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A participatory study of patient views on psychotherapy for complex post-traumatic stress disorder, CPTSD

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ABSTRACT

Background: A new diagnosis of Complex Post-traumatic Stress Disorder, CPTSD, is included in ICD-11 which was adopted in May 2019 by the World Health Organisation, WHO. In addition to the symptoms of PTSD, CPTSD includes emotional dysregulation, negative self-concept, and disturbances in relationships. It may be a helpful diagnosis for trauma survivors with experiences of human mistreatment such as torture and abuse.

Aims: This study explores the views of patients in the community on psychotherapy for the diagnosis of CPTSD, taking a qualitative, participatory approach.

Method: Twenty-four former patients from an NHS secondary mental health service in London interviewed each other about their treatment. Participants also collaborated in data analysis. All had a diagnosis of PTSD, with additional symptoms of CPTSD identified at assessment.

Results: The key factor in recovery was rebuilding relationships, beginning with the therapist. Groupwork was helpful in promoting relationships with others, as it may result in shame reduction. Involvement in the wider community through peer support groups was also valuable.

Conclusions: The rebuilding of relationships based on trust was an active mechanism of change and recovery from CPTSD. Participants felt that sufficient time, at least one year of psychotherapy with weekly sessions, was needed.

Introduction

There have long been concerns about the effectiveness of PTSD treatment for people with more complex histories, such as those with experiences of war, torture, childhood abuse and other human mistreatment (Cloitre, 2015; Herman, 1992; Steenkamp et al., 2015). The new diagnosis of Complex PTSD, now included in ICD-11, was formulated with such patients in mind. As well as the core PTSD symptoms of re-experiencing, avoidance and hyperarousal, which may be experienced after a single trauma such as a traffic accident, CPTSD is characterized by additional symptoms of emotional dysregulation, negative self-concept, and interpersonal difficulties.

Given that CPTSD is a new diagnosis, this is an opportune time to study patient views on psychotherapy for CPTSD, especially since there is a lively controversy among clinicians about what kind of psychotherapy might be helpful. A special issue of the American Psychological Association's journal 'Psychotherapy' in 2019 (Norcross & Wampold, 2019) was devoted to critiques of the Association's new Clinical Practice Guideline on PTSD (APA, 2017) due to its contested focus on the biomedical model at the expense of clinical expertise, and patient characteristics and preference.

As there are few studies yet of psychotherapy for CPTSD, indirect evidence may be gained from the views of those who have received psychotherapy for a PTSD diagnosis, while also experiencing the additional symptoms which would now be diagnosed as CPTSD.

Herman, who first used the term "complex PTSD" in her seminal book (1992), recommended a phased approach which many clinicians have adopted in therapy for abuse survivors (Classen et al., 2001; Cloitre et al., 2010; Fallot & Harris, 2002). It includes stabilisation techniques to manage disturbing symptoms, as well as help with social re-integration to follow trauma-focused work.

The literature on psychotherapy for refugees (Tribe et al., 2019) often mentions practical and social factors such as immigration status, housing need, and coping with loss of family and home, as obstacles to engaging in trauma therapy, and advocates either adapted modalities (Hinton & Good, 2016; Schauer et al., 2011) or psychosocial interventions (Pointon, 2005).

Some research groups have recently reiterated the call for stand-alone trauma-focused treatment, arguing that it provides good outcomes for CPTSD (De Jongh et al., 2016; Ter Heide et al., 2016). Confronting trauma directly through talking, visualising it, writing about it or being exposed to it, is seen as crucial. Theoretical models underlying this

research come largely from cognitive and behavioural perspectives (Brewin, 2014; Foa et al., 1989). The adaptive approach, however, includes as a theoretical underpinning the significance of disrupted attachment which may result from interpersonal trauma (De Zulueta, 2006). Interpersonal trauma exposure in childhood "tends to be more toxic", according to Karatzias et al. (2019, p. 6).

This study was implemented as part of a professional doctorate by a psychotherapist (first author) who wanted to research what kind of psychotherapy was most useful to patients in the service she ran. The aim was to explore patient views on psychotherapy for CPTSD. A separate paper explores whether participation in research can promote recovery for people with CPTSD (Matheson & Weightman, 2019).

Method

The setting

The study was done in the London borough of Lewisham which has a population of 303,536. It is one of the most ethnically diverse in the UK with 46.4% of the population from a black, Asian or minority ethnic background (Lewisham Borough Council, 2018) and there are high levels of multi-dimensional poverty (Lewisham Poverty Commission, 2017).

