.

Weine, S., Durrani, A., & Polutnik, C. (2014). Using mixed methods to build knowledge of refugee mental health. *Intervention, 12*, 61-77.

Whittaker, S., Hardy, G., Lewis, K., & Buchan, L. (2005). An exploration of psychological well-being with young Somali refugee and asylum-seeker women. *Clinical Child Psychology and Psychiatry, 10*, 177-196.

Yeh, M., & Weisz, J. (2001). Why are we here at the clinic? Parent-child (dis)agreement on referral problems at outpatient treatment entry. *Journal of Consulting and Clinical Psychology, 69*, 1018-1025.

## **Part 2: Empirical Paper**

Asylum-seeking peoples' experiences of  
Narrative Exposure Therapy

## Abstract

**Aims:** Despite growing evidence to support the use of Narrative Exposure Therapy (NET) with refugee and asylum-seeking people experiencing trauma symptoms after prolonged and repeated traumatic events, little is known about the recipients' views of the appropriateness of NET. This qualitative study aimed to explore asylum-seeking peoples' experiences of receiving NET, including their views on its acceptability and effectiveness.

**Methods:** Semi-structured interviews were carried out with 11 participants meeting criteria for post-traumatic stress disorder within three months of completing NET. Data were analysed using thematic analysis.

**Results:** The analysis yielded eight themes organised into two domains: the process of therapy and outcomes of therapy. Participants reported that therapy was extremely challenging, but that building a trusting therapeutic relationship enabled them to speak about traumatic experiences. They described experiencing benefits following NET, both in terms of some reduction in trauma symptoms and in improvements in general wellbeing, social relationships and community participation.

**Conclusions:** The findings suggest that the asylum-seeking people interviewed found NET to be an acceptable and useful intervention. This lends support to offering trauma-focused interventions to this population despite uncertainty related to refugee status. Further research is needed to explore potential adverse subjective experiences of NET.

## Introduction

The United Nations Refugee Agency (2017) estimated that the number of people displaced worldwide due to conflict and human rights violations has reached the highest levels ever recorded at 68.5 million, including 25.4 million refugees<sup>1</sup> and 3.1 million asylum-seeking people<sup>2</sup>. Refugees and asylum-seeking people are forced to flee their homes and migrate to other countries for safety due to threats including war, persecution, and torture. Despite falling below the average for new asylum claims as a percentage of the population when compared with other European Union countries (The House of Commons library, 2018; Refugee Council, 2017), the increase in numbers of refugees and asylum-seeking people in the UK has significant social, political, and clinical implications.

As outlined in part 1 of this thesis, due to exposure to multiple traumatic events before, during and after migration, refugees and asylum-seeking people are at increased risk of developing Post Traumatic Stress Disorder (PTSD) (Mollica et al., 1998; Scholte et al., 2004). There is a need for the provision of effective and accessible psychological support for refugees and asylum-seeking people in the countries they resettle in, particularly as symptoms of PTSD negatively impact quality of life and are unlikely to remit without treatment (Lamkaddem et al., 2014; Priebe et al., 2009).

There is considerable research evidence to suggest that PTSD symptoms occur because heightened levels of fear during the traumatic event result in the event being processed and recorded in the person's memory in a fragmented way (Brewin, Dalgleish & Joseph, 1996; Ehlers, Clark, Hackmann, McManus & Fennell, 2005). The revised dual representation theory of PTSD suggests that the memory is normally stored in two

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<sup>1</sup> According to Article 1 of the 1951 United Nations Convention and Protocol Relating to the Status of Refugees, a refugee is a person who: "owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion, is outside the country of his nationality, and is unable to or, owing to such fear, is unwilling to avail himself of the protection of that country".

<sup>2</sup> An asylum seeker is someone who has applied for asylum and is awaiting a decision on whether they will be granted refugee status.

associated memory systems: one that contains sensory and affective information from the event which is retrieved involuntarily (S-reps), and one that stores autobiographical contextual information such as time and place which can be deliberately retrieved and verbalised (c-reps) (Brewin, Gregory, Lipton & Burgess, 2010). The first system is thought to be governed by areas of the brain involved in perception of threat and fear and to initiate action, such as the amygdala, while the second system is thought to require activation within the prefrontal cortex and hippocampus. It is hypothesised that during traumatic events the amygdala becomes highly reactive and high levels of hormones, such as glucocorticoids, are released in response to fear which inhibits the hippocampus in modulating the fear response by assessing contextual information about the threat. This results in sensory and emotional information from the event being stored without connection to autobiographical or contextual information. When traumatic memories are later triggered by matching internal or external cues they are intrusively re-experienced through flashbacks and nightmares without the corresponding contextual information that allows the person to know the event happened in the past, creating a current sense of threat. This is compounded by a tendency to avoid thinking about the event, preventing coherent processing from taking place (Brewin et al., 2010).

The revised dual representation theory of PTSD therefore suggests that in order to reduce the re-experiencing of past traumatic events through flashbacks and nightmares the sensory parts of the memory (s-reps) and the contextual information related to the event (c-reps) need to be integrated (Brewin et al., 2010). It is thought that exposing the person to the traumatic memory by asking them to recall the event in detail enables the memory to be attended to, allowing the sensory and contextual information to be integrated and associations made between the two representations of the event. This allows the sensory and fear responses to the memory to be regulated by contextual information and inhibited by the prefrontal cortex (Brewin et al., 2010). Therefore, the exposure mechanism is not

thought to extinguish the initial stimulus-fear response in the amygdala through repeated exposures, but to inhibit the fear response through activation of parts of the brain that allow this response to be regulated (LeDoux, 2000).

However, these theories were developed to explain the development of PTSD following a single traumatic event; therefore, it is less clear how applicable they may be to people who have suffered prolonged and repeated traumas (Green et al., 2000). There is also currently a debate within the field as to whether the current DSM-V criteria (American Psychiatric Association, 2013) for PTSD adequately encapsulate the experiences of people exposed to prolonged, interpersonal and repeated traumas, such as those experienced by some refugees and asylum-seeking people. Some suggest that the psychological impact of these experiences could be better understood as Complex post-traumatic stress disorder and that this calls for adapted or alternative therapeutic interventions (McDonnell, Robjant and Katona, 2012). A phased-based approach to treatment has been proposed which takes into account difficulties in engagement due to mistrust, and limited stability and safety (Cloitre et al., 2012). The recently released ICD-11 reflects these views and includes separate diagnostic categories for PTSD and Complex PTSD (WHO, 2018).

The current UK clinical guidelines (NICE, 2005) for the treatment of PTSD following a traumatic event recommends between eight to 12 sessions of trauma-focused therapy, either Trauma-Focused Cognitive Behavioural Therapy (tfCBT) or Eye Movement Desensitisation and Reprocessing (EMDR). There is a significant evidence-base for the use of tfCBT models such as Ehlers and Clark's (2000) for single event traumas (Ehlers et al., 2010), and some evidence for EMDR (Watts et al., 2013). However, the evidence is less clear for people who have experienced multiple traumas, particularly refugees and asylum-seeking people (Slobodin & de Jong, 2015). NICE (2005) guidance acknowledges that for people who have experienced multiple and prolonged traumas the number of sessions should be increased, and time dedicated to developing a trusting therapeutic relationship and

emotional safety before discussing the traumas in line with a phased-based approach (Cloitre et al., 2012).

A key component of effective trauma-focused therapies, such as tfCBT and EMDR, is the use of exposure to the traumatic memories to reduce cognitive avoidance and allow coherent processing of the memory (Ehlers et al., 2010; Schnyder et al., 2015). In line with the above theoretical framework for understanding how PTSD symptoms develop, once the traumatic memory is properly processed the re-experiencing should decrease. In tfCBT exposure involves “reliving”, or talking through the trauma in the present tense to allow the memory to be fully processed. This work is supplemented by cognitive restructuring to update the meanings of the worst moments of the trauma, and behavioural experiments to address negative appraisals and behaviours which may be maintaining distressing experiences (Ehlers & Clark, 2000). EMDR involves thinking about the traumatic event while simultaneously focusing on another task, followed by restructuring the memory (Shapiro, 1989). This dual-attention task may involve the person focusing on the traumatic memory while also tracking the therapist’s finger visually, listening to alternating tones, or tapping their fingers (Shepherd, Stein, & Milne, 2000).

Narrative Exposure Therapy (NET) was designed specifically to treat people who have experienced multiple and complex traumas and was initially used in low-income countries and refugee camps by lay practitioners (Schauer, Neuner, & Elbert, 2005). NET also has exposure to traumatic memories as its main component, but with an additional focus on testifying and bearing witness to the person’s experiences. Exposure in NET involves the individual narrating in detail in the past tense each traumatic event chronologically, differing from the methods of exposure in other trauma-focused therapies. The therapist is more directive during the individual’s narration and utilises the person’s responses to elicit information about the traumatic event (Robjant, Roberts & Katona,

2017). The individual is guided to attend both to past experiences and the present simultaneously during the exposure. The person's ability to discriminate between the present and the past is enhanced and maintained by linking past experiences to episodic facts and contextual information, such as time and place. In this way, the individual is exposed to the traumatic memories as they are contextualised and processed into autobiographical memory, thus reducing the sense of current threat (Schauer et al., 2005). Positive events are also discussed to enable a holistic narrative of the person's life. At the end of therapy the therapist presents the individual with a written testimony of their life experiences. Within NET there is therefore less focus on working directly with negative appraisals and behaviours which may be maintaining the PTSD symptoms, and any changes in the meaning of events happens more implicitly (Grey & Young, 2008).

Emerging evidence from randomised-controlled trials suggests that NET significantly reduces PTSD symptoms in refugees and asylum-seeking people who have experienced multiple traumas, with large effect sizes at six months to a year post therapy (Nose et al., 2017; Robjant & Fazel, 2010; Thompson, Vidgen & Roberts, 2018). Trials have so far been completed in low and middle-income countries where NET has been delivered in refugee camps (Neuner, Schauer, Klaschik, Karunakara & Elbert, 2004) as well as in high income countries (Halvorsen & Stenmark, 2010). There have been no published controlled trials of NET for refugees and asylum-seeking people living in the UK.

However, the conceptual approach and methodological quality of these studies has been criticised (Mundt, Wünsche, Heinz & Pross, 2014; Nose et al., 2017; Patel, Kellezi & Williams, 2014). Mundt et al. (2014) question the diagnostic validity of PTSD in non-western cultures and suggest that NET may be too brief an intervention to address the complexities of people's distress following repeated and prolonged traumatic events. The authors also question whether NET adequately considers the wider cultural and political context of

people's experiences or the social disruption of state level violence and oppression, as well as forced migration. Although many of the NET trials report large effect sizes post-therapy, methodological issues may limit the strength of evidence supporting the effectiveness of the therapy. Many of the NET trials do not include an explanation for why the therapy might have a delayed benefit, a discussion of negative results at follow-up post-therapy, or data on confounding variables that might better explain improvement in wellbeing post-therapy including reunification with family, changes in asylum status or access to social, welfare or financial resources (Mundt et al., 2014). Furthermore, many trials use measures of PTSD that have been developed and validated on western populations who have experienced single event traumas (Patel et al., 2014). Both the reviews conducted by Nose et al. (2017) and Patel et al. (2014) rate the quality of evidence from NET trials as low to very low and highlight the risk of bias due to many of the trials having been conducted by the same group of researchers who developed the NET manual.

There are a few qualitative studies exploring peoples' experiences of trauma-focused therapies, but to date no published qualitative studies of refugees and asylum-seeking peoples' experiences of receiving NET. Shearling, Lee and Clohessy (2011) interviewed seven people who had completed tfCBT for a single-event trauma about their experiences of reliving. The constructed themes included overcoming ambivalence towards reliving, the importance of a trusting therapeutic relationship and positive changes experienced after reliving despite the process being distressing. A qualitative study focusing on seven asylum-seeking peoples' experiences of tfCBT also identified the importance of the therapeutic relationship, conflicts about whether to engage in therapy, and gaining some benefits from therapy even though it was challenging (Vincent, Jenkins, Larkin & Clohessy, 2013). Qualitative research exploring asylum-seeking peoples' experiences of receiving NET would allow for a deeper exploration of the acceptability, effectiveness and potential adverse effects of the therapy which may not be captured through quantitative

measures (Barker, Pistrang & Elliott, 2016). Qualitative research may also provide useful clinical information about the experience of undergoing the therapy which may help to guide how NET is delivered (Silverstein, Auerback, & Levant, 2006).

The present study aimed to add to the growing literature on psychological interventions designed specifically for refugees and asylum-seeking people. The experience, acceptability and effectiveness of NET were explored by conducting semi-structured interviews with asylum-seeking people after completing NET. A qualitative method was chosen to allow for complexities and ambiguities in peoples' experiences and evaluations of NET (Barker et al., 2016). Semi-structured interviews were conducted to enable the researcher to take a flexible approach, following up and exploring participants' responses (Smith, 1995).

The study aimed to explore the following research questions:

1. What are asylum-seeking peoples' experiences of undergoing NET?
2. What elements of the therapy are viewed as helpful or unhelpful?
3. What benefits or harmful effects, if any, do asylum-seeking people experience during or following NET?

## **Method**

### **Setting**

The study took place at a UK based charity sector organisation working with survivors of torture and other cruel, inhuman or degrading treatment. A large percentage of the people supported by the charity are refugees or asylum seekers. A range of services are offered including medio-legal reports, welfare support, social groups and psychological therapies.

## **Intervention**

NET is the routinely offered psychological therapy at the charity for people who meet the criteria for a diagnosis of PTSD. Some people are offered tfCBT rather than NET if they have experienced a few discrete traumas, but this is the minority. The average number of NET sessions is sixteen, over a period of roughly six months, but can vary from ten to twenty. The therapy begins with the construction of the “lifeline”. The therapist and individual work together to create a physical representation of the person’s life from birth until the present, using stones to represent traumatic events and flowers to represent significant positive events. During each subsequent session a portion of the lifeline is narrated by the individual in the past tense, with particular time and attention given to exposure to traumatic events. During the narration of traumatic events the therapist asks detailed questions about both the emotional, cognitive, sensory and physiological experience as well as contextual information. Following every session the therapist transcribes the individual’s narration and then re-reads it at the beginning of the next session. At the end of therapy the therapist re-reads the whole narration and provides the individual with a copy to keep (Schauer et al., 2005).

## **Ethical approval**

Ethical approval for the study was granted by the UCL Research Ethics committee in October 2017 (see Appendix C). Informed consent was gained from all participants before each interview (see Appendices D and E).

## **Inclusion and Exclusion criteria**

To be eligible to participate in the study people were required to:

- 1) be aged 18 or over
- 2) be seeking asylum or have been granted refugee status

- 3) have a diagnosis of PTSD
- 4) have finished NET within the past three months.

People were not invited to participate if they were;

- 1) using substances such as drugs and alcohol at a level which would interfere with conducting interviews
- 2) experiencing psychotic symptoms, such as delusions or paranoia, at a level which would inhibit the person's capacity to provide informed consent
- 3) assessed by clinicians as displaying a level of risk to others and or themselves which would prohibit engagement in an interview.

### **Recruitment process and participants**

The study was outlined to psychology staff and posters advertising the study were displayed in the charity's reception. Potential participants were identified by staff and provided with the study information sheet (Appendix D). If a person expressed interest, consent was gained by staff to pass their contact details to the researcher. The researcher then arranged a face-to-face meeting with the person to provide further information and answer any questions before gaining written consent to participate (Appendix E).

There were two routes to recruitment. In one route (route B) people were approached by staff and invited to participate in the study following the completion of NET. In the other route (route A) people were approached before starting NET and invited to participate in both a pre-therapy and post-therapy interview. In these cases consent for the post-therapy interview was re-confirmed once therapy had ended. The pre-therapy interviews formed part of a larger research project and are not included in the analysis or results of the present study.

Twenty-nine people were approached and invited to participate; 10 after the completion of their therapy and 19 before the start. In the post-therapy recruitment route (route B) four people completed a post-therapy interview. In the pre-therapy recruitment route (route A) 13 people completed a pre-therapy interview. Seven out of these 13 people then re-consented to complete a second interview following the completion of their therapy. This resulted in a final sample of 11 people who completed post-therapy interviews. Reasons for non-participation were not collected systematically. Please see Figure 1 for a summary of the recruitment process.