The study was led by a clinician (first author) in a secondary mental health team at an outpatient unit at University Hospital Lewisham. The team is run by the South London and Maudsley NHS Mental Health Foundation Trust, SLaM. It accepted an average of 378 referrals a year (2012–2017) of which 75 were allocated to the trauma service. As patients with core PTSD are expected to be treated in primary care, most trauma referrals had CPTSD symptoms.

The patients

The majority of patients fall into two groups: those who have been tortured, and those who have been abused as children. The first group are refugees or asylum seekers, with the largest number from Sri Lanka: 122 referrals in the last six years (2012–2018). Other countries of origin include Afghanistan, Iran, Iraq, Turkey, Nigeria, and Democratic Republic of Congo.

The second group includes mostly women (with occasional referrals of men) who have been sexually abused in childhood in the UK, although some have immigrated from countries such as Nigeria and Jamaica.

Adapted psychotherapy models

Both trauma-focused therapy and a range of adapted psychotherapy models have been provided by the team to treat CPTSD. These include women's groups for those with a history of childhood abuse (Fallot & Harris, 2002), and men's groups for Sri Lankan Tamil men which includes horticultural activities (Pointon, 2005). Individual modalities included: Eye Movement Desensitisation and Reprocessing (EMDR), trauma-focused Cognitive Behavioural Therapy (tf-CBT), Narrative Exposure Therapy, (NET), individual systemic and psychodynamic psychotherapy. A peer support service offered group activities, including gardening, arts and crafts, and social outings.

Participatory approach

The study took a participatory approach informed by theories from liberation psychology (Martín-Baró et al., 1994), as well as community-based participatory research (Gaventa & Cornwall, 2001). A more specific literature on patient involvement in research (Brett et al., 2014; Frost et al., 2018; Gillard et al., 2012; Greenhalgh et al., 2019) was informative, as was recent literature by those who have used mental health services themselves (Rose, 2003; Rose et al., 2006) and Springham et al. (2011). These writers describe various methods of patient participation including consultation where patients advise on research aims and design; collaboration where they work with clinicians and researchers, or take the lead in design and research implementation

The literature on participatory research in health divides methods into three categories: user-led research, collaboration and consultation (Nierse et al., 2012; Trivedi & Wykes, 2002). This study comes under collaboration between service users and professionals. This involved recruiting and training former patients to pilot interview questions, carry out interviews and participate in data analysis. Researchers were paid £10 an hour but other participants were not paid.

Ethical approval for the study (17/LO/1391) was obtained from the Westminster NHS Research Ethics Committee on 12/9/2017. In our study the main reason for taking a participatory approach was to privilege the subjective experiences of patients in the context of a professional debate about psychotherapy for the new diagnosis of CPTSD. A secondary aim of the approach was to contribute to recovery through boosting confidence and skills.

Participants

Participants were selected chronologically from a total of 235 referrals to the trauma service between 2014 and 2017, beginning with those most recently discharged. A letter of invitation and an information sheet were sent out to 69 former patients, followed up by phone calls.

Selection criteria were:

- Completed at least 12 sessions of therapy
- More than 12 weeks since end of therapy
- Currently resident in Lewisham

There were two exclusion criteria: patients in treatment with other teams or patients too unwell to participate as advised by the clinician who had treated them, or by the

patients themselves. One person was excluded on these grounds.

There were two categories of participants in the study: those recruited to participate in the research design, data collection and analysis, and those recruited to be interviewed about their experiences of treatment. In total, a purposive sample of 24 former patients took part, of whom six had a researcher role.

Researcher selection and training

In addition to the criteria for participants above, there were two extra criteria for researchers: not in employment and adequate English for researcher training.

Training was first given by the psychotherapist (first author) in interview techniques, use of digital recorders; and obtaining informed consent. The researchers implemented a pilot of the semi-structured interview and agreed changes. The questions included queries about emotional health, stabilisation techniques, the usefulness of talking about trauma, views on different modalities, changes to self-concept and interpersonal relationships, and views on other activities beyond therapy (yoga, gardening, arts and crafts). At this training the researchers decided to interview each other first to ensure their views were included. A seventh service user attended this training, but withdrew without giving a reason.

A second training session was then provided for service user researchers by the Trust Volunteer Co-ordinator in the ethics of patient care including safeguarding and confidentiality. They completed the necessary police checks for working with vulnerable people and assumed a formal role as NHS Volunteers.

Participant sociodemographic data

Gender & sexuality: 14 women and 10 men (gender at birth) took part in the study. There were two homosexual participants and one transgender participant.

Age: Average age of the participants was 45.5 years.

Ethnic origins & language: Nineteen of the 24 participants were of Black, Asian or minority ethnic origin. This may reflect the origins of some of those with Complex PTSD who came from global conflict areas such as Sri Lanka (four people) and the Democratic Republic of Congo, DRC, (three people). There were also four women who came from Jamaica, or had a parent who did, reflecting immigration patterns into the UK.

Treatment length and modality: Treatment length varied from 12 sessions to 74 sessions with an average of 36.5 sessions. Twelve out of the 24 participants had attended groups, with one having additional individual sessions, and 12 had individual treatment only. A summary of participant sociodemographic data is shown in Table 1 below.

Data collection

The researchers conducted 24 individual interviews, beginning with each other, in an outpatient unit at University Hospital Lewisham. A translator was provided if needed. The psychotherapist contacted researchers and participants to agree interview times. She arranged rooms, provided digital recorders and organised transcription of the interviews. There were three group feedback meetings between the researchers and the clinician after interview sessions. This was to provide emotional containment from peer support and clinician, as well as to ensure adherence to procedures. Researchers did a varying number of interviews according to their availability.

Table 1. Characteristics of participants ($n = 24$).

Participant ID	Gender	Age	Ethnic origins	First language	Number of sessions	Type of therapy
Researcher 1.	Female	55	Black British	English	60	Women's group
Researcher 2.	Female	40	Middle Eastern/British	Arabic/English	45	Women's group & individual
Researcher 3.	Female	57	White British	English	35	Women's group
Researcher 4.	Withdrew					
Researcher 5.	Male	71	Latin American	Spanish	17	NET
Researcher 6.	Female	40	Black British	English	60	Women's group
Researcher 7.	Male	40	Congolese	Lingala/French	74	EMDR
Patient A	Female	43	White British	English	45	EMDR
Patient B	Female	37	Vietnamese	Vietnamese	44	NET
Patient C	Female	44	Somali	Swahili	22	Systemic
Patient D	Female	51	Black British	English	46	Women's group
Patient E	Male	33	Sri Lankan	Tamil	24	Men's group
Patient F	Male	24	Sri Lankan	Tamil	30	Men's group
Patient G	Female	47	Black British	English	38	Women's group
Patient H	Male	61	Kurdish/Syrian	Kurdish/Arabic	24	NET
Patient J	Male	51	Sri Lankan	Tamil	18	Men's group
Patient K	Male	27	Sri Lankan	Tamil	21	Men's group
Patient L	Female	45	Japanese	Japanese	43	Women's group
Patient M	Female	63	White British	English	12	EMDR
Patient N	Male	57	Congolese	Lingala/French	60	Systemic
Patient O	Female	28	White British	English	22	Systemic
Patient P	Male	43	Spanish	Spanish	50	EMDR
Patient Q	Female	47	Ugandan	Luganda	21	CBT
Patient R	Female	29	Congolese	Kinyarwanda/French	41	EMDR
Patient S	Male	59	White British	English	24	Integrative

EMDR: Eye Movement Desensitization and Reprocessing; NET: Narrative Exposure Therapy; CBT: Cognitive Behavioural Therapy.

Data analysis-stage 1

After the interview transcripts were completed, a data analysis meeting with the researchers agreed themes for analysis. They had been sent transcripts of interviews they had done themselves and their own interview. The clinician asked researchers to answer two questions:

- What were the most important points people made about their treatment?
- What were the points most often mentioned?

The meeting had some similarities to a focus group which is intended to decrease the power and control of the organiser (Smithson, 2008).

Data analysis-stage 2

The clinician recorded and transcribed the data analysis meeting. Following the codes identified by the researchers, she searched the interview transcripts and analysis meeting to create nodes in NVivo (Braun & Clarke, 2006). For example, researchers selected the theme "trust', so the clinician searched transcripts for opinions on trust including words with similar meanings. The main criterion was relevance to the research question. Separate coding by clinical researchers and service user researchers (Sweeney et al., 2013) was considered but we decided that coding by the researchers was the method more in keeping with the aim of highlighting patient views.