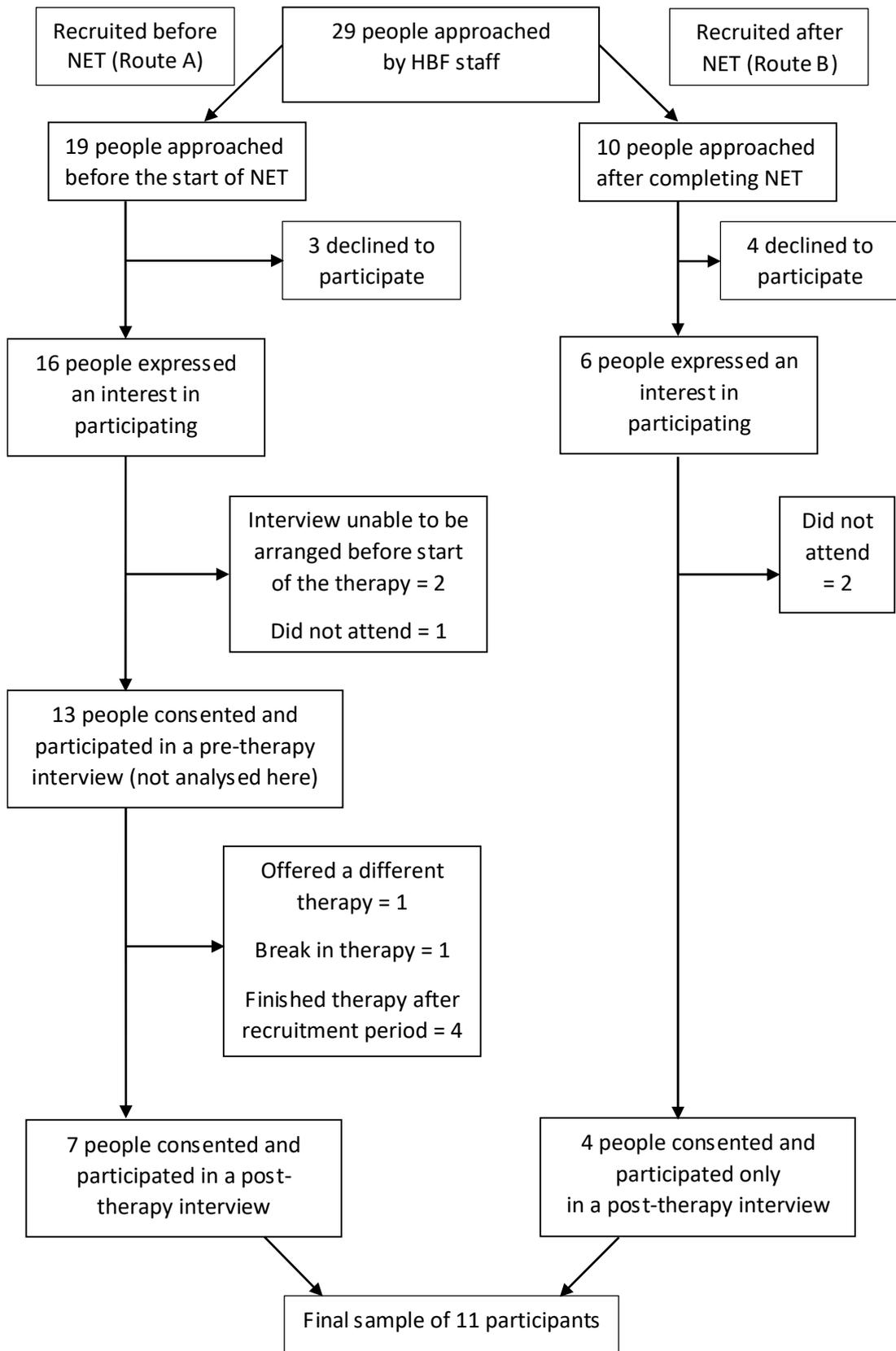


Figure 1. Recruitment flow diagram

Participants ranged in age from 27 to 62; the mean age was 39. There were seven (64 %) female participants. Participants originated from a range of different countries including those in Eastern Europe, Sub-Saharan Africa and the Middle East. The average amount of time living in the UK was 6 years (range one to 17) and four participants had dependents in the UK. Four participants were victims of trafficking: two within the UK, one outside of the UK and one both inside and outside the UK. All of the participants had made an asylum application to the Home Office, although at the time they were interviewed none of the participants had been granted refugee status. Types of trauma experienced were multiple for all participants and included sexual and physical assault, forced labour and slavery, detainment, state-sponsored torture and political persecution. Two participants had never attended school, four had some level of secondary school education and five had further training or education post school. Five participants described themselves as Christian, three as Muslim, one as Hindu and two as non-religious. Nine of the participants had received NET from a trainee clinical psychologist, the remaining two from a qualified clinical psychologist. All participants met criteria for PTSD at the start of NET, assessed by a diagnostic interview and the Clinical Administered PTSD scale (CAPS-V) (Weathers et al., 2013). Participant characteristics are summarised in Table 1, age and area of origin are provided in general terms to protect confidentiality.

Table 1: *Participants' characteristics*

| ID   | Gender | Age   | Area of origin     | Years in UK | Use of translator |
|------|--------|-------|--------------------|-------------|-------------------|
| P1   | Female | 25-35 | Eastern Europe     | 1-5         | No                |
| P 2  | Female | 55-65 | Central America    | 10-15       | No                |
| P 3  | Male   | 25-35 | East Asia          | 10-15       | No                |
| P 4  | Male   | 45-55 | Sub-Saharan Africa | 1-5         | No                |
| P 5  | Female | 35-45 | Middle East        | 1-5         | Yes               |
| P 6  | Male   | 35-45 | South-East Asia    | 1-5         | No                |
| P 7  | Female | 45-55 | Sub-Saharan Africa | 5-10        | No                |
| P 8  | Female | 35-45 | Middle East        | 1-5         | Yes               |
| P 9  | Male   | 18-25 | Sub-Saharan Africa | 1-5         | Partial           |
| P 10 | Female | 25-35 | Sub-Saharan Africa | 1-5         | Yes               |
| P 11 | Female | 25-35 | Sub-Saharan Africa | 15-20       | No                |

### **Procedure**

Interviews took place within three months of the completion of NET and lasted between 40 and 83 minutes. Demographic details were collected including; age, sex, religion, length of time in the UK, and refugee status. Interviews were recorded with permission of the participants using a hand-held audio recorder and four interviews were conducted alongside translators. One participant preferred not to be recorded so hand-written verbatim quotes were collected by the researcher during the interview. All of the interviews were completed at the charity. Participants were reimbursed for any travel expenses incurred to attend interviews but were otherwise not paid for participating in the study.

### **Semi-structured interview**

An initial semi-structured interview schedule was designed specifically for this study (see Appendix F). Throughout the construction of the interview schedule psychologists providing NET were consulted and relevant literature was reviewed.

The interview schedule focused on participants' experiences of NET, helpful and unhelpful aspects of the therapy, changes they had noticed since the therapy and the therapeutic relationship with their therapist. The schedules were used flexibly to guide the interviews in order to allow for unpredicted aspects of peoples' experiences to be discussed and to concentrate on the aspects of participants' experiences which felt most relevant to them (Smith, Flowers, & Larkin, 2009). Participants were initially asked broad questions before moving to more specific aspects of their experience, and responses were followed up with additional clarifying questions as needed. Attention was given to questions about unhelpful or challenging aspects of therapy, as well as helpful, to try to capture a well-rounded view of peoples' experiences and to avoid the researcher giving more weight to positive aspects.

Care was given when constructing the order and wording of questions to try to make the interview process more comfortable, minimise participants' distress and to avoid them having to discuss previous traumatic experiences in any detail. To check the sensitivity and relevance of the interview questions an asylum-seeking person who had recently completed NET at the charity was consulted prior to the study starting. Following this meeting several of the questions were revised. For example, rather than asking if there were times when therapy had been difficult, the service-user suggested asking specifically about times people thought about stopping therapy. The person was given a £10 gift card following the meeting to thank them for sharing their expertise and time. This person was not invited to participate in the study. The interview was then piloted and as no significant

changes were made to the interview schedule the data from this interview was included in the final analysis.

## **Analysis**

Thematic analysis was used to analyse the interviews. Analysis was guided by the research questions and conducted in six phases as outlined by Braun and Clarke (2006). First, the interviews were transcribed verbatim by the researcher and identifiable information was removed to protect participants' anonymity. The researcher spent time re-reading the transcripts and noting initial ideas and meanings in the data. Second, each transcript was coded line by line, keeping close to the original words and meanings of the interviewees using NVivo (NVivo Qualitative Data Analysis Software, 2017). Data under each code were collated together and compared for similarities and discrepancies to ensure consistent coding. Third, codes were reviewed and combined into preliminary themes based on perceived connections between them. An initial map of the themes was created, considering how the themes related to each other. Fourth, data extracts under each of the themes were reviewed to see if they described a consistent aspect of the data, or if the theme needed to be revised. Transcripts were then re-read to check that the themes represented the original data and that all relevant data had been coded. Attention was paid to "negative cases" or data which might challenge the themes (Mays & Pope, 2000). Fifth, themes were named to demonstrate which aspect of the data they described and how they related to the study questions and other themes. Finally, the analysis was written up, allowing for the final fine-tuning of themes and participant quotes were identified to illustrate each theme. Appendix G includes examples from the analysis.

## **Validity checks**

In line with guidance on conducting qualitative research the following validity checks (Elliot, Fischer & Rennie, 1999; Mays & Pope, 2000; Stiles, 1999) were undertaken. Firstly, a

subset of the transcripts was read by the research supervisor and the initial coding and themes were discussed on an ongoing basis before reaching a final consensus. Secondly, opinions and feedback were sought on the final themes from a service user group at the charity, as well a consultant clinical psychologist who works in a separate specialist trauma service for forced migrants. Thirdly, a range of illustrative quotations were selected to not over-represent certain perspectives or more eloquent participants, and to provide the reader with enough examples to evaluate the findings. Fourthly, the findings were compared to previous research as outlined in the discussion. Lastly, the researcher's own background and assumptions are shared below.

### **Position as a researcher**

The validity of qualitative research can be increased through the disclosure of the researcher's perspective (Caelli, Ray & Mill, 2003; Elliot et al., 1999). I am a white, British, female who approached the research from a "critical realist" position (Willig, 2012). This position guided the interviews and the analysis: I took the stance that participants were able to reflect and communicate about their experiences of therapy but recognised that their comments, my questions and analysis would be influenced by each of our individual assumptions and experiences. I attempted to "bracket" my own assumptions to enable me to remain open to participants' experiences by keeping a research journal, noting my initial reactions after interviews, as well as my ideas during the analysis, and discussing these with my research supervisors (Ahern, 1999; Fischer, 2009).

Previous to this research I had limited contact with asylum-seeking people: I had worked therapeutically with one person with refugee status, however, this had not involved exposure-based interventions. Based on this experience, as well as previous training and work with survivors of sexual abuse, I presumed that people would struggle to complete the therapy because of the intense emotions involved in exposure to the

traumatic memories. I had also learnt that interpersonal trauma creates additional challenges in developing a trusting relationship with a therapist. I was therefore particularly interested in what enabled people to overcome their resistance to talking about the past and how they described the therapeutic relationship. By the time I reached the analysis stage I had begun working clinically in a specialist trauma service for forced migrants. It is highly likely that these experiences influenced and changed my understanding of the interviews. For example, I had first-hand knowledge of the challenge of guiding people to talk through their worst experiences in detail.

### **Results**

During the analysis eight themes were constructed and organised into two overarching domains (Table 2). The first domain, “Process of therapy” includes four themes and describes participants’ experiences of undergoing NET. The second, “Outcomes of therapy” consists of four themes which outline the changes experienced by participants following NET, as well as the challenges remaining at the end of therapy. A brief overview is included first to provide the reader with contextual information, followed by a description of each theme with illustrative quotations. Each quote is attributed to a participant by a number (e.g. P1 for participant one) (see Table 1). In some instances, “PX” is used to protect the participant’s anonymity.

Table 2: *Summary of themes*

| Domain                 | Themes  |
|------------------------|---|
| 1. Process of therapy  | <p>1.1 Trust and the therapeutic relationship: from stranger to friend</p> <p>1.2. Overcoming the challenges of telling my story</p> <p>1.3. Hearing the narrative retold brought mixed feelings</p> <p>1.4. Threat of deportation derailed therapy</p> |
| 2. Outcomes of therapy | <p>2.1. Reducing the impact of the trauma: learning to manage</p> <p>2.2. Moving forward: “I’m heading for a better life”</p> <p>2.3. “My therapy [is] not finished yet”</p> <p>2.4. Without asylum status “I can’t be like normal people”</p>          |

### **Contextual overview**

All the participants discussed having emotional difficulties before starting NET, using descriptions including “depression” (P1, 9), “worried” (P7), “hopeless” (P3, 13), and “at my wit’s end” (P11). Two participants reported suicidal attempts preceding therapy. All participants spoke about experiences that correlate with diagnostic criteria for PTSD: describing living in fear, being “watchful” (P8) and “jumpy” (P11), memories of the past being triggered by certain sounds or smells, having nightmares, lacking concentration and poor memory. Many explained their current difficulties, alongside their past traumatic experiences, had left them feeling “irritable” (P6) and “aggressive” (P8) towards others and unable to trust people. These relational difficulties resulted in their losing friends, feeling that “people don’t understand me” (P1), and struggling to interact with people.

Although a few of the participants had tried to seek help previously this was the first experience of formal psychological therapy for all of them. Many described not knowing what therapy meant, what it would involve or what to expect: “I am a novice”

(P7). In the absence of previous knowledge, some developed their own ways of making sense of therapy, comparing it to going to see a doctor, going to church, or wondering if it was part of their asylum claim. Some were motivated to try therapy for the benefit of their children or because they were “fed up” (P8) with their current situation: they wanted to feel less scared, to “live a normal life” and “be free” (P11). Others struggled to believe that anything could help them. There was a sense that participants started therapy because they were desperately struggling and were willing to try anything that might change this, rather than because they had a clear idea of how therapy might help.

Despite lacking familiarity with therapy, having completed NET all participants said that they would recommend it to others based on the changes they had experienced including feeling “stronger” (P1), “lighter” (P2) and more alive:

*I will advise them you know what seek therapy ASAP because that’s the leeway really to freedom. When you talk about it with a professional, not with a friend. Then you’ll feel much lighter like I do now. (P11)*

*I will let them know, that if you have a chance of doing it, you will like yourself, because you will enjoy it, and finally come back to life (P7).*

### **Domain 1: Process of therapy**

This domain comprises themes that describe participants’ experiences of the process of therapy and the key components of NET.

#### **Theme 1.1: Trust and the therapeutic relationship: from stranger to friend.**

*As a human being when you fall down you need somebody to pick you up. When I fell at that time, she picked me up. (P11)*

Despite all participants describing their therapists positively, using words such as “friendly” (P6), “strong” (P1) “kind” (P5), “warmth” (P8), “positive” (P2), “gentle” (P3), “good heart” (P4), and “calm” (P5), most described difficulties trusting their therapist initially. They felt that their therapist could not help or understand them, did not want to

talk to the therapist, and worried that the therapist would judge them negatively for their past experiences:

*At first I didn't trust her. (P2)*

*You don't want to talk anything... and you tell her all the stories, a kind of story. How do you look at me at the end? (P6)*

Trust built over time as participants began to believe that their therapist genuinely wanted to help them, with a few participants describing their therapist becoming a "friend" (P1, P9, P13). Therapists gained their trust through the way they interacted with them: talking in a way that showed they were knowledgeable about the participants' difficulties, asking questions with intelligence and communicating their concern.

*She talk nice and she make me understand that she help me, it's not like she is danger to me or she do something to harm to me, and build like trust from me then the time slowly, slowly then I can like share with her. (P3)*

Despite initial fears, therapists were experienced by participants as listening non-judgmentally and trying to understand their experiences, giving them "courage" (P4), "hope" (P3), "reassurance" (P11), "encouragement" (P10) and "comfort" (P6) and allowing them to feel "safe" (P8) and "relaxed" (P5).

Although some participants initially had misgivings about talking to their therapist based on the therapist's age or gender, most felt that the therapist's attitude and knowledge was more important:

*I know she's young that me, um, I can see while she is talking, the first word I can know you you you are, you've got good knowledge and then you know how to help, yeah that's, it's not about the age or whatever. (P4)*

Having assurance that the sessions were confidential was particularly important to some in providing the reassurance and safety they needed to share their stories and say things they had never told anyone else:

*You can be my friend, but I will not let you know what happened to me. But but these people are confidential. Whatever you tell them they don't expose you. I have, I have some [friends] that I would never ever...I I could not tell them the deep*

*problem I was having. They know literally about me but not the deepest one that make me cry internally. (P7)*

A few participants stressed that a trusting relationship with their therapist was a crucial part of their being able to talk in such a detailed way about their past:

*If you don't trust your therapist, then it's also a problem. You don't, you don't er that's that's the main important part I guess. If you don't trust your therapist you don't tell everything. If you don't tell everything, it's you you can't, you can't, you can't get any better I think. (P6)*

Participants' trust in their therapist and belief that their concern was authentic was further strengthened by therapists actively supporting wider practical concerns including housing, liaising with the GP, legal support and asylum related issues:

*Not just about the therapy she was helping me, she was helping me with my papers, with my with questions, with my housing...with my GP I was have trouble, she was trying to help me with everything you know. (P1)*

Participants were not directly asked about building relationships with translators or how this impacted therapy, however two participants out of the four who were interviewed alongside translators commented that the translator also became a friend and source of support.

The importance and significance of the therapeutic relationship was also communicated by some participants when discussing the end of therapy. Given the therapist's role of trusted confidant and how socially isolated many participants were, understandably they described feeling "upset" (P1, P11) and "lonely" (P5).

### **Theme 1.2: Overcoming the challenges of telling my story**

Participants reported that the process of narrating their past experiences in therapy was very "difficult" (P1, P11) and "hard" (P7, P13, P9). Some felt that therapy was more challenging than they expected and that they could not have been fully prepared:

*The first day of therapy I was like, oh my god! It was as if, though I have never been hit by a, by a truck before, but that's how I felt. I don't know the feeling but that's how I can explain it you know....because I was a wreck. (P11).*

*I didn't know that it would be that hard, so to be prepared, even when they told me, but I wasn't really prepared for, you know, that to be that difficult. (P10)*

Initially they did not want to talk about the past as it felt too difficult and distressing to remember, especially as for many it was the first time telling another person the full details of what they had endured:

*It's my first time to to to try to say all my stories in my life you see, when they try to kill you, I don't wanna say these stories sometimes it makes me, I can cry, make me nervous. (P4)*

*When I talk about it, I am angry like I, it's really hard for me to talk about it. (P9)*

Some further explained that when they narrated the past during therapy sessions they would re-experience the traumatic events and feel as if they were playing out in front of their eyes:

*When I am talking to her, I always feel like I am sitting in a fil- cinema house, looking at everything I was saying, like a drama. (P7)*

*What you see, what you smell, how did you feel, what happenings, who beat you kind of stuff. You ask and you you getting a very clear picture and you remember everything... like you feel like you are in the situation and you, you are seeing kind of stuff. (P6)*

Others described experiences which might indicate that their high level of distress during the narration lead to dissociation:

*I was um...um...losing myself like...I wasn't aware of where I am. (P1)*

*Sometimes my spirit would leave my body. (P2)*

Furthermore, having gaps in memories and feeling shame about what had happened made narrating the “stones”, or traumatic events, even more challenging:

*I feel so ashamed inside but she [the therapist] is determined I have to go through that lifeline. (P2)*

*It was hard because there were a lot of blanks. A lot that I could not remember. (P11)*

Participants explained that their therapists continued to ask them for details despite their hesitancy and desire to avoid talking about the past. This persistence was

experienced by some as pushing for information and a few participants acknowledged feeling annoyed or angry with their therapist at times:

*Sometime I get angry because like she, I feel bit angry because she ask me very deep about my my past story. (P3)*

As a result of talking in therapy participants' traumatic memories also came back to them more often outside of sessions during the day and at night in flashbacks and nightmares, meaning that they initially felt worse after therapy rather than better and struggled to cope at home:

*In the beginning it was, it's like... um, something fresh again, you you you start again to remind a lot of things, flashback, those things has come again,...it was very tough. (P4)*

*When I keep talking about this then it keep coming back. (P3)*

Perhaps understandably this led some to question what they had been told about the benefits of talking about the past and wonder how they were going to tolerate talking through the "stones" and if they should stop:

*She's saying for me like if you are gonna talk about this it will help you. Ok I start talk, I believe her. I start talking, I feel worser! (P1)*

*It was really painful so I was keep asking some question to myself, so what is gonna happen then? How am I going been able to talk, to say everything that happened to me? (P10)*

In spite of these mixed feelings about therapy participants kept going due to a strong desire to feel better, their own resilience, a hope therapy might help and trust in their therapist. Several participants described how therapists were empathic and non-judgemental when they felt they couldn't attend, while simultaneously proactively encouraging them to come back to therapy.

Trusting their therapists, alongside understanding the rationale for talking about the past, helped participants to respond to their therapists' encouragement to continue to disclose:

*She pushing me but with very, very intelligence, she is pushing me. Look, sometimes when I say, no I'm not gonna say that, she say no, yeah you have to say. (P4)*

*But after that she explain to me why I need doing that...because she want to make me understand like why I need to think about all about my past. (P3)*

Participants appeared to have assimilated the metaphors used to describe the rationale for therapy into their own understanding of the process of NET, using them to make sense of the activities and goals of therapy and as a way to communicate these ideas during the interviews.

*That is your brain is like now, it's a, it's a messed up closet and we are going to do like um, like organise in a, in a good way. (P6)*

Although the interviewer did not enquire about grounding strategies many participants spontaneously described them as one of the most helpful elements of their therapy. Therapists helped participants to stay present in the room and tolerate their distress, allowing them to continue their narration, by engaging the participants' senses with smells, squeeze balls, pictures of the UK and verbally reminding them where they were:

*She showed me to relax my body, it was very helpful to me. And she gave me the smell, and then, you know, to print some pictures. (P8)*

*She keep reminding me that, most of things that I was saying that happened to me was in the past, so to make the difference between the past and the present. (P10)*

As participants became more familiar with the therapy it became easier to tolerate, although the sessions were still distressing. Others described that starting to experience relief from their distressing memories after the narrations provided some evidence to support the rationale for talking about their past:

*Yeah it's going down because like I spoke this one day time that's why I think it's going down, when you talk about something you are going to, you remember everything and er sometimes it's coming, like it's not like before, it's going down. (P9)*

*It's not easy, but gradually you can to, you know, you can feel the differences. (P8)*

Alongside beginning to experience some small amount of benefit after having

narrated their experiences a few participants reported that talking about the “flowers”, or positive memories, gave them some relief. Narrating “flowers” was viewed as a helpful as it created opportunities to remember happy memories they might have forgotten and lifted their spirits:

*When I spoke about good thing...Just, make me like, sometimes we laughing and er spoke about many things, I don't know, I just, it's really good, it's helping me a little. (P9)*

### **Theme 1.3: Hearing the narrative retold brought mixed feelings**

Therapists reading aloud the narrations at the beginning of each session evoked both positive and distressing emotions for participants: hearing “flowers” brought positive feelings while hearing the “stones” was painful:

*I felt like some good er events, nice events, flowers, it was like kind of happiness, some, then getting to big stones, you feel like, er bad. Yeah you feel like...you know, just kind of sad. (P6)*

A few participants described preferring to leave their narrations contained to the previous session and not wanting to listen to and be reminded of their traumatic experiences:

*Each week when she had to, you know, recap on the last week, ahhh it's like errr my mind wanted to explode. I felt very angry you know in my body, it was bringing everything back again. So it was tough. At times you know, I would try to just block my mind off, not hear what she was reading to me. (P11)*

*It was too stressful... hearing the same thing over and over made me feel depressed inside and worthless. (P2)*

For others listening to the narration made them feel understood as it demonstrated to them that their therapist had heard and remembered what they had said. They also highlighted that the narrations provided a helpful orientation as due to memory difficulties they would not always remember what they had already discussed:

*I feel like she, remember all my thing more than me remember my thing...it feel like someone understand me. (P3)*

One participant explained that they experienced a decrease in the intensity of their emotions when the narration was read by the therapist compared to when they spoke about the events themselves:

*When I spoke about these things this week, when I come next week, she start reading that one. That's why I am not feeling like first week the next week, because I spoke about it, everything like last week already, that's why it's not making me like, like first one angry. (P9)*

None of the other participants explicitly identified the therapist's narration as an opportunity for exposure to the traumatic memories or associated it with any benefits they gained from therapy. The few participants who discussed their feelings about receiving a copy of the final complete narration reported not knowing what to do with it or locking it away because it was too painful to consider.

#### **Theme 1.4: Threat of deportation derailed therapy**

Participants were not asked questions about the legal process of seeking asylum in the UK, however most made reference to it during the interview. One participant's experience in particular illustrated how the asylum process could undermine therapy. Despite already having experienced some benefit from therapy, receiving a letter from the Home Office mid-way through NET led them to feel that therapy was "worthless" and "not going to work" because they no longer felt safe in the UK. The fear that was triggered by the letter led the person to disengage from therapy and experience suicidal thoughts:

*Because if I go there [the Home Office] they will put me in the jail and then they will deport me so I'm going to die anyway, in back home, so why should I go and die there, you know their hands, by getting tortured, I can do myself. (PX)*

The therapist responded to this crisis by being in contact every day, liaising with other services including the GP and solicitor, and offering a crisis session to create a support and management plan for attending the Home Office appointment. This support and advocacy was highly valued by the participant and enabled them to have the courage to attend the Home Office appointment alone and then return to therapy:

*She [the therapist] called me, say “[participant name] everything ok?” I say everything is, thank you very much for your support. [P laughing] She say, “would you like to come to therapy” now, she say. I say, yes yes of course definitely I come, because because I feel ok, everything is fine. Then I started the therapy again and it was. So, I never, I will never forget this. (PX)*

## **Domain 2: Outcomes of therapy**

This domain describes the outcomes of NET identified by participants and ongoing difficulties that remained at the end.

### **Theme 1.1: Reducing the impact of the trauma: learning to manage**

Participants reported that by the end of therapy their psychological wellbeing was gradually improving as their distressing experiences were having less of an impact on their daily lives. They reported still re-experiencing their traumatic memories through nightmares and flashbacks; however, the frequency and intensity of these experiences had reduced somewhat:

*My nightmares are getting less. (P8)*

*It’s not as severe but it still comes on. (P2)*

In addition, most participants felt they had gained from therapy some understanding of why these past memories were intruding into the present, giving them a way of making sense of their experiences:

*I, we we understand, not true now, it was past, and the PTSD, something happen in the past that’s bringing to the present moment but that’s not really happening, it’s kind of imagination, er it’s kind of illusion so, so. But the re-experiencing in your body, in your mind, and it’s like, you feel like same in the, in the past, but it’s not real. (P6)*

*How brain working, how body reacting, we talk about this so many times because sometimes I was confused and my reaction I was get it lost, I say like it’s not normal, she say, it is, it’s normal. (P1)*

This increased understanding seemed to facilitate participants in being better able to manage their distressing experiences outside of therapy, with several participants highlighting the usefulness in learning and using grounding strategies. For some this was

the most helpful outcome of therapy as it empowered them to help themselves:

*I put it [pictures of the UK] on the wall in my bedroom when I am having nightmares. I wake up from my nightmare, I look at this and I remember that I live in [city] and I am in the UK. (P5)*

*I can try to help myself...put a sweetie...cool breeze...come back into myself. (P2)*

However, although these strategies and techniques were appreciated by the participants, it was not always easy to apply them without the support of the therapist:

*I practice these things, but only when I am well. But when I lose my patience, I am not able to think about anything. (P5)*

A further part of reducing the impact of the traumatic events expressed by some was that talking through their memories helped them to fill in the gaps and create a more coherent personal history:

*My memories come to, kind of, you know, in an order. And also the some of the things and I wasn't able to remember, she helped me to remember those memories. (P8)*

*There's some information in my mind that has been blocked, but now, no I am not like that. (P5)*

For some this was an important part of being able to share their life story with their families:

*Everything I do, the therapy I'm doing, is to find myself and it's for me to be able to give answers to my son as he grows. (P11)*

Others described a sense of freedom and release from the hold of the past after having shared their experiences:

*I was able to tell them, I was able to to throw, throw it out of me and...it um it makes me feel relieved of my problem. (P7)*

*It's [therapy] not about the help to be like, to get, get millions, but help to be free on your mind. (P4)*

One participant described how they struggled to talk about the abuse that they had endured and to use the word "rape". Being able to name and share this experience with their therapist allowed them to feel they could move on from it:

*When I name it...and she tried to like kind of understand and support me you know, it make for me easy you know...I was always like, it very bad I cannot take this, it's destroying my life, it's destroying everything around me, I lose, I lose everything because of this. Yes I did, just now it's make me something like, you know to believe I can walk out from this one. (PX)*

## **Theme 2.2: Moving forward: "I'm heading for a better life"**

*I wanna live, I wanna be happy and it's enough to suffering, enough cry. I I wanna, have better life. (P1)*

Although NET is focused on reducing distress caused by re-experiencing past traumatic events, participants identified broader changes which had occurred during and following therapy. These changes included how they felt about interacting with others, their activity levels, how they felt about themselves and their outlook on the future.

Most participants reported that interacting with other people had become easier as they felt less afraid, less aggressive towards others and more confident to engage in conversations. This had improved their existing relationships with family as well as enabling them to begin to make new relationships:

*My [spouse] say to me that now I can, so we can sit and have a normal conversation so, which was difficult before. (PX)*

*I don't have many friends before... now I can chat with people and I talk to people, I make many friends, like in football place, music place, and at community, my community... I a a a I have many friends now. (PX)*

Many were now engaging in more activities including exercise, attending religious services, playing more with their children, and doing things they used to enjoy but had lost interest in:

*These days I go for a walk in the morning and afternoon. I used to stay in room, now I walk for, good for me, go to park, ah for walking, go to library for reading and I I am doing good things. (P6)*

*I want to go to a music class on Saturdays...it will lift my spirit and feel like I am back in myself. (P2)*

Others described that following therapy they felt more self-confident, they liked

themselves more and they realised that they were not responsible for their traumatic experiences:

*They learnt me, no, I wasn't the one to be blamed... that's a relief of mind! Because I've been blaming myself, I've been having the guilty in me. But they explained everything to me. Look at this, look at this this way, look at it this way, and we came to arrive to the same answer that I wasn't the one to be blamed. And that erased the guilty conscience in me. (P7)*

Most participants expressed that therapy had enabled them to start to think about what they would like to work towards and given them some hope for the future:

*[I am] looking for the future at the moment, better way. I was so pessimistic but not that much anymore. (P8)*

*It's [therapy] changed me, like, you know, I have life, I have to do something for my future like I'm gonna go [have] family maybe (P9)*

They outlined plans to move on in their lives by enrolling in education, improving their English, starting new relationships and having children.

### **Theme 2.3: "My therapy [is] not finished yet"**

Even though NET was a challenging experience, most participants said there were no unhelpful aspects of NET, with a few describing the pride and relief they felt at having completed their therapy:

*If you ask me maybe during that time of therapy, I would say talking in depth, I didn't want it. To me that would have been the negative. But...it helped. It was something I had to do to overcome my past. So there's no negative for me. (P11)*

However, several participants wanted their therapy to continue as they felt it was benefiting them and there was more they could have talked about:

*The session are so limited, for me, the therapy can even take a year, so that the only change I can, if I can make a change, so to make it a bit longer. (P10)*

*Still some things inside I want to come out... it feels left in the air. (P2)*

Others expressed concerns that they would lose some of the progress they had made during therapy:

*I was ok two or three weeks after the therapy but I feel that I am back to how I was, but not as bad as before. (P5)*

*I really don't wanna go back, I really don't wanna feel the same way. (P1)*

#### **Theme 2.4: Without asylum status “I can't be like normal people”**

Several participants commented that despite having experienced some improvement after therapy they were prevented from fully recovering and progressing with their lives due to the ongoing uncertainty of their asylum status:

*You are trying your level best to, you know, help us, people like us um you know um to um manage these things but something is there, it's still, you know, pulling you down all the time. Reminding you, no, you are not safe, you are not safe... Now there is lots of improvement, but back of my mind, something is clearly says, “[name] you are not safe”. You know? They [Home Office] are in control, they have the power. And this is um stopping you to recover. (PX)*

### **Discussion**

This qualitative study explored asylum-seeking people's views and experiences of receiving NET. Generally, participants were positive about NET, despite having little knowledge of therapy before starting, and all said they would recommend therapy to others. Findings were reported within two domains: the process of therapy and the outcomes of therapy.

#### **The process of undergoing NET**

Building a trusting therapeutic relationship was a crucial part of the process of therapy for all participants. The importance of the therapeutic relationship has been reported across different therapeutic modalities and identified as a predictor of positive outcomes in therapy (Del Re, Flückiger, Horvath, Symonds & Wampold, 2012; Levitt, Pomerville, & Surace, 2016). Previous qualitative research of both adults who have experienced a single trauma, and asylum-seeking people's experiences of tfCBT have echoed the central importance of the therapeutic relationship (Shearling, et al., 2011;

Vincent et al., 2013). It may be that as many of the participants' traumatic experiences involved interpersonal trauma, building a trusting therapeutic relationship held even more importance in allowing them to participate in the therapy.

Participants highlighted that trust took time to develop, aided by the therapists' core therapeutic skills such as empathy and non-judgemental listening (Rogers, 1957). It may be that building trust was particularly difficult as participants' previous experiences frequently involved interpersonal trauma and they struggled to feel safe around others (Gorman, 2001; Tribe, 2002). Trust and a sense of genuine regard from therapists was also aided by therapists addressing participants' practical concerns. Previous research exploring refugee and staff experiences of psychological interventions have also identified offering support to address refugees' complex practical concerns as enabling a positive experience of therapy (Karageorge, Rhodes, Gray & Papadopoulos, 2017; Mirdral, Ryding, & Sondej, 2012). Including dedicated time to the development of safety within the therapeutic relationship and addressing practical concerns are recommended components of a phased-based approach to treatment for people who have experienced multiple and prolonged traumas (Cloitre et al., 2012; NICE, 2005).

In line with theories which highlight the role of cognitive avoidance in maintaining re-experiencing symptoms within PTSD, participants described not wanting to talk about the past, finding it painful to remember and re-experiencing memories during narrations (Brewin et al., 1996; Ehlers & Clark, 2000). Participants also reported increased re-experiencing symptoms between sessions. It is not immediately clear how this can be explained in relation to the revised dual-representation theory of PTSD. Initial symptom increase has been reported in previous studies of exposure-based therapies for PTSD in the general adult population, and has been suggested to be unrelated to poorer outcomes or higher dropout rates and may present another opportunity for exposure (Foa, Zoellner,

Feeny, Hembree & Alvarez-Conrad, 2002; Hembree et al., 2003; Larsen, Wiltsey Stirman, Smith, & Resick, 2016; Schauer, et al., 2005). In this study participants completed their therapy despite their symptoms increasing in the subsequent few days after a session. However, as only people who completed NET were interviewed, it is not possible to draw any conclusions about the contribution of symptoms increasing to other individuals choosing to not proceed with NET.

Participants were able to overcome their avoidance and hesitancy about the exposure-based component of NET, despite struggling with gaps in memory, shame and dissociation. Within NET the therapist takes a more directive approach to address cognitive avoidance and although this was experienced as pushy at times, this appeared to be outweighed by the participants' belief in the therapists' genuine care and a growing understanding of the rationale for narrating the past. The importance of informed consent to treatment and the individual understanding the rationale and tasks of therapy has been previously emphasised (Bordin, 1979; Ehlers & Clark, 2000; Gorman, 2001). Of particular note was the usefulness of metaphors, which allowed these ideas to be communicated without the need for psychological terminology which may not hold meaning for asylum-seeking people with different cultural frameworks and limited experience of therapy. Metaphors are commonly used in cognitive behavioural therapies and have formed part of adapting exposure-based interventions to increase acceptability for refugees (Otto & Hinton, 2006; Stott, Mansell, Salkovskis, Lavender, & Cartwright-Hatton, 2010).

For some participants therapist narration appeared to aid feeling understood and strengthened the therapeutic relationship, while others described wanting to avoid listening to therapists re-reading their narrations due to painful memories and emotions. Therapist narration is a unique feature of NET and is proposed to provide another opportunity for exposure to the traumatic memories, along with an opportunity to correct

the final testimony provided at the end of therapy (Schauer, et al., 2005). However, only one person connected hearing the therapist's narration to feeling less distressed and others seemed at a loss as to what to do with the final testimony. It may be that participants did not fully understand the rationale for the therapist's narration within the process of NET or that exposure that does not involve the person themselves recalling and describing the event does not allow for re-processing of the fragmented memory.

### **Outcomes of NET**

Participants expressed some meaningful subjective reduction in the frequency and intensity of their re-experiencing symptoms, but these experiences were still present by the end of NET, leading some participants to express a wish for further therapy. It is not possible to conclude why participants continued to report re-experiencing symptoms. In reference to the dual-representation theory of PTSD, it may be that participants may not have been able to tolerate exposure to the memories to a sufficient level to allow activation of the fear response in order for it to then be regulated and inhibited by the hippocampus and pre-frontal areas of the brain. Additionally, it may be that the number of sessions offered was not sufficient to allow for re-processing of all of the traumatic memories. Exposure to higher numbers of traumatic events, commonly reported by refugees and asylum-seeking people, may be linked to increased number of re-experiencing and avoidance symptoms and therefore may need more time to improve (Minihan, Liddell, Byrow, Bryant, & Nickerson, 2018). Previous reviews of the efficacy of NET have suggested increased reduction in symptoms six months post therapy although it is not possible to draw conclusions about any delayed effects NET may have from these studies due to limited reported information about confounding variables (Nose et al., 2017; Robjant & Fazel, 2010). Alternatively, it may be that the dual-representative theory cannot be straightforwardly applied to people who have experienced prolonged and repeated

traumatic events and that the intervention therefore needs to be adapted and extended beyond exposure-based treatments. Despite participants continuing to have symptoms, learning how to manage their re-experiencing symptoms and gaining a way of making sense of their experiences appeared to be a valuable outcome in and of itself. This is supportive of the inclusion of symptom management as part of a phased-based approach to treatment and to promote self-efficacy (Cloitre et al., 2012; Grey & Young, 2008; Robertson, Blumberg, Gratton, Walsh & Kayal, 2013).