Data analysis-stage 3

It was not possible to hold a second data analysis meeting with researchers for validation. Some of the researchers had struggled to attend for health reasons, both mental and physical. Instead, the clinician recorded and transcribed the data analysis meeting and enlisted academic colleagues in a seminar group at the University of (anon) to study the transcript for validation of themes she had identified as selected by the researchers.

Analysis

Summary of results

The clinician generated an initial thematic table (Table 2 below) showing the six themes selected by the researchers as the most important or most frequent points made by participants, with the number of mentions.

After consideration of the initial analysis, the clinician felt it reflected more accurately the researchers' conceptualisation to group the themes into a matrix where the themes of trust, time and anger were applied to different levels of relationship where this was applicable. (These words are in bold italics in the findings below.) She then refined the thematic analysis according to these cross-cutting themes in Table 3.

Relationship with therapist

Establishing ***trust*** in the relationship with the therapist was identified as the most crucial factor in recovery for a number of patients. This was initially because it enabled people to talk about their trauma which was experienced as healing: a "release" and a "relief". Subsequently, it was also the foundation for rebuilding all other relationships because suspicion and mistrust of others had been a near universal symptom. In the findings which follow, the type of therapy experienced by participants is in brackets, if not in the text.

Patient Q (individual psychodynamic therapy), who had been persecuted in Uganda for being homosexual, described the relationship as 'like the roots', because the therapist was the first person she had been able to talk to openly, and once she had done so, she did not feel so scared of others. She said:

> I was not ***trust*** anybody in the world … and I think everybody who gonna be close to me was gonna kill me … If I didn't tell her [the therapist], I couldn't get more improvement … I started to love people, to ***trust*** people.

Researcher 7 (EMDR individual therapy), who was imprisoned in Congo for political activities, agreed with the significance of forming ***trust*** in the relationship with the therapist:

> If someone come for therapy, the therapist have to help people because we face problem to ***trust*** in people. They have to work on it and give us, as a trauma people, the ***trust***. When someone

Table 2. Themes selected by researchers and number of interviewees who mentioned them.

Themes	No. of patients	Illustrative quotations
Relationship with therapist	14	I worked with [the therapist] for a year and probably for the first 5 months it felt really dangerous to be in a relationship with her (Patient A, individual EMDR therapy)
Relationship with group	15	Once I felt more comfortable & confident within the group, the group was definitely far better than talking to a single person … (Researcher 3, women's group)
Relationship with community	24	I can socialise more now without feeling panicky or thinking that I am going to be attacked or something (Patient P, EMDR individual therapy)
Trust	9	We face problem to trust in people. When someone trust you … he can open his mind and start to tell you the things he's facing … (Researcher 7, EMDR & psychodynamic therapy)
Time	8	It's too much to ask, we are gonna get you ready in one year after 35 years of craziness … (Patient P, individual EMDR therapy)
Anger	5	In the beginning of the group therapy, I had so much rage in me, I could have beaten a baby with a cricket bat to death (Researcher 1, women's group).

EMDR: Eye Movement Desensitization and Reprocessing.

Relationship levels	Themes		
Relationship with therapist	Trust	Time	
Relationships in group	Trust	Time	
Relationships in community	Trust	Time	Anger

trusts you, he can open his mind and start to tell you the things he's facing.

Enabling patients to confront their trauma was seen as vital for recovery by most people, including some asylum seekers:

> I was keeping everything to myself so that was like another torture, like I was feeling very down and also felt [like] committing suicide at the time, but after talking to someone and letting it out, I felt better … (Patient E, refugee group)

Relationships in group

Establishing *trust* with others in group therapy was an important factor in recovery for a number of patients as it was a prerequisite for sharing experiences, which reduced shame, and feelings of being alone. A number of people said they had felt anxious or ashamed initially and had concerns about confidentiality and what others would think of them:

> At first I was embarrassed because … I wanted to talk, but in order to talk I had to talk in the group where I was telling my story to others. Obviously they're going to tell their stories to me, but …I did feel a bit embarrassed them knowing about all the awful things that I'd gone through even though …but after a while it was OK because there was a sort of bonding…a sort of relief that, OK, it's not only you, there are others (Researcher 1, women's group).

One of the groups offered was only for Sri Lankan Tamil men, who were mostly asylum seekers, and this promoted a social network for some patients:

> [The therapist] organised a group which has got a lot of Tamil people in it, so it helped us and then it made us realise that, OK, I am not being alone like some other people, it is like family and I have got a lot of friends from the group … (