Previous research into the efficacy of psychological interventions for torture survivors and refugees has been criticised for not reporting whether reductions in PTSD symptoms translate to meaningful improvements in quality of life, social relationships or community participation (Palic & Elklit, 2011; Patel et al., 2014). However, participants in this study identified a range of wider benefits following NET including improvements in interpersonal relationships, increased activity levels, and more optimism for the future. The qualitative study conducted by Vincent et al. (2013) which explored asylum-seekers' experience of tfCBT reported similar findings, suggesting that these benefits may not be unique to NET.

### **Therapy within the context of uncertain asylum status**

Within recommendations for clinical work with refugees and asylum-seeking people it is suggested that a certain amount of stability and safety is needed before engaging in psychological interventions (Cloitre et al., 2012). However, opinions vary as to what constitutes sufficient safety with some suggesting that therapy does not have to be delayed until refugee status has been granted (Grey & Young, 2008). The findings of this study suggest that while people with uncertain asylum status can nonetheless benefit from NET, this can be undermined at any time by difficulties encountered in the asylum process. For the participant who discussed their experience of this, the advocacy of the therapist

and strength of the therapeutic relationship enabled them to overcome this barrier and re-engage with therapy. Ultimately, as highlighted by some participants, many of whom had been waiting several years for their asylum decision, regardless of how effective therapy might be, a lasting sense of psychological safety can only be obtained once refugee status has been granted.

### **Limitations**

There are several limitations to the current study. As participants were initially approached by therapists at the charity they may have been more likely to select those who they felt had benefited from NET. As no information was recorded on those who did not agree to participate no comparisons can be made with the final sample. There was large variability across participants in respect to age, countries of origin, cultural beliefs, time in the UK, traumas experienced and proficiency of English, which makes generalising the findings to other samples difficult. The setting may also have been influential to the positive outcomes experienced following NET as participants spoke very highly of the support regarding housing, asylum procedures and finances that they received from the service, in addition to therapy. This positive relationship with the service and with the therapists may have made it difficult for participants to share negative experiences, especially as the interviews took place at the service. Participants were also relying on memory to recall details of the therapy which took place over several months and many reported experiencing concentration and memory difficulties (Herlihy, Scragg, & Turner, 2002). The use of translators for four interviews may have introduced misrepresentation of participants' views, particularly as back translation was not employed, and hindered deeper discussion of their experiences. As mention above, previous research has suggested that beneficial outcomes may continue several months after the completion of NET. However, as participants were interviewed within three months of completion of NET some of the

benefits may not have been captured and participants may have been more focused on the negative feelings associated with the loss of the trusted therapeutic relationship.

### **Clinical implications**

Notwithstanding considerable evidence to suggest that exposure-based interventions are effective within the general adult population, previous surveys have suggested that clinicians are concerned that exposure will lead to negative outcomes including increased symptoms, suicidality and drop-out rates (Black Becker, Zayfert & Anderson, 2004; Frueh, Cusack, Grubaugh, Sauvageot, & Wells, 2006; Van Minnen, Hendriks & Olff, 2010). The findings in this study suggest that asylum-seeking people were able to tolerate an initial increase in symptoms, continue therapy and experience benefits in general well-being and some symptom reduction by the end. By discussing openly and explaining the possibility of initial symptom increase, as well as identifying ways to cope and manage, for example by teaching grounding strategies, individuals can be given the opportunity to make an informed decision about whether or not to proceed with NET. Similarly, dissociation may also be perceived as a contraindication to offering NET. However, participants in this study described the usefulness of their therapists helping them to stay grounded in the present, allowing them to continue their narrations. This is supported by Halvorsen, Stenmark, Neuner and Nordahl's (2014) study which indicated that dissociative symptoms did not moderate the outcomes of NET with a randomised-controlled clinical trial.

Despite undergoing NET while living with the uncertainty of an unresolved asylum claim, all participants said that they would recommend NET to others. It is possible that some element of social desirability might have affected their answers; however, it is an interesting finding given that concerns are often raised about the level of stability needed to engage in exposure-based therapies. Although phased-based approaches are commonly

suggested, there is limited evidence to support the effectiveness of extended stand-alone stabilisation before therapy (De Jongh et al., 2016). Participants in the present study discussed learning grounding and self-soothing strategies during the process of NET and as they mentioned, no amount of any type of therapy can fully counteract the threat to safety of a pending asylum claim. Clinicians may feel unable and unqualified to address asylum-seeking peoples' crucial practical concerns. Findings from this study support therapy being conducted in a context where therapists are either supported to also take on advocacy for individuals, or work within a multi-disciplinary context whereby other professionals can help to address practical concerns alongside therapy.

### **Future research**

This study explored the general acceptability and efficacy of NET for asylum-seeking people. As only people who completed NET were included in this sample understanding of potential adverse outcomes of NET could be increased by also exploring experiences of people who decided to finish therapy early. Similarly, it would be interesting to learn about peoples' reasons for declining offers of NET and other trauma-focused therapies. Although participants described some reduction in symptoms and improvements in wellbeing, activity levels and social relationships following NET, they reported that their distress and re-experiencing symptoms still endured and some were seeking further therapy. This raises questions about the adequate dose of NET and its effectiveness and acceptability compared to other trauma-focused therapies; most participants in the current study had received approximately six months of NET, more sessions than reported in NET trials (Nose et al., 2017; Robjant & Fazel, 2010). In order to examine this further, future studies could utilise mixed method approaches and explore refugee and asylum-seeking peoples' views and understandings of the key components and mechanisms of change within NET.

## References

- Ahern, K. (1999). Ten Tips for Reflexive Bracketing. *Qualitative Health Research*, 9, 407–411.
- American Psychiatric Association (2013). *Diagnostic and statistical manual for mental disorders* (5<sup>th</sup> ed.). Arlington, VA: American Psychiatric Publishing.
- Barker, C., Pistrang, N., & Elliott, R. (2016). *Research methods in clinical psychology: An introduction for students and practitioners* (3<sup>rd</sup> ed.). Chichester: Wiley.
- Black Becker, C., Zayfert, C., & Anderson, E. (2004). A survey of psychologists' attitudes towards and utilization of exposure therapy for PTSD. *Behaviour Research and Therapy*, 42, 277–292.
- Bordin, E. (1979). The generalizability of the psychoanalytic concept of the working alliance. *Psychotherapy: Theory, Research & Practice*, 16, 252-260.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Brewin, C., Dalgleish, T., & Joseph, S. (1996). A dual representation theory of post-traumatic stress disorder. *Psychological Review*, 103, 670 – 686.
- Brewin, C., Gregory, D., Lipton, M., & Burgess, N. (2010). Intrusive images in psychological disorders: characteristics, neural mechanisms, and treatment implications. *Psychological Review*, 117, 210-232.
- Caelli, K., Ray, L., & Mill, J. (2003). 'Clear as mud ': toward greater clarity in generic qualitative research. *International Journal of Qualitative Methods*, 2, 1–13.
- Cloitre, M., Courtois, C., Ford, J., Green, B., Alexander, P., Briere, J., ... Van der Hart, O. (2012). *The international society for traumatic stress studies (ISTSS) expert*

*consensus treatment guidelines for complex PTSD in adults*. Retrieved on 10<sup>th</sup> June 2018 from [www.istss.org](http://www.istss.org).

- De Jongh, A., Resick, P., Zoellner, L., Van Minnen, A., Lee, C., Monson, C., ... Bicanic, I. (2016). Critical analysis of the current treatment guidelines for complex PTSD in adults. *Depression and Anxiety, 33*, 359-369.
- Del Re, A., Flückiger, C., Horvath, A., Symonds, D., & Wampold, B. (2012). Therapist effects in the therapeutic alliance-outcome relationship: A restricted-maximum likelihood meta-analysis. *Clinical Psychology Review, 32*, 642-649.
- Ehlers, A., Bisson, J., Clark, D., Creamer, M., Pilling, S., Richards, D., ... Yule, W. (2010). Do all psychological treatments really work the same in post-traumatic stress disorder? *Clinical Psychology Review, 30*, 269-276.
- Ehlers, A., & Clark, D. (2000). A cognitive model of post-traumatic stress disorder. *Behaviour Research and Therapy, 38*, 319 –345.
- Ehlers, A., Clark, D., Hackmann, A., McManus, F., & Fennell, M. (2005). Cognitive therapy for post-traumatic stress disorder: Development and evaluation. *Behaviour Research and Therapy, 43*, 413 –431.
- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38*, 215-229.
- Fischer, C. (2009). Bracketing in qualitative research: conceptual and practical matters. *Psychotherapy Research: Journal of the Society for Psychotherapy Research, 19*, 583–90.

- Foa, E., Zoellner, L., Feeny, N., Hembree, E., & Alvarez-Conrad, J. (2002). Does imaginal exposure exacerbate PTSD symptoms? *Journal of Consulting and Clinical Psychology, 70*, 1022-1028.
- Frueh, B., Cusack, K., Grubaugh, A., Sauvageot, J., & Wells, C. (2006). Clinicians' perspectives on cognitive-behavioural treatment for PTSD among persons with severe mental illness. *Psychiatric Services, 57*, 1027–1031.
- Gorman, W. (2001). Refugee survivors of torture: trauma and treatment. *Professional Psychology: Research and Practice, 32*, 443-451.
- Green, B. L., Goodman, L. A., Krupnick, J. L., Corcoran, C. B., Petty, R. M., Stockton, P., & Stern, N. (2000). Outcomes of single versus multiple trauma exposure in a screening sample. *Journal of Traumatic Stress, 13*, 271 –286.
- Grey, N., & Young, K. (2008). Cognitive Behaviour Therapy with refugees and asylum seekers experiencing traumatic stress symptoms. *Behavioural and Cognitive Psychotherapy, 36*, 3-19.
- Halvorsen, J., & Stenmark, H. (2010). Narrative exposure therapy for post-traumatic stress disorder in tortured refugees: A preliminary uncontrolled trial. *Scandinavian Journal of Psychology, 51*, 495-502.
- Halvorsen, J., Stenmark, H., Neuner, F., & Nordahl, H. (2014). Does dissociation moderate treatment outcomes of narrative exposure therapy for PTSD? A secondary analysis from a randomized controlled clinical trial. *Behaviour Research and Therapy, 57*, 21-28.
- Hembree, E., Foa, E., Dorfan, N., Street, G., Kowalski, J., & Tu, X. (2003). Do patients drop out prematurely from exposure therapy for PTSD? *Journal of Traumatic Stress, 16*, 555-562.

- Herlihy, J., Scragg, P., & Turner, S. (2002). Discrepancies in autobiographical memories – implications for the assessment of asylum seekers: repeated interviews study. *British Medical Journal*, *324*, 324-327.
- Karageorge, A., Rhodes, P., Gray, R., & Papadopoulos, R. (2017). Refugee and staff experiences of psychotherapeutic services: a qualitative systematic review. *Intervention*, *15*, 51-69.
- Lamkaddem, M., Stronks, K., Deville, W., Olf, M., Gerritsen, A., & Essink-Bot, M. (2014). Course of post-traumatic stress disorder and health care utilisation among resettled refugees in the Netherlands. *BMC Psychiatry*, *14*, DOI: 10.1186/1471-244X-14-90.
- Larsen, S., Wiltsey Stirman, S., Smith, B., & Resick, P. (2016). Symptom exacerbations in trauma-focused treatments: Associations with treatment outcome and non-completion. *Behavioural Research and Therapy*, *77*, 68-77.
- LeDoux, J. (2000). Emotion circuits in the brain. *Annual Review of Neuroscience*, *23*, 155-184.
- Levitt, H., Pomerville, A., & Surace, F. (2016). A qualitative meta-analysis examining clients' experiences of psychotherapy: A new agenda. *Psychological Bulletin*, *142*, 801-830.
- Mayes, N., & Pope, C. (2000). Assessing quality in qualitative research. *British Medical Journal*, *320*, 50-52.
- McDonnell, M., Robjant, K., & Katona, C., (2012). Complex post-traumatic stress disorder and survivors of human rights violations. *Current Opinion Psychiatry*, *26*, DOI: 10.1097/YCO.0b013e32835aea9d.
- Minihan, S., Liddell, B., Byrow, Y., Bryant, R., & Nickerson, A. (2018). Patterns and predictors of post-traumatic stress disorder in refugees: a latent class analysis. *Journal of Affective Disorders*, *232*, 252-259.

- Mirdal, G., Ryding, E., & Sondej, M. (2012). Traumatized refugees, their therapists, and their interpreters: Three perspectives on psychological treatment. *Psychology and Psychotherapy: Theory, Research and Practice, 85*, 436-455.
- Mollica, R. F., McInnes, K., Pham, T., Smith-Fawzi, M. C., Murphy, E., & Lin, L. (1998). The dose–effect relationships between torture and psychiatric symptoms in Vietnamese ex-political detainees and a comparison group. *Journal of Nervous and Mental Disease, 186*, 543 –553.
- Mundt, A., Wünsche, P., Heinz, A., & Pross, C. (2014). Evaluating interventions for post-traumatic stress disorder in low and middle income countries: Narrative Exposure Therapy. *Intervention, 12*, 250-266.
- National Institute for Health and Clinical Excellence (NICE). (2005). *Post-traumatic stress disorder: management. CG26*. London: National Institute for Health and Clinical Excellence.
- Neuner, F., Schauer, M., Klaschik, C., Karunakara, U., & Elbert, T. (2004). A comparison of narrative exposure treatment, supportive counselling and psychoeducation for treating post-traumatic stress disorder in an African refugee settlement. *Journal of Consulting and Clinical Psychology, 72*, 597-587.
- Nose, M., Turrini, G., Imoli, F., Ballette, F., Ostuzzi, G., Cucchi, F., ... Barbui, C. (2017). Prevalence and correlates of psychological distress and psychiatric disorders in asylum seekers and refugees resettled in an Italian Catchment Area. *Journal of Immigrant and Minority Health, 20*, 263-270.
- NVivo Qualitative Data Analysis Software. (2017). QSR International Pty Ltd. Version 11. Los Angeles, CA.

- Otto, M. & Hinton, D. (2006). Modifying exposure-based CBT for Cambodian refugees with post-traumatic stress disorder. *Cognitive and Behavioural Practice, 13*, 261-270.
- Palic, S., & Elklit, A. (2011). Psychosocial treatment of post-traumatic stress disorder in adult refugees: A systematic review of prospective treatment outcome studies and a critique. *Journal of Affective Disorders, 131*, 8–23.
- Patel, N., Kellezi, B., & Williams, A. (2014). Psychological, social and welfare interventions for psychological health and well-being of torture survivors. *Cochrane Database of Systematic Reviews, 11*, DOI: 10.1002/14651858.CD009317.pub2.
- Priebe, S., Matanov, A., Janković Gavrilović, J., McCrone, P., Ljubotina, D., Knezević, G., ... Schützwohl, M. (2009). Consequences of untreated post-traumatic stress disorder following war in former Yugoslavia: morbidity, subjective quality of life, and care costs. *Croatian Medical Journal, 50*, 465-75.
- Refugee Council. (2017). *Statistics on asylum in Europe*. Retrieved on 10<sup>th</sup> June 2018 from [www.refugeecouncil.org.uk/stats](http://www.refugeecouncil.org.uk/stats).
- Robertson, M., Blumberg, J., Gratton, J., Walsh, E., & Kayal, H. (2013). A group-based approach to stabilisation and symptom management in a phased treatment model for refugees and asylum seekers. *European Journal of Psychotraumatology, 4*, DOI:10.3402/ejpt.v4i0.21407.
- Robjant, K., & Fazel, M. (2010). The emerging evidence for narrative exposure therapy: A review. *Clinical Psychology Review, 30*, 1030-1039.
- Robjant, K., Roberts, J., & Katona, C. (2017). Treating post-traumatic stress disorder in female victims of trafficking using narrative exposure therapy: a retrospective audit. *Frontiers in Psychiatry, 8*, DOI: 10.3389/fpsyt.2017.00063.
- Rogers, C. (1957). The necessary and sufficient conditions of therapeutic personality change. *Journal of Consulting Psychology, 21*, 95-103.

- Schauer, M., Neuner, F., & Elbert, T. (2005). *Narrative Exposure Therapy. A short term intervention for traumatic stress disorders after war, terror or torture*. Germany: Hogrefe & Huber.
- Schnyder, U., Ehlers, A., Elbert, T., Foa, E., Gersons, B., Resick, P., & Cloitre, M. (2015). Psychotherapies for PTSD: what do they have in common? *European Journal of Psychotraumatology*, 6, DOI:10.3402/ejpt.v6.28186
- Scholte, W., Olf, M., Ventevogel, P., de Vries, G., Jansveld, E., Cardozo, B., & Crawford, C. (2004). Mental health symptoms following war and repression in eastern Afghanistan. *Journal of the American Medical Association*, 292, 585–593.
- Shapiro, F. (1989). Eye movement desensitization: a new treatment for post-traumatic stress disorder. *Journal of Behavior Therapy and Experimental Psychiatry*, 20, 211–217.
- Shearling, V., Lee, D., & Clohessy, S. (2011). How do clients experience reliving as part of trauma-focused cognitive behavioural therapy for post-traumatic stress disorder? *Psychology and Psychotherapy: Theory, Research and Practice*, 84, 458-472.
- Shepherd, J., Stein, K., & Milne, R. (2000). Eye movement desensitization and reprocessing in the treatment of post-traumatic stress disorder: a review of an emerging therapy. *Psychological Medicine*, 30, 863–871.
- Silverstein, L., Auerback, C., & Levant, R. (2006). Using qualitative research to strengthen clinical practice. *Professional Psychology: Research and Practice*, 37, 351–358.
- Slobodin, O., & de Jong, J. (2015). Mental health interventions for traumatized asylum seekers and refugees: What do we know about their efficacy? *International Journal of Social Psychiatry*, 61, 17-26.
- Smith, J. (1995). Semi-structured interview and qualitative analysis. In: Smith, J. A., Harre, R. and Langenhove, L. V. (Eds.). *Rethinking Methods in Psychology* (pp. 9-26). London: Sage.

- Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: Sage.
- Stiles, W. (1999). Evaluating qualitative research. *Evidence-Based Mental Health*, 2, 99-101.
- Stott, R., Mansell, W., Salkovskis, P., Lavender, A., & Cartwright-Hatton, S. (2010). *Oxford guide to metaphors in CBT: Building cognitive bridges*. Oxford: Oxford University Press.
- The House of Commons library. (2018). *Asylum statistics: briefing paper*. Retrieved on 10<sup>th</sup> June 2018 from [www.researchbriefings.parliament.uk/ResearchBriefing/Summary/SN01403](http://www.researchbriefings.parliament.uk/ResearchBriefing/Summary/SN01403).
- Thompson, C., Vidgen, A., & Roberts, N. (2018). Psychological interventions for post-traumatic stress disorder in refugees and asylum seekers: A systematic review and meta-analysis. *Clinical Psychology Review*, 63, 66-79.
- Tribe, R. (2002). Mental health of refugees and asylum-seekers. *Advances in Psychiatric Treatment*, 8, 240–247.
- United Nations Refugee Agency. (2017). *Global trends report: forced displacement in 2017*. Retrieved on 25<sup>th</sup> June 2018 from [www.unhcr.org](http://www.unhcr.org).
- Van Minnen, A., Hendriks, L. & Olf, M. (2010). When do trauma experts choose exposure therapy for PTSD patients? A controlled study of therapist and patient factors. *Behaviour Research and Therapy*, 48, 312-320.
- Vincent, F., Jenkins, H., Larkin, M., & Clohessy, S. (2013). Asylum-seekers' experiences of trauma-focused Cognitive Behavioural Therapy for post-traumatic stress disorder: a qualitative study. *Behavioural and Cognitive Psychotherapy*, 41, 579-593.

- Watts, B., Schnurr, P., Mayo, L., Young-Xu, Y., Weeks, W., & Friedman, M. (2013). Meta-analysis of the efficacy of treatments for post-traumatic stress disorder. *Journal of Clinical Psychiatry, 74*, DOI: 10.4088/JCP.12r08225.
- Weathers, F., Blake, D., Schnurr, P., Kaloupek, D., Marx, B., & Keane, T. (2013). The Clinician-Administered PTSD Scale for DSM-5 (CAPS-5). National Center for Post-traumatic Stress Disorder, Boston.
- Willig, C. (2012). Perspectives on the epistemological bases for qualitative research. In H. Cooper (Ed.), *APA handbook of research methods in psychology: Vol. 1 Foundations, planning, measures and psychometrics* (pp.5-21). Washington, DC: American Psychological Association.
- World Health Organization. (2018). *The ICD-11 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva: World Health Organization. Retrieved on 25<sup>th</sup> June 2018 from [www.who.int/classifications/icd/en/](http://www.who.int/classifications/icd/en/)

## Part 3: Critical Appraisal

## **Introduction**

This critical appraisal focuses on the empirical study described in part two and is presented in two sections. The first considers my experiences of conducting the interviews and the second is an exploration of both epistemological and personal reflexivity (Willig, 2013).

### **Experience of conducting the interviews**

During the process of interviewing participants several difficulties were encountered and negotiated. These included the challenges of building trust with participants, gaining informed consent, taking up a research rather than clinical role and working with translators.

#### **Building trust with participants.**

Building trust within the interview was key in enabling the participants to share their experiences and feel comfortable. As highlighted in the results section, participants expressed difficulties trusting others' motives and intentions. Traumatic events experienced by asylum-seeking people can have a negative impact on the person's ability to trust, particularly in the case of interpersonal traumas such as torture (Williams & Van der Merwe, 2013). For some, mistrusting others and authority figures can become an adaptive way to survive living under an oppressive regime (Raghallaigh, 2014). Trust in others can also be conceptualised as an interaction; asylum-seeking people's mistrust of others may also be strengthened by the post-migration experiences of being mistrusted and misbelieved by host countries' authorities during the asylum-seeking process (Hynes, 2003). A qualitative study of refugees' experiences of Home Office interviews reported that 19 out of the 27 participants described negative reactions from the Home Office officials during the asylum interview, with one describing the experience in the following way:

*“The Home Office officials have a ‘diplomatic way’ of torture. The Home Office interview was worse than the repeated rape and detention I suffered. The rape was physical, at least I could close my eyes while it happened and try to forget about it... They [the Home Office] torture you inside, for example I was asked by a female interviewer: ‘How come you don’t have any sexual diseases like syphilis or AIDS, but you tell me that you were raped?’.” (Bögner, Brewin & Herlihy, 2010, p. 526).*

I was aware that the experience of a research interview had the potential to remind participants of previous experiences of being interviewed, interrogated or questioned.

During one of the earlier interviews a participant described their experience of being repeatedly questioned throughout their time in the UK and how this had left them feeling powerless:

*“Since I come in the UK the same things. I think today [the research interview] is going to be the last ...every time you just explain, you just talking, you just talking all the same story, what happened, what happening since I come here, it’s about three years... all they ask you, the same question, you see the same question, they say “why you came here? Why you do?” The same question but different people... many people... I don’t know, it’s like manipulations, you see for me, it’s like manipulations, the question. You manipulate me because I am refugee, just you need to be asking me any question. Just if you don’t answer, we are not going to give you food. If you are not answering, we are not going to give you place to stay.”*

I therefore took several steps to try to avoid participants experiencing the research interview negatively and to build trust through transparency. Firstly, participants were approached by staff at the charity who knew them well to introduce the idea of the research to them. Secondly, interviews were conducted at the charity where participants were seen for therapy as it was hoped that the charity represented a safe and trusted environment. Thirdly, the interview schedule was designed to avoid any explicit discussion of previous traumatic experiences and was amended following service user feedback to try to ensure the sensitivity of the questions. Fourthly, although part of the ethical conduct of research involves explaining your role, the purpose of the research, the bounds of confidentiality, how the data will be stored, what will happen with the results and how they will be used I tried to dedicate extra time to highlighting these points.

However, I soon realised that I had been naïve in assuming that explaining my role and the purpose of the research would help to put people at ease. Communicating both points was more complicated than I had anticipated, particularly in the context of varying levels of English language proficiency. There was a wide range of previous experiences and cultural backgrounds amongst the participants and for some the idea of research was not familiar. This required me to provide a much fuller explanation of how and why I was conducting the study and to be careful to adapt my language to make my explanations meaningful. Although interviewing participants at the charity did seem to help people to trust me as they appeared to view me as an extension of the charity, at times this created further complications. The charity offers a range of support including psychological therapy, welfare support, social groups and medico-legal reports which meant that participants had often met a variety of staff with different roles. Explaining that I was working with, but not for, the charity, and was therefore not a member of staff, as well as that I was trainee clinical psychologist but not taking up a therapeutic role in this context, proved challenging. I felt it was important to make this distinction, not only for transparency, but also to enable participants to share negative experiences of the therapy. I quickly began to recognise the central importance that the charity had taken on in many of the participants' lives, as demonstrated by one participant's comment:

*"[service name] they have helped me from...when my solicitor referred me, they have been there for me you know. I feel with them, like you know, they're like that family I didn't have so, it was they that give the love I never had".*

I noticed that participants would often express high levels of gratitude towards the staff during the interviews and began to wonder if this might make it difficult for participants to talk about more disappointing and difficult aspects of their therapy for fear of seeming ungrateful and perhaps concern that I would share this with the charity. As I completed more interviews I modified my explanation of the research, emphasising that I was interested in both positive and negative aspects of their experiences in therapy and

outlining precisely the ways in which information would be feedback to the charity once the study was completed. Hynes (2003) suggests preparing a separate dissemination plan to provide to participants and I think this would have been helpful to increase clarity and confidence in sharing negative experiences.

### **Gaining informed consent.**

The difficulties in explaining my role and communicating the idea of research to some participants, alongside my observations of the gratitude expressed towards the service, further prompted me to reflect on the process of gaining informed consent from refugee and asylum-seeking people. The British Psychological Society's (BPS) code of human research ethics (2014) outlines that researchers should ensure that every person has freely consented to participation after considering adequately detailed information about the study. The guidelines also stress the importance of individuals not being coerced into participating and of recognising the role of power dynamics in relationships with vulnerable people within this process. The BPS suggests that "those in a dependent or unequal relationship" (BPS, 2014, p. 31) could be classed as vulnerable. By giving informed consent, normally through the signing of a formal consent form, the participant should be made aware of how to withdraw consent at any stage and how to formally complain about any adverse effects of the research. However, given refugee and asylum-seeking people often do not have access to the same resources and knowledge to protect their legal rights in host countries it has led some to question how feasible it would be for participants to raise concerns about research and hold researchers accountable (Hugman, Bartolomei & Pittaway, 2011).

While respecting that the terms "refugee" and "asylum-seeker" represents a huge number of people across the world in a vast variety of different situations, it could be argued that the political process of seeking asylum within the UK leaves people dependent

on, and vulnerable to, the decisions of the state. Given that owing to this broader political context most participants relied heavily on support from the charity, it raises the question of how easily people felt they could decline to participate in the research. In light of this, it would have been helpful to collect reasons for non-participation, although this too would have had to be sensitively done so as not to make people feel that they had to justify or defend their choices. Additionally, I could have formally re-confirmed consent at the end of each interview once participants knew what information they had shared (Josselson, 2013).

### **Researcher versus clinical role.**

There are similarities between research interviews and clinical interactions as they both involve core interpersonal skills such as eliciting information and listening, but there is also a need to consider the boundaries of the role of the researcher, and to not confuse this with a therapeutic role (Josselson, 2013). Josselson (2013) makes a distinction between the roles of therapy and research by suggesting that within a therapeutic relationship the individual approaches the therapist for help, whereas in research it is the researcher who is seeking help from the participant. I found this a helpful distinction to keep in mind during the interviews. I felt a certain freedom in purely trying to listen and hear the participants' stories without feeling responsible for supporting them towards an agreed therapeutic goal. Over time this helped me to develop confidence in being more flexible in my interviewing style and following up interesting comments or stories shared by participants, rather than sticking rigidity to the interview schedule (Smith, 1995). This allowed for aspects of experience which had not been incorporated into the interview schedule to be discussed; for example, the impact of the asylum process on therapy.

However, there were times during interviews where I found myself moving more towards a therapist role. From listening back to the interviews and reflecting on changes in my stance throughout I noticed this particularly happened when participants became

distressed or spoke about times when they had wanted to harm themselves. Although I did not ask direct questions about the past, all the participants had endured extremely traumatic circumstances and while explaining their experiences with therapy many referred to distressing past events. Initially I was concerned that my questions might be too upsetting or straying too far from the focus of evaluating their experience of receiving NET. However, I came to realise that worrying about participants showing distress was in part due to my fears of becoming upset during the interview myself, and underestimating participants' emotional resilience, as illustrated by a participant's comment about talking about her past experiences:

*There's no day I will discuss my life that I will not shed tears because my life is, was full of... something that can make me cry... Yeah because there are some things you ask me, that you might not know, it's a relief to me as well, though I have bad [memories] of it, which is remembering my son...but I'm still ok with it. Because to me, I now believe if I say something out and I will get someone who can make me laugh at the end, I'm ok.*

Josselson (2013) proposes that when the participants express significant emotional distress the researcher should primarily respond with humanity and empathy, and temporarily put aside the researcher role. In these instances, I aimed to respond with genuine empathy towards the participant, checked the person was still happy to continue the interview and afterwards discussed the impact on myself during supervision with the research team (Orb, Eisenhauer, & Wynaden, 2000).

### **Working with translators.**

Four of the interviews were conducted via a translator. There are various models of translation that can be employed within a research interview; for example, in some cases translators may aim for verbatim translation whereas in others they make take on more of the role of cultural broker and offer cultural and contextual information (Tribe & Lane, 2009). Concerns that researchers may have about the use of translators within interviews can be influenced by their epistemological position (Temple & Young, 2004). A researcher

who positions themselves within a realist perspective might employ methods such as back translation to verify the accuracy of the translation. Alternatively, a social constructivist researcher may be interested in the act of translation, how translators contribute to the production of the discourse and the co-construction of meaning.

Although I approached the research from a critical realist position I found it helpful to reflect on the power that the translators held within the interview process and how they chose to represent participants' experiences to me. All the participants that I interviewed alongside a translator had worked with the translator throughout their therapy and had built close relationships with them. The process of translation was complicated because some participants spoke English to a level which meant they sometimes answered my questions directly without using the translator. It was during these instances when I was able to speak both the translator and the participant directly that I began to feel that sometimes that the participant's experiences of therapy were being filtered through the interpreter's own understanding and memories of the process of the therapy. The below excerpt demonstrates one such time when a translator interrupted with the intention to correct a participant:

*Interviewer: When you first met her, when you think back to say your first session with her, what was that like? When you first came?*

*Participant: First time, like when I met her and we spoked, I was thinking this thing is not gonna change me, I say myself. You know we put something like, we talk about, how we start is always like, so amazing, you know? She put some line, like stones, something like this, and we starting to / [translator interrupts]*

*Translator: yeah he wanted to explain to you that one, she put string on the floor and then she is taking stones*

*Interviewer: the lifeline?*

*Participant: It's like yeah / [translator interrupts]*

*Translator: [starts laughing] sorry go on, go on, I shouldn't have said*

On reflection it would have been helpful to dedicate more time at the beginning of each session to discuss the role of the interpreter within the research and how this might

differ from translating in other circumstances (Tribe & Lane, 2009). If more funding for the project had been available, back translation of interviews could also have been used to check the fidelity of the translation.

### **Self-reflexivity**

Qualitative research aims to explore and understand people's subjective experiences, allowing for a more complex and nuanced description than quantitative measures may allow for. As the researcher is intrinsically involved in the process of qualitative research, their beliefs, assumptions and feelings about the research will influence how the data is collected and analysed (Barker, Pistrang & Elliott, 2016). To address this, qualitative researchers can engage in "reflexivity" or reflecting on and considering how their subjectivity has influenced and shaped the research process and findings (Fischer, 2009).

As outlined by Willig (2012), how qualitative researchers think about and make use of reflexivity within their research is influenced by their epistemological position. A researcher who takes a more realist position may use reflexivity to identify their hypotheses and assumptions about a research topic in order to put them to one side to minimise the impact or bias they might have on the collection and analysis of the data. Whereas a social constructivist researcher may feel they cannot be separated out from the process of the research and use reflexivity to analyse the interviews for the role they have taken in co-constructing the interview and how their responses have allowed or silenced certain aspects of the participant's experience. Within this research I took a critical realist position and therefore used reflexivity to consider how my own pre-existing assumptions were influencing the design of the study, the collection of the data and the analysis.

Willig (2013) further distinguishes reflexivity into two interrelated types: epistemological and personal reflexivity. Epistemological reflexivity relates to the

assumptions that the researcher has about what kind of knowledge can be gained, the ways to go about obtaining this information and how this impacts the construction of the research questions. Personal reflexivity focuses on how the researcher's experiences, values and aims have influenced the research, as well as how the researcher has been changed and influenced by conducting the research.

### **Epistemological reflexivity**

I approached the research from a critical realist position; I felt that qualitative methods would allow me to gather data which would tell me something about participants' experiences, while recognising that this would not be a straightforward rendition of what had happened. In relation to the research topic, I felt that it was important to evaluate individual's experiences of Narrative Exposure Therapy (NET) as I believed their voices and opinions could provide valuable clinical knowledge. However, I simultaneously recognised that participants may not be fully aware of the influences that impacted their reactions or feelings throughout therapy, and that this might limit how much I could learn about the mechanisms of change within the therapy. I therefore decided to approach the research interviews from an evaluative perspective, hoping to hear about participants' views of the acceptability and usefulness of the therapy. This influenced the focus of the questions within the interview schedule. In this way, my epistemological position influenced the content of the interviews and precluded somewhat from the outset an exploration of the connections the participants made between the experience of therapy and the outcomes of therapy.

Before starting the project, I had a theoretical understanding of trauma-focused interventions including NET and Ehlers and Clarke's (2000) model of trauma-focused Cognitive Behavioural Therapy (tfCBT). However, clinically I had only completed assessment for trauma-focused interventions, rather than delivering the therapy myself. During the

data collection I attempted to stay open and neutral towards participants' views and experiences of NET, "bracketing" and putting to one side my previous knowledge of the theory underlying trauma-focused interventions (Fischer, 2009). I noted my initial ideas and impressions after interviews and discussed these with my research supervisors.

During the data collection I felt that I was more able to focus on participant's descriptions of therapy without superimposing my own ideas or translating what they had said into my own theoretical framework. This became more challenging by the analysis stage as by this point I had begun a clinical placement in a specialist trauma service for refugee and asylum-seeking people. Providing both NET and tfCBT made it harder to approach the analysis from a neutral stance, although in some cases it aided my understanding. For example, initially I had been surprised that participants frequently mentioned learning grounding strategies as one of the most helpful parts of the therapy. From my theoretical knowledge this was not a part of NET and tfCBT and was more in line with a phased-based approach to treatment which might involve a period of stabilisation before starting the exposure-based intervention (Cloitre et al., 2012; Grey & Young, 2008). I wondered if people were talking about grounding strategies in the interviews because it was a practical intervention which was less emotive and easier to explain than the exposure-based elements of the therapy. I had read literature which reported that experiencing higher numbers of traumatic events is associated with increased numbers of re-experiencing symptoms, but I had no real sense of the frequency (Minihan, Liddell, Byrow, Bryant, & Nickerson, 2018). Despite some exploratory studies which used ecological momentary assessment to try to record re-experiencing symptoms associated with post-traumatic stress disorder (PTSD) in the general population I struggled to find literature exploring this within an asylum-seeking population (Kleim, Graham, Bryant & Ehlers, 2013; Kleindienst et al., 2017). However, once I started working with people who were struggling with these difficulties I began to realise the high quantity of flashbacks and nightmares that

people were experiencing. Recognising the extent of the impact of these experiences on their daily lives aided me in understanding participant's emphasis on the importance of learning grounding strategies. It also reminded me of the value of practice-based evidence and qualitative research in informing and contributing to quantitative research agendas; for example the growing argument that current standardised measures of PTSD have a ceiling effect which curtails meaningful measurement of re-experiencing symptoms in people who have experienced multiple and prolonged traumatic events (Priebe et al., 2013).

### **Personal reflexivity**

Throughout the research I also attempted to remain aware of the influences of my previous experiences and values, and how these might shape the development of the research. In particular I was aware that as a white British clinical psychology trainee my life experiences, educational background and cultural upbringing was very different to many of the participants. From reviewing the initial interviews, I noticed that participants often described their emotional experiences and interpersonal interactions using language which was quite removed from psychological terms; for example, describing the benefits of therapy enabling them to feel a sense of freedom, lightness or that their spirits were lifting. I had to be careful not to assume that I understood the meaning these descriptions held for participants and I noticed that sometimes I failed to ask follow-up questions. Reflecting on this, and recognising my concern about seeming disrespectful or challenging, helped me to overcome my avoidance of these questions during interviews, which hopefully lead to richer accounts of participants experiences with NET.

At other times during data collection and analysis it was helpful to bracket and remain aware of how my clinical work experiences influenced the research process. Before data collection I had worked clinically with one person with refugee status in the context of an adult mental health placement, although this had not involved exposure-based work.

This clinical experience was a very challenging piece of work due to high levels of mistrust and suicidality and had left a lasting impression on me. I was aware that I was therefore a little sceptical of how meaningful change might be achieved in a relatively short number of sessions and whether participants would be able to tolerate therapy. I became aware that during interviews I was particularly following up participants' comments about the positive outcomes and aspects of therapy. Initially I wondered whether this was because of my belief as a clinical psychology trainee that seeking therapy is a helpful way to address distress. However, on further consideration and through discussion with my research supervisors I recognised that it was not only this, but also my underlying scepticism. As a result of my doubt that NET would be helpful to participants given their extensive exposure to traumatic past events and ongoing instability due to pending asylum applications I was particularly interested in understanding how NET had been helpful. The consequence of this was that I found I was paying less attention to potential adverse effects of NET. Recognising how my reactions to participants' responses were shaping the direction of the interview was helpful in reminding me to try to pay equal attention to positive and negative aspects of participants' experiences.

Additionally, not only was the research shaped by my assumptions, beliefs and experiences, but I was also shaped by conducting the research. I noticed that throughout conducting the interviews I became more interested in how research can be used to inform policy-level change and the benefits of clinical psychologists working at a macro-level. Through listening to the participants' experiences, I became more certain that working at an individual level could only do so much to alleviate distress, which led me to question the value of the study given that it focused on evaluating an individual therapy. In light of this I became more focused on how to meaningfully disseminate the findings to widen the potential impact of the study and consulted a newly set up service user group at the charity for their views on how best to do this. This consultation encouraged me to learn more

about participatory action research frameworks as a way to meaningfully involve refugees and asylum-seeking people as partners in the research process and makes changes to clinical practice (Ellis, Kia-Keating, Yusuf, Lincoln & Nur, 2007; Löfman, Pelkonen, & Pietilä, 2004; Meyer, 2000). I wondered how my research questions and focus might have been different if I had consulted the service user group at the start of the process or worked alongside a co-researcher who had direct experience of seeking asylum in the UK or NET during the analysis phase. These reflections and initial introductions to partnership in research have made a lasting impression on me and will inform the way that I conduct future research, be it an empirical study or a service-based evaluation.

### References

- Barker, C., Pistrang, N., & Elliott, R. (2016). *Research methods in clinical psychology: An introduction for students and practitioners* (3rd ed.). Chichester: Wiley.
- Bögner, D., Brewin, C., & Herlihy, J. (2010). Refugees' experiences of Home Office interviews: a qualitative study on the disclosure of sensitive personal information. *Journal of Ethnic and Migration Studies*, 36, 519-535.
- British Psychological Society (BPS). (2014). Code of human research ethics. Retrieved on 20<sup>th</sup> June 2018 from [https://www1.bps.org.uk/system/files/Public%20files/inf180\\_web.pdf](https://www1.bps.org.uk/system/files/Public%20files/inf180_web.pdf)
- Cloitre, M., Courtois, C., Ford, J., Green, B., Alexander, P., Briere, J., ... Van der Hart, O. (2012). *The international society for traumatic stress studies (ISTSS) expert consensus treatment guidelines for complex PTSD in adults*. Retrieved on 10<sup>th</sup> June 2018 from [www.istss.org](http://www.istss.org).

- Ehlers, A., & Clark, D. M. (2000). A cognitive model of post-traumatic stress disorder. *Behaviour Research and Therapy, 38*, 319–345.
- Ellis, B., Kia-Keating, M., Yusuf, S., Lincoln, A., & Nur, A. (2007). Ethical research in refugee communities and the use of community participatory methods. *Transcultural Psychiatry, 44*, 459-481.
- Fischer, C. (2009). Bracketing in qualitative research: conceptual and practical matters. *Psychotherapy Research: Journal of the Society for Psychotherapy Research, 19*, 583–90.
- Grey, N., & Young, K. (2008). Cognitive Behaviour Therapy with refugees and asylum seekers experiencing traumatic stress symptoms. *Behavioural and Cognitive Psychotherapy, 36*, 3-19.
- Hugman, R., Bartolomei, L., & Pittaway, E. (2011). Human agency and the meaning of informed consent: reflections on research with refugees. *Journal of Refugee Studies, 24*, 655-671.
- Hynes, T. (2003). The issue of 'trust' and 'mistrust' in research with refugees: choices, caveats and considerations for researchers. *New Issues in Refugee Research, Working Paper No. 98 UNHCR*, Retrieved on 20<sup>th</sup> June <http://www.unhcr.org/3fcb5cee1.pdf>
- Josselson, R. (2013). *Interviewing for Qualitative Inquiry: A Relational Approach*. New York: The Guilford Press.
- Kleim, B., Graham, B., Bryant, R., & Ehlers, A. (2013). Capturing intrusive re-experiencing in trauma survivors' daily lives using ecological momentary assessment. *Journal of Abnormal Psychology, 122*, 998-1009.

- Kleindienst, N., Priebe, K., Petri, M., Hecht, A., Santangelo, P., Bohus, M., & Schulte-Herbrüggen, O. (2017) Trauma-related memories in PTSD after interpersonal violence: an ambulatory assessment study, *European Journal of Psychotraumatology*, 8, DOI: 10.1080/20008198.2017.1409062
- Löfman, P., Pelkonen, M., & Pietilä, A. (2004). Ethical issues in participatory action research. *Scandinavian Journal of Caring Sciences*, 18, 333-340.
- Meyer, J. (2000). Using qualitative methods in health related action research. *British Medical Journal*, 320, 178-181.
- Minihan, S., Liddell, B., Byrow, Y., Bryant, R., & Nickerson, A. (2018). Patterns and predictors of post-traumatic stress disorder in refugees: a latent class analysis. *Journal of Affective Disorders*, 232, 252-259.
- Orb, A., Eisenhaur, L., & Wynaden, D. (2000). Ethics in qualitative research. *Journal of Nursing Scholarship*, 33, 93-96.
- Priebe, K., Kleindienst, N., Zimmer, J., Koudela, S., EbnerPriemer, U., & Bohus, M. (2013). Frequency of intrusions and flashbacks in patients with post-traumatic stress disorder related to childhood sexual abuse: An electronic diary study. *Psychological Assessment*, 25, 1370–1376.
- Raghallaigh, M. (2014). The causes of mistrust amongst asylum seekers and refugees: Insights from research with unaccompanied asylum-seeking minors living in the Republic of Ireland. *Journal of Refugee Studies*, 27, 82-100.
- Smith, J. (1995). Semi-structured interview and qualitative analysis. In: Smith, J. A., Harre, R. and Langenhove, L. V. (Eds.). *Rethinking Methods in Psychology* (pp. 9-26). London: Sage.

Temple, B., & Young, A. (2004). Qualitative research and translation dilemmas. *Qualitative Research, 4*, 161-178.

Tribe, R., & Lane, P. (2009). Working with interpreters across language and culture in mental health. *Journal of Mental Health, 18*, 233-241.

Williams, A., & Van der Merwe, J. (2013). The psychological impact of torture. *British Journal of Pain, 7*, 101-106.

Willig, C. (2012). Perspectives on the epistemological bases for qualitative research. In H. Cooper (Ed.), *APA handbook of research methods in psychology: Vol. 1 Foundations, planning, measures and psychometrics* (pp.5-21). Washington, DC: American Psychological Association.

Willig, C. (2013). *Introducing qualitative research in psychology*. (2<sup>nd</sup> ed.) Berkshire: Open University Press.

**Appendix A:**

**Critical Appraisal Skills Programme Qualitative Research Checklist**

## **Critical Appraisal Skills Programme Qualitative Research Checklist (CASP, 2017).**

### **1. Was there a clear statement of the aims of the research?**

Consider:

- What was the goal of the research
- Why it was thought important
- Its relevance

### **2. Is a qualitative methodology appropriate?**

Consider:

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

### **3. Was the research design appropriate to address the aims of the research?**

Consider:

- If the researcher has justified the research design (E.g. have they discussed how they decided which method to use)

### **4. Was the recruitment strategy appropriate to the aims of the research?**

Consider:

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

### **5. Was the data collected in a way that addressed the research issue?**

Consider:

- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc)
- If the researcher has discussed saturation of data

### **6. Has the relationship between researcher and participants been adequately considered?**

Consider:

- If the researcher critically examined their own role, potential bias and influence during;
  - (a) Formulation of the research questions
  - (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

### **7. Have ethical issues been taken into consideration?**

Consider:

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

### **8. Was the data analysis sufficiently rigorous?**

Consider:

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

### **9. Is there a clear statement of findings?**

Consider:

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers' arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

### **10. How valuable is the research?**

Consider:

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

**Appendix B:**

**Contributions of included studies to the meta-synthesis analytic themes**

Table 5: Contribution of included studies to meta-synthesis analytic themes

| Meta-synthesis analytic themes  | Most relevant themes or sub-themes from the original included studies   |
|---|---|
| <b>1. Individuals' conception of their difficulties</b>                               |   |
| <i>Barriers</i>   |   |
| 1.1 Socio-political and spiritual conception leads to community and spiritual support | <p><b>Evidence from 15 studies</b></p> <p><i>Behnia, 2004:</i> Use of formal mental health services; Community Peer Groups</p> <p><i>Bernardes et al., 2011:</i> How to improve mental health? Recommendations for service; Coping strategies to tackle mental health needs</p> <p><i>Bettman et al., 2011:</i> Non-medical treatments for mental illness; Causes of Mental Illness; Spirit Possession Causing Mental Illness; Qur'an as Treatment for Mental Illness</p> <p><i>Carroll, 2004:</i> Murug; Gini</p> <p><i>De Anstiss &amp; Ziaian, 2010:</i> Low priority placed on mental health; Cross-cultural differences in explanatory models</p> <p><i>Ellis et al., 2010:</i> Friends and School as Gateway Providers: Connecting or Disconnecting to Mental Health Services; Identification of Need: Community Talk</p> <p><i>Fazel, 2016:</i> Impact of the asylum application process</p> <p><i>Kokanvoic et al., 2008:</i> Somali and Ethiopian participants' accounts of 'depression'; What helps people to recover from depression? - Somali and Ethiopian accounts</p> <p><i>Maier &amp; Straub, 2011:</i> Sociocultural depravity; Attribution of Suffering to Earlier Trauma vs. Current Living Conditions; Concepts of Illness</p> <p><i>Markova &amp; Sandal, 2016:</i> Explanatory model of depression; Personality/psychological causes; Social support; Religious or supernatural practices; Supernatural, religious or traditional causes</p> <p><i>Omar et al., 2017:</i> Family support; Faith-based treatment</p> <p><i>Palmer &amp; Ward, 2007:</i> Alleviating distress; Emotional and practical support</p> <p><i>Shannon et al., 2015:</i> Talking Does Not Help</p> <p><i>Valibhoy et al., 2017:</i> Explanatory models</p> <p><i>Whittaker et al., 2005:</i> Family and community; Services; Navigation and acculturation; Secrets; Religion</p> |
| 1.2 Young people prefer to seek support from friends                                  | <p><b>Evidence from 5 studies</b></p> <p><i>De Anstiss &amp; Ziaian, 2010:</i> Informal help-seeking; Formal help-seeking</p> <p><i>Ellis et al., 2010:</i> Identification of Need: Community Talk; Identification of Need: Youth; Friends and School as Gateway Providers: Connecting or Disconnecting to Mental Health Services</p>   |

|  |   |
|--|---|
|  | <p><i>Fazel, 2016: Impressions of receiving a mental health service in the school location</i></p> <p><i>Valibhoy et al., 2017: Explanatory models; Need for autonomy</i></p> <p><i>Whittaker et al., 2005: Confidentiality and trust</i></p>   |
| 1.3 Lack of familiarity with Western conception of mental health | <p><b>Evidence from 10 studies</b></p> <p><i>Carroll, 2004: Causes of mental illness</i></p> <p><i>De Anstiss &amp; Ziaian, 2010: Mental health and service knowledge; Stigma and misconception</i></p> <p><i>Ellis et al., 2010: Friends and School as Gateway Providers: Connecting or Disconnecting to Mental Health Services</i></p> <p><i>Kokanvoic et al., 2008: Somali and Ethiopian participants' accounts of 'depression'</i></p> <p><i>Majumder et al., 2015: Descriptions of mental health; Opinions of treatments</i></p> <p><i>Markova &amp; Sandal, 2016: Explanatory model of depression</i></p> <p><i>Palmer &amp; Ward, 2007: Conceptions of mental health</i></p> <p><i>Posselt et al., 2017: Access and engagement</i></p> <p><i>Shannon et al., 2015: Lack of Knowledge About Mental Health</i></p> <p><i>Valibhoy et al., 2017: Stigma</i></p>   |
| <i>Facilitators</i>  |   |
| 1.4 Familiarity with Western conception of mental health         | <p><b>Evidence from 14 studies</b></p> <p><i>Behnia, 2004: Use of formal mental health services</i></p> <p><i>Bernardes et al., 2011: How to improve mental health? Recommendations for services</i></p> <p><i>Bettman et al, 2015: Description of Mental Illness; Medical Treatments for Mental Illness</i></p> <p><i>Carroll, 2004: Murug; Waali</i></p> <p><i>Ellis et al., 2010: Identification of Need: Youth</i></p> <p><i>Fazel, 2016: Understanding of and impressions of the therapeutic intervention received; How therapeutic intervention helped the individuals seen</i></p> <p><i>Kokanvoic et al., 2008: Somali and Ethiopian participants' accounts of 'depression'</i></p> <p><i>Maier &amp; Straub, 2011: Scientific–technical concept; Treatment Expectations; Attitudes Toward Medical Treatment, Especially Medication; Concepts About the Treatment Process</i></p> <p><i>Majumder et al., 2015: Descriptions of mental health; Opinions of treatments; Experiences of using services</i></p> <p><i>Markova &amp; Sandal, 2016: Explanatory model of depression; Biological causes; Bio-medical treatment</i></p> <p><i>Omar et al., 2017: Intergenerational differences in traditional practices</i></p> <p><i>Palmer &amp; Ward, 2007: Talking therapies; Alleviating distress</i></p> <p><i>Valibhoy et al., 2017: Explanatory models; Need for autonomy</i></p> |

## 2. Beliefs about the social meaning and consequences of having mental health difficulties

### Barriers

2.1 Mental health difficulties mean you are “crazy”

#### **Evidence from 14 studies**

*Behnia, 2004*: Use of formal mental health services

*Bernardes et al., 2011*: Experiences of social and health services in the UK

*Bettman, et al., 2015*: Description of Mental Illness; Stigma of Mental Illness; Non-Medical Treatments for Mental Illness;

*Carroll, 2004*: Murug; Waali; Gini

*De Anstiss & Ziaian, 2010*: Mental health and service knowledge; Stigma and misconception

*Ellis et al., 2010*: Friends and School as Gateway Providers: Connecting or Disconnecting to Mental Health Services;

Identification of Need: Youth

*Fazel, 2016*: Impressions of receiving a mental health service in the school location

*Maier & Straub, 2011*: Knowledge About Psychotherapy as a Treatment Modality

*Majumder et al., 2015*: Descriptions of mental health; Experiences of using services

*Omar et al., 2017*: Definition of mental illness

*Palmer & Ward, 2007*: Conceptions of mental health

*Posselt et al., 2017*: Organisational and structural barriers; Access and engagement

*Shannon et al., 2015*: Fear of being seen as “crazy”; Fear of alienation from the community.

*Valibhoy et al., 2017*: Unfamiliarity with existence of services or thresholds for entering; services; Stigma; Need for autonomy; Explanatory models

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2.2 Fear of community gossip and rejection leads to denial and concealment

#### **Evidence from 10 studies**

*De Anstiss & Ziaian, 2010*: Informal help-seeking; Formal help-seeking; Trust and distrust; Stigma and misconception; Family Privacy

*Ellis et al., 2010*: Identification of Need: Community Talk; Identification of Need: Youth; Friends and School as Gateway Providers: Connecting or Disconnecting to Mental Health Services

*Fazel, 2016*: Impressions of receiving a mental health service in the school location; How therapeutic intervention helped the individuals seen

*Majumder et al., 2015*: Descriptions of mental health; Experiences of using services

*Omar et al., 2017*: Lack of mental health literacy

*Palmer & Ward, 2007*: Immigration; Confidentiality and stigma; Suggestions for improvements

*Posselt et al., 2017*: Access and engagement; Treatment and service delivery

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|   |   |
|---|---|
|   | <p><i>Shannon et al., 2015</i>: Fear of being seen as “crazy”; Fear of alienation from the community; Loss of job or housing; Culture</p> <p><i>Valibhoy et al., 2017</i>: Stigma; Need for autonomy</p> <p><i>Whittaker et al., 2005</i>: ‘Get on with it’ approach; Family and community; Services; Concealing concepts and emotions; Confidentiality and trust</p>   |
| <i>Facilitators</i>                                       |   |
| 2.3. Community will care for you                          | <p><b>Evidence from 1 study</b></p> <p><i>Bettman, et al., 2015</i>: Stigma of mental illness; Causes of mental illness</p>   |
| 2.4 Talking to professionals protects from gossip         | <p><b>Evidence from 2 studies</b></p> <p><i>Carroll, 2004</i>: Murug</p> <p><i>Whittaker et al., 2015</i>: Services</p>   |
| <b>3. Existing knowledge and expectations of services</b> |   |
| <i>Barriers</i>   |   |
| 3.1 Lack of knowledge of services                         | <p><b>Evidence from 10 studies</b></p> <p><i>Behnia, 2004</i>: Use of formal mental health services</p> <p><i>Bettman et al, 2015</i>: Medical Treatments for Mental Illness</p> <p><i>De Anstiss &amp; Ziaian, 2010</i>: Mental health and service knowledge</p> <p><i>Maier &amp; Straub, 2011</i>: Treatment Expectations; Concepts About the Treatment Process; Knowledge About Psychotherapy as a Treatment Modality; Additional Medical and Nonmedical Service Utilization</p> <p><i>Majumder et al., 2015</i>: Opinions of treatments</p> <p><i>Markova &amp; Sandal, 2016</i>: Psychological treatment</p> <p><i>Posselt et al., 2017</i>: Organisational and structural barriers; Access and engagement</p> <p><i>Shannon et al., 2015</i>: Lack of Knowledge About Mental Health</p> <p><i>Valibhoy et al., 2017</i>: Unfamiliarity with existence of services or thresholds for entering services</p> <p><i>Whittaker et al., 2005</i>: Services</p> |
| 3.3 Services are not culturally appropriate               | <p><b>Evidence from 9 studies</b></p> <p><i>Behnia, 2004</i>: Use of formal mental health services</p> <p><i>Bettman et al., 2015</i>: Non-Medical Treatments for Mental Illness</p> <p><i>De Anstiss &amp; Ziaian, 2010</i>: Trust and distrust; Formal help-seeking</p> <p><i>Ellis et al., 2010</i>: Friends and School as Gateway Providers: Connecting or Disconnecting to Mental Health Services:</p> <p><i>Kokanvoic et al., 2008</i>: What helps people to recover from depression? - Somali and Ethiopian accounts</p> <p><i>Omar et al., 2017</i>: Lack of mental health literacy</p>   |

|  |  |
|--|--|
|  | <p><i>Posselt et al., 2017</i>: Access and engagement; Training and resources</p> <p><i>Valibhoy et al., 2017</i>: Explanatory models; Negative expectations about receiving help from mental health professionals</p> <p><i>Whittaker et al., 2005</i>: Services</p>  |
| 3.4 Fears of hospitalisation and forced medication   | <p><b>Evidence from 6 studies</b></p> <p><i>Bettman et al., 2015</i>: Medical Treatments for mental illness</p> <p><i>Maier &amp; Straub, 2011</i>: Chronological concept</p> <p><i>Majumder et al., 2015</i>: Descriptions of mental health</p> <p><i>Omar et al, 2017</i>: Lack of mental health literacy</p> <p><i>Shannon et al., 2015</i>: History of political repression can render refugees speechless; Fear of being hospitalized; Fear that there are no effective treatments; Talking does not help; Avoidance of symptoms</p> <p><i>Valibhoy et al., 2017</i>: Negative expectations about receiving help from mental health professionals</p>   |
| 3.5 Discrimination against refugees                  | <p><b>Evidence from 3 studies</b></p> <p><i>Bernardes et al., 2011</i>: Experiences of social and health services in the UK</p> <p><i>Posselt et al., 2017</i>: Access and engagement</p> <p><i>Whittaker et al., 2005</i>: Services</p>   |
| 3.6 Talking about the past has negative consequences | <p><b>Evidence from 6 studies</b></p> <p><i>De Anstiss &amp; Ziaian, 2010</i>: Stigma and misconception</p> <p><i>Fazel, 2016</i>: Understanding of and impressions of the therapeutic intervention received</p> <p><i>Maier &amp; Straub, 2011</i>: Chronological concept; Concepts about the treatment process; Expectations concerning treatment outcomes</p> <p><i>Palmer &amp; Ward, 2007</i>: Talking therapies</p> <p><i>Shannon et al., 2015</i>: History of political repression can render refugees speechless; Fear of being hospitalized; Fear that there are no effective treatments; talking does not help; avoidance of symptoms</p> <p><i>Valibhoy et al., 2017</i>: Negative expectations about receiving help from mental health professionals</p> |
| 3.8 Practical concerns take priority                 | <p><b>Evidence from 10 studies</b></p> <p><i>Benhia, 2004</i>: Use of formal mental health services</p> <p><i>Bernardes et al., 2011</i>: Experiences of social and health services in the UK; How to improve mental health? Recommendations for services</p> <p><i>Fazel, 2016</i>: Impact of the asylum application process</p> <p><i>Kokanvoic et al.,2008</i>: What helps people to recover from depression? - Somali and Ethiopian accounts</p> <p><i>Maier &amp; Straub, 2011</i>: Treatment Expectations</p>  |

|   |   |
|---|---|
|   | <p><i>Omar et al., 2017: Lack of mental health literacy</i><br/> <i>Palmer &amp; Ward, 2007: Alleviating distress; Talking therapies; Suggestions for improvements</i><br/> <i>Posselt et al., 2017: Treatment and service delivery</i><br/> <i>Valibhoy et al., 2017: Explanatory models</i><br/> <i>Whittaker et al., 2005: Services</i></p>  |
| <i>Facilitators</i>   |   |
| 3.2 Services available in country of origin                     | <p><b>Evidence from 2 studies</b><br/> <i>Bettman et al., 2015: Medical Treatments for Mental Illness</i><br/> <i>Maier &amp; Straub, 2011: Concepts of Illness; Knowledge About Psychotherapy as a Treatment Modality</i></p>  |
| 3.7 Services can help distress                                  | <p><b>Evidence from 8 studies</b><br/> <i>Behnia, 2004: Use of formal mental health services</i><br/> <i>Bernardes et al., 2011: Coping strategies to tackle mental health needs; How to improve mental health? Recommendations for services</i><br/> <i>Carroll, 2004: Murug</i><br/> <i>Maier &amp; Straub, 2011: Expectations Concerning Treatment Outcomes; Attitudes Toward Medical Treatment, Especially Medication</i><br/> <i>Majumder et al., 2015: Opinions of treatments</i><br/> <i>Markova &amp; Sandal, 2016: Psychological treatment</i><br/> <i>Palmer &amp; Ward, 2007: Talking therapies</i><br/> <i>Whittaker et al., 2005: Services</i></p> |
| 3.9 Professionals engaging with practical concerns builds trust | <p><b>Evidence from 2 studies</b><br/> <i>Fazel, 2016: Impact of the asylum application process</i><br/> <i>Posselt et al., 2017: Treatment and service delivery</i></p>  |
| <b>4. Trust in services and beliefs about professionals</b>     |   |
| <i>Barriers</i>   |   |
| 4.1 Impact of political oppression                              | <p><b>Evidence from 5 studies</b><br/> <i>Behnia, 2004: Use of formal mental health services</i><br/> <i>Majumder et al., 2015: Experiences of using services</i><br/> <i>Posselt et al., 2017: Access and engagement</i><br/> <i>Shannon et al., 2015: Fear of spies or lack of confidentiality; Talking does not help</i></p>   |

*Vaibhoy et al., 2017*: Stigma; Negative expectations about receiving help from mental health professionals; Structural obstacles to accessing services; Host society socio-political context

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4.3 Professionals do not care or understand

**Evidence from 7 studies**

*Behnia, 2004*: Use of formal mental health services

*Bernardes et al., 2011*: Experiences of social and health services in the UK

*De Anstiss & Ziaian, 2010*: Trust and mistrust

*Majumder et al., 2015*: Experiences of using services

*Posselt et al., 2017*: Access and engagement; Training and resources

*Shannon et al., 2015*: Talking does not help

*Valibhoy et al., 2017*: Negative expectations about receiving help from mental health professionals; Structural obstacles to accessing services

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4.5 Concerns about confidentiality

**Evidence from 6 studies**

*Bernardes et al., 2011*: Experiences of social and health services in the UK

*De Anstiss & Ziaian, 2010*: Trust and distrust

*Palmer & Ward, 2007*: Confidentiality and stigma; Suggestions for improvements

*Posselt et al., 2017*: Access and engagement

*Shannon et al., 2015*: Fears of spies or lack of confidentiality

*Valibhoy et al., 2017*: Stigma; Negative expectations about receiving help from mental health professionals; Host society socio-political context

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*Facilitators*

4.2 Schools can be a trusted environment

**Evidence from 2 studies**

*Ellis et al., 2010*: Friends and School as Gateway Providers: Connecting or Disconnecting to Mental Health Services

*Fazel, 2016*: Impressions of receiving a mental health service in the school location

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4.4 Feeling safe and understood

**Evidence from 8 studies**

*Behnia, 2004*: Use of formal mental health services

*Bernardes et al., 2011*: Experiences of social and health services in the UK; How to improve mental health? Recommendations for services

*De Anstiss & Ziaian, 2010*: Trust and distrust

*Fazel, 2016*: How therapeutic intervention helped the individuals seen

*Majumder et al., 2015*: Experiences of using services

*Posselt et al., 2017*: Training and resources

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|  |   |
|--|---|
|  | <i>Valibhoy et al., 2017: Stigma; Negative expectations about receiving help from mental health professionals</i><br><i>Whittaker, et al., 2005: Services</i>   |
| 4.6 Considering the cultural background of professionals | <b>Evidence from 3 studies</b><br><i>De Anstiss &amp; Ziaian, 2010: Trust and mistrust</i><br><i>Kokanvoic et al., 2008: What helps people to recover from depression?— Somali and Ethiopian accounts</i><br><i>Palmer &amp; Ward, 2007: Suggestions for improvements</i>   |
| <b>5. Service delivery</b>                               |   |
| <i>Barriers</i>  |   |
| 5.1 Service related barriers                             | <b>Evidence from 6 studies</b><br><i>Bernardes et al., 2011: Experiences of social and health services in the UK</i><br><i>Bettman et al., 2015: Medical treatments for mental illness</i><br><i>Palmer &amp; Ward, 2007: Referrals, access and waiting time</i><br><i>Posselt et al., 2017: Access and engagement; Treatment and service delivery</i><br><i>Valibhoy et al., 2017: Structural obstacles to accessing services</i><br><i>Whittaker et al., 2005: Services</i> |
| <i>Facilitators</i>                                      |   |
| 5.2. Increasing accessibility                            | <b>Evidence from 2 studies</b><br><i>Palmer &amp; Ward, 2007: Suggestions for improvements</i><br><i>Posselt et al., 2017: Treatment and service delivery</i>   |

**Appendix C:**

**Letter of ethical approval from UCL Research Ethics Committee**



31<sup>st</sup> October 2016

Professor Chris Barker  
Research Department of Clinical, Educational and Health Psychology  
UCL

Dear Professor Barker

**Notification of Ethical Approval**

**Re: Ethics Application 9713/001: Clients' experience and outcomes of undergoing Narrative Exposure Therapy. A mixed methods study.**

Further to your satisfactory responses to the committee's comments, I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the REC until **30<sup>th</sup> September 2018**.

Approval is subject to the following conditions.

1. You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form': <http://ethics.grad.ucl.ac.uk/responsibilities.php>
2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator ([ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.
3. For non-serious adverse events the Chair or Vice-Chair of the Ethics Committee should again be notified via the Ethics Committee Administrator ([ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)) within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Yours sincerely



**Professor John Foreman**  
Chair, UCL Research Ethics Committee

Cc: Francesca Cicconi

Academic Services, 1-19 Torrington Place (9<sup>th</sup> Floor),  
University College London  
Tel: +44 (0)20 3108 8216  
Email: [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)  
<http://ethics.grad.ucl.ac.uk/>

**Appendix D:**

**Participant information sheet**



## **Clients' experience of Narrative Exposure Therapy:**

### **Information Sheet for Participants**

We would like to invite you to participate in this research study. You should only participate if you want to. Before you decide whether you want to take part, it is important for you to understand why the research is taking place and what it will involve.

Please take time to read the information and discuss it with others if you wish.

Please ask us if there is anything that is not clear or if you would like more information.

#### **What is this study about?**

Narrative Exposure Therapy is a talking therapy designed to help people who are experiencing distressing memories, flashbacks and nightmares after traumatic events. We would like to find out about people's experiences of receiving the therapy. We are interested in hearing from both people who find the therapy helpful, and people who do not find the therapy helpful. We hope that this research will help us understand how best to support people who have had traumatic experiences.

#### **Who is conducting this study?**

The study is being conducted by Francesca Cicconi, a Trainee Clinical Psychologist, who is currently completing an academic course at University College London. This study will form part of this academic course (Doctorate in Clinical Psychology).

#### **Who can take part?**

We are inviting anyone who is currently receiving therapy at the [the service], or has finished therapy up to three months ago, to take part.

#### **What does taking part involve?**

If you decide to take part in this study, you will be given a copy of this information sheet to keep and you will be asked to sign a consent form. We will invite you to take part in an interview one month after the end of your therapy. This will last up to 60 minutes and can be arranged at a time which is convenient for you. During the interview we will ask you some questions about your experiences of the therapy and what you found helpful and unhelpful.

We are also interested in hearing from people who decide to finish therapy earlier than expected. If this happens we would like to send out a short questionnaire for you to complete via email or post with a stamped addressed envelope so that you can send this back to us. You do not have to complete this questionnaire if you don't want to.

Deciding to take part in this study will not influence the support you receive from the [the service] in any way, and you will be able to join or leave your therapy at any time, just like you would if you were not taking part in this study.

### **Will I be recorded and how will the recordings be used?**

With your permission, we will audio-record the interview so that we do not miss anything important that you say. The audio-recordings will be transcribed and all identifying information will be removed. No one outside of the research team will be allowed access to the original recordings. Once the study is complete the original recordings will be destroyed. During the study the original recordings will be stored electronically and protected through password and encryption.

When the study is written up for publication quotations from your interview may be included, but any quotations used will have all personally identifiable information removed to make them anonymous so it will not be possible to identify you. Any further presentations or publications resulting from the study may include anonymous quotations.

### **What are the risks and benefits of taking part?**

It is possible that you will find it upsetting to talk about your experiences of therapy. If this happens you can take a break, or stop the interview at any time. You will not have to answer any questions you do not feel comfortable answering. You may find talking about your experiences interesting, giving you the chance to reflect on your therapy and what you took away from it. We hope that the information we learn from the study will give us more understanding of how and why the therapy is helpful and what could be done differently to make sure that it is as useful for as many people as possible.

### **Confidentiality and anonymity**

The interview will be confidential. The answers that you give to the interview questions will not be shared with your health care team unless you or someone else is deemed to be at risk. If answering the questions makes you aware of a problem you should tell your GP or therapist at the [the service].

The data will be collected and stored in accordance with the Data Protection Act 1998. Electronic data will be encrypted and password protected.

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

The results of the study will be written up as part of the researcher's Doctorate in Clinical Psychology at University College London and may also be submitted for publication in a scientific journal and presented at conferences. These written documents may include quotations from your interview, but any quotations used will have all personally identifiable information removed to make them anonymous. It will not be possible to identify you from the quotations. A summary of the results will be sent to everyone who participated in the study. We hope that the findings of this study will help us understand how best to support people who have experienced traumatic events, and how to reduce their distress and improve their quality of life.

### **What do I do now?**

If you would like to take part in this study or if you have any questions, please contact the researcher, Francesca Cicconi, by email (email address).

You do not have to take part in this study if you do not want to. If you decide to take part, you are still free to withdraw at any time without giving a reason, and this will not affect the support you receive from [the service].

Thank you for reading this information sheet. If you have any questions or comments, please contact:

Francesca Cicconi

Prof. Chris Barker

Researcher

Principal investigator

[email]

[email]

[phone number]

[details of lead clinicians at the service]

This study has been approved by the UCL Research Ethics Committee (Project ID Number: 9713/001)

**Appendix E:**

**Participant consent forms**



**Consent form for participation in the  
“Clients’ experience of Narrative Exposure Therapy” study**

Thank you for considering taking part in this study.

Please complete this form after you have read the Information Sheet and listened to an explanation of the study. If you have any questions about the study, please ask the researcher before deciding whether to take part. You will be given a copy of this consent form to keep and refer to at any time.

|   | Please initial |
|---|----------------|
| I confirm that I have read and understood the information sheet provided for this study.  |                |
| I have had the opportunity to read and consider the information sheet and to ask any questions.   |                |
| I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and that this will not affect the support I receive from [the service].   |                |
| I consent to the processing of my personal information for the purposes of this research study. I understand that the information will be treated as confidential and handled in accordance with the provisions of the UK Data Protection Act 1998. |                |
| I understand that the answers I give to the interview questions will not be shared with my health care team unless I or someone else is deemed to be at risk.   |                |
| I understand that anonymised quotations from the study may be subject to review by academic staff at University College London as required as the study forms part of the Clinical Psychology Doctorate course.                                     |                |
| I agree to take part in the above study.  |                |

Name of researcher.....

Signature of researcher.....

Date:

Name of participant.....

Signature of participant.....

Date:



**Consent form for recording the interview as part of  
“Clients’ experience of Narrative Exposure Therapy” study**

Thank you for considering taking part in this study.

Please complete this form after you have read the Information Sheet and listened to an explanation of the study. If you have any questions about the study or the recording, please ask the researcher before deciding whether to take part. You will be given a copy of this consent form to keep and refer to at any time.

|   | Please initial |
|---|----------------|
| I confirm that I have read and understood the information sheet provided for this study.  |                |
| I have had the opportunity to read and consider the information sheet and to ask any questions about recording.   |                |
| I consent to my interview being audio recorded and the use of the recordings for the purpose of this study.   |                |
| I understand that my comments from the interview may be reported in quotations within the final report of the study or later publications, but in an anonymous way so that it will not be possible to identify me.                                  |                |
| I understand that the recording of the interview will be held confidentially, and not shared with any person outside of the study.  |                |
| I consent to the processing of my personal information for the purposes of this research study. I understand that the information will be treated as confidential and handled in accordance with the provisions of the UK Data Protection Act 1998. |                |
| I understand that anonymised quotations from the study may be subject to review by academic staff at University College London as required as the study forms part of the Clinical Psychology Doctorate course.                                     |                |
| I agree to the recording of my interview.   |                |

Name of researcher.....

Signature of researcher.....

Date:

Name of participant.....

Signature of participant.....

Date:

## **Appendix F:**

### **Semi-structured interview schedule**

## **Clients' experience of undergoing NET:**

### **Semi-Structured Interview Schedule**

Note to interviewer: prompts are suggestions only and can be omitted

#### **Introduction**

I am going to be asking you some questions about your experience of Narrative Exposure Therapy at the [the service]. The interview should last up to one hour.

If you would like to stop or take a break at any point please let me know. Similarly, if there are any questions you would prefer not to answer, let me know and we can skip that question.

Do you have any questions?

Are you happy to start the interview now?

#### **Overview of the therapy**

**1) How have you been feeling since your therapy ended?**

**2) Overall, what was the therapy like for you?**

#### **Before starting therapy**

**3) What made you decide to start therapy?**

Prompts:

- What made you decide to have therapy now (as opposed to another time)?
- Whose idea was it for you to start therapy?
- Did you talk to anyone about whether or not to start therapy?

**4) What were you told about therapy?**

Prompts:

- Who told you?
- When did they tell you?
- How did they tell you? Written information?
- Was this helpful/unhelpful?

**5) How were you feeling before your therapy started?**

#### **Perception of talking therapies**

**6) Have you had therapy before?**

Prompts:

- Could you describe what it was like?
- Was it helpful/unhelpful?
- In what ways?
- What was it like compared to NET?

**7) What did you think about therapy before you started your sessions?**

Prompts:

- How did you think it could help you?
- What did you think it would involve?
- Did you have any concerns about starting therapy?

**8) Did you tell anyone (friend/partner/member of your community) about starting therapy?**

Prompts:

- Why/why not?
- Do you know anybody else who has had therapy?
- What did you think other people would think about you starting therapy? Has this changed?
- If you were having these difficulties in {home country}, who would you have seen/told?

**Outcomes of NET**

**9) What changes, bad or good, have you noticed in yourself and your difficulties since finishing your therapy sessions?**

Prompts:

- What has been the biggest change?
- How important was the change to you?
- How has this affected your life?
- Was the change what you expected to happen?
- When did the change occur?
- Did anything change in a way that you weren't expecting?
- Have you noticed any changes in your thoughts, feelings, what you are doing?
- Relationships with others?

**10) Is there anything you would have liked to change after therapy that hasn't changed?**

Prompts:

- How important is this change to you?
- How would this affected your life?

**Helpful/unhelpful aspects of NET**

**11) What was the most helpful part of your therapy?**

Prompts:

- What difference did it make to you?
- Was there any particular therapy session which was more helpful than others?

**12) What was the most unhelpful part of your therapy?**

Prompts:

- What difference did it make to you?
- Was there any particular therapy session which was more unhelpful than others?

**13) Can you tell me about anything during the therapy sessions which was difficult?**

Prompts:

- Was there anything that helped you to cope with this?
- Friends/Family/Religion/Values?
- How did this help you? In what ways?
- Were you able to tell your therapist how you felt about it? Was this helpful?

**14) Can you tell me a little bit about any times when you thought about stopping therapy?**

Prompts:

- What helped you to keep coming to therapy?
- What influenced your decision?
- Did you discuss this with your therapist?
- Was there anything that the therapist did that helped you to continue?

**15) How did you feel when the therapist explained the therapy would involve talking about your past experiences? (Experience of exposure)**

Prompts:

- Did you have any concerns about it?
- Were you able to tell your therapist how you felt about it?
- How easy/difficult?
- Anything that made you feel more comfortable to talk?
- Anything that stopped you from talking?
- Were there things that felt too difficult to tell your therapist?

**16) What was it like when the therapist read your experiences back to you? (Narrative element of therapy)**

Prompts:

- Helpful/unhelpful?
- In what ways? Did it change anything for you? How?
- What did you think/feel when the therapist first explained they would be reading out your account?
- Did you have any concerns about it?
- Were you able to tell your therapist how you felt about it?

### **Therapeutic alliance**

#### **17) Can you tell me a little bit about what your therapist was like?**

Prompts:

- What was your first impression/feelings about your therapist?
- Did this change in any way over the course of your therapy?
- Were there things that the therapist did that made them more/less helpful?
- Were there things that you would have liked therapist to do differently?
- What qualities do you think are important in a therapist?
- Did you feel able to give feedback to your therapist?

#### **18) Was talking to your therapist different/similar to talking to other people?**

Prompts:

- Other professionals?
- friends, family, other people from your community?
- In what ways?
- Helpful/unhelpful?

### **Sources of support outside of therapy**

#### **19) Can you tell me a little bit about any activities you have been doing outside of therapy which help you to cope with your difficulties? (e.g Study/socialising/religion/attending groups/work)**

Prompts:

- Do you find this helps you to cope with your difficulties?
- In what ways? How does this help?
- Unhelpful? In what way?
- How do they help?

### **Ending of the interview**

#### **20) Would you recommend NET to a friend or family member?**

Prompts:

- How would you describe the therapy to them?
- Is there any reason why you would not recommend the therapy to someone?

#### **Is there anything else you would like to tell me about your experience of NET that we have not covered in the interview today?**

We have now finished the interview, thank you for agreeing to take part and making time to attend today.

Do you have any comments or questions on the interview, or the research in general?

After the project is completed, would you like to receive a summary of the findings of the research? What would be the best way to send a summary to you?

## **Appendix G:**

### **Illustration of the stages of analysis**

Table G1: Example of analysis of an extract from one transcript

| Extract   | Initial notes  | Coding   | Domain and theme   |
|---|--|--|--|
| <p>I: It sounds like what she did is really listen to what was important to you [P: yeah], and remind you of what you were working towards?</p> <p>P: Yeah</p> <p>I: And kind of focus in on that.</p> <p>P: Yeah, the more important [I: mm]. Like she say, you will talk today, you will remember this today, yeah it will difficult for you for a few days just, in the end you will move on, and you will get what you really want [I: mm]. So it's kind of like for the child, you know [I: yeah] if you are going to eat this one, you will get a toy [I: yeah]. Same things it was for me [I: yeah]. So she find a way, that one which, after finish session I was surprise myself how how she make me [P: laughing].</p> <p>I: Really? What at the, do you mean after you finished all the sessions or after you finished those sessions which were really hard?</p> <p>P: Those those days because when I was, come, like some days I was cancel therapy, I couldn't come [I: mm]. I was crying, I was depressing at home [I: mm]. And er I did, end of the January I did suicide, I take all those medications [I: yeah]. It was...difficult and er just, still some days I could manage to came here [I: mm] just since when I come out from the house it was in my mind, I don't wanna talk. Whatever she gonna say, I'm not going to talk [I: you're not going to talk, ok] yeah. Believe me, I was coming like that. I was convince myself I'm not going to talk [I: mm]. When we finished therapy I'm going home, and just thinking, how she make me talk? [P: laughing].</p> <p>I: How did she get you to change your mind, yeah.</p> | <p>Therapeutic relationship<br/>Therapist encouraging to disclose</p> <p>Cancelling<br/>Feeling unable to attend</p> <p>Didn't want to talk in therapy</p> | <p>Therapist was encouraging</p> <p>Initially didn't want to talk about the past</p> <p>Thinking about not attending to avoid being distressed</p> <p>Initially didn't want to talk about the past</p> | <p>Process: Trust and the therapeutic relationship</p> <p>Process: overcoming the hardship of telling my story</p> |

|   |   |   |   |
|---|---|---|---|
| <p>P: And I was just like, I kind of, I feel better you know? When I, I even say for her like, when we finished therapy I feel relaxed like you know, like something very heavy was in my heart, in my chest, I couldn't breathe, it's gone [I: mm]. You know, it it was getting better and better and easy and easy every each session I feel better [I: mm]. When I came home I was like my brain started working like back up you know [I: mm]. Everything what we was talking just keep coming in my mind, you know. What was happening, how it was happening, I was just keep remembering, it's coming in that, in that point it was getting for me difficult you know [I: yeah]. I would start crying, I would I don't wanna eat, I would keep, like you know tired, I feel like my whole body in the pain, even though I didn't do nothing, was feeling my whole body in pain, like I get it so tired. Just we was working the breathing, the exercise. I try do breathing exercise. What was the most helpful for me, it's um smell different like she was putting in the office aroma, and then mints, like er different aroma oil [I: mm-hm]. I have at home aroma er candles [I: mm]. So it was helpful for me to change mind, to come out from the house, to breathe like, to to move on like you know. Just it was taking me time. From beginning it was very difficult sometimes was taking for me weeks to work out that information which was we remember with what we was talking. Now, it's easy. One, two days I cry, and then I'm good [P: laughing].</p> <p>I: Ok [P: yeah]. So over time the amount of time that you would be upset after the sessions [P: yeah] got less and less?</p> <p>P: yes [I: yeah]. Get less and less and more easy to me to like before I couldn't say like, I couldn't name of the, what was happening with me [I: mm mm]. Now I could say like, yeah, they they raped me they abused me for three four months around [I: yeah]. Before, I couldn't I couldn't say it, she was just saying to name it. She say for me, name it what was happen, how it was happen. She say doesn't matter which kind of name it's gonna be just name it how you feel it, ok [I: mm]. I couldn't name it. I couldn't open my mouth. I couldn't say it [I: yeah]. It was, very horrible for me to go this whole all the through just step by step, now she gone, I cannot be without her [I: mm]. I need her. And I'm really kind of lost because it's</p> | <p>Feeling some relief after talking in therapy</p> <p>Finding it hard to cope between sessions</p> <p>Using techniques at home to try to help self</p> <p>It gets easier</p> <p>Hard to put words to experiences</p> <p>Naming abuse</p> <p>Feeling loss of therapist and relationship</p> | <p>Gradually started to feel better</p> <p>Feeling worse after sessions</p> <p>Talking in therapy brought back memories</p> <p>Grounding strategies helped to manage at home &amp; in session</p> <p>Gradually talking in therapy got easier</p> <p>Being able to name the abuse</p> <p>Feeling lost after the end of therapy</p> | <p>Process: overcoming the hardship of telling my story</p> <p>Outcomes: Reducing the impact of the trauma: learning to manage</p> <p>Process: Trust and the therapeutic relationship</p> |
|---|---|---|---|

|  |  |   |   |
|--|--|---|---|
| <p>end so fast, for me.</p> <p>I: Yeah it felt so rushed. And what difference does it make, do you think, for you that, now that you have had some sessions, that you are able to say, put a name to certain things that have happened to you. What difference does that make do you think?</p> <p>P: it's make like different in my mind, you know. [I: mm]. I'm I'm taking this information much easy from before. Before I'm I don't wanna say it [I: mm], I don't wanna name it, I don't wanna like think about it you know? Now, yeah I don't wanna think about it by now, like I don't wanna think about it, I don't wanna...I don't wanna this event follow me [I: no]. So when I name it, when I start talk about her and she tried to like kind of understand and support me you know, it make for me easy you know. It wasn't making for me that much difficult or bad you know. I was always like, it very bad I cannot take this, it's destroying my life, it's destroying everything around me, I lose, I lose everything because of this [I: mm]. Yes I did just now it's make me something like you know to believe I can walk out from this one you know [I: mm]. I can get it something better instead. [I: yeah yeah] So I don't know like, she made this way you know so it kind of would change my mind about to to talk about this much easier.</p> | <p>Finished therapy in a rush</p> <p>Not wanting to think about the past</p> <p>Therapist's approach made it easier</p> <p>Feeling moving forwards is possible</p> | <p>Talking about the past was hard<br/>Didn't want to remember the past</p> <p>Feeling understood</p> <p>Reducing impact of past on the present</p> <p>Feeling life can be better in the future</p> | <p>Process: overcoming the hardship of telling my story</p> <p>Process: Trust and the therapeutic relationship</p> <p>Outcomes: Reducing the impact of the trauma: learning to manage</p> |
|--|--|---|---|

Table G2: Example of codes in the theme: Moving forward: "I'm heading for a better life"

| Codes   | Example for each code from the transcripts  |
|---|---|
| <ul style="list-style-type: none"> <li>• More hopeful for the future</li> </ul>           | <p>P: I was as well I was a really low mood and er I couldn't imagine, even I was I was even thinking like I'm disabled I'm not gonna work anymore [l:mm] and er after this therapy ah I feel like, yes I can do something yeah.</p>  |
| <ul style="list-style-type: none"> <li>• Attending groups at the service</li> </ul>       | <p>P: yeah like um I am in here, at [service name] I am part of the community group [l: mm]<br/>           I: were you doing that before you started therapy, the community group?<br/>           P: no</p>   |
| <ul style="list-style-type: none"> <li>• Able to cook for myself again</li> </ul>         | <p>P: Before I was couldn't even cook properly you know, I was, what was make me happy I couldn't, if I cook I cook by force like because I have to do it and I didn't enjoy the food, and now again I start enjoying my food.</p>  |
| <ul style="list-style-type: none"> <li>• Looking after self-care</li> </ul>               | <p>P: I'm cutting my hair, I'm shaving and I wash my clothes. I wear, um um these days I am wearing nice clothes, I think so. Because I'm I'm, already I have these things but there there was no interest in those things before</p>   |
| <ul style="list-style-type: none"> <li>• Going out walking</li> </ul>                     | <p>P: These days I go for a walk in the morning and afternoon. I used to stay in room, now I walk for, good for me, go to park</p>  |
| <ul style="list-style-type: none"> <li>• Keeping myself busy &amp; doing more</li> </ul>  | <p>I: yeah. So what kinds of things are you doing now at home?<br/>           P: like in the morning when I wake up then I do some relaxing, do shower, cleaning [l: mm-hm] play with my children, yeah, like make myself more busy</p>   |
| <ul style="list-style-type: none"> <li>• Feeling more confident</li> </ul>                | <p>P: she helped me to, you know to build my confidence, and I can manage to go out, to do certain things</p>   |
| <ul style="list-style-type: none"> <li>• Able to interact more with people now</li> </ul> | <p>P: The fact that I can interact with other people, so, it's like um, I'm feeling like I'm a bit comfortable because I've got company [l: mm] company and then, I can still see that people still find some interest talking to me as well, or staying with me</p>  |
| <ul style="list-style-type: none"> <li>• Being able to make friends</li> </ul>            | <p>P: Yeah you know at college, ah, I can't speak people like this, I'm little bit like shy, and I can speak now at college, like I had er friends there</p>  |
| <ul style="list-style-type: none"> <li>• Becoming a "normal" person</li> </ul>            | <p>P: I scared all the time , I stay inside, squeeze myself, lock the door, and don't go and see outside and only go for my food even if no one is in the kitchen only I go and eat my food and come to room, and it's not like, like, you know you can understand. Now it's not like that, I just becoming normal person</p> |

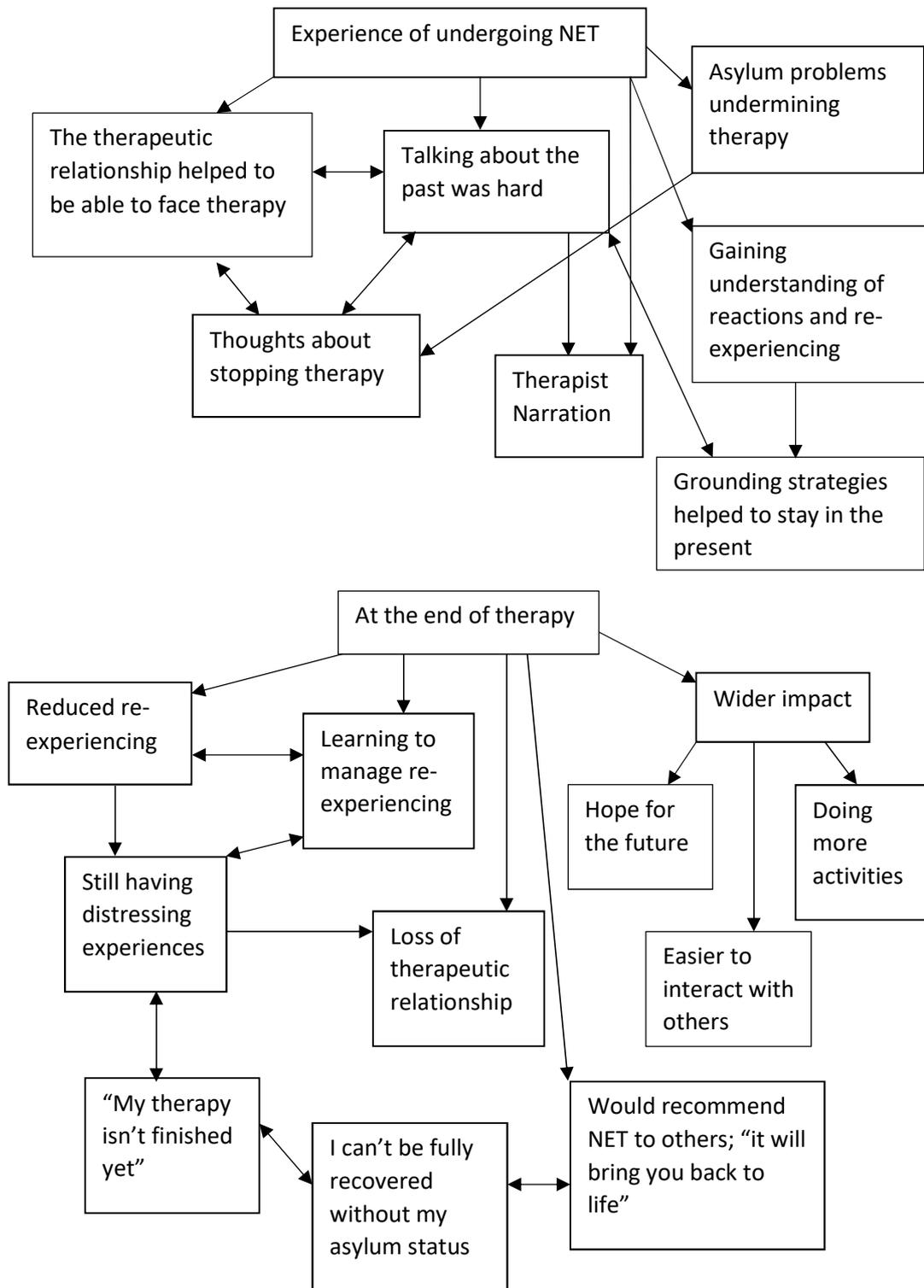


Figure G1: Initial map of themes and the connections between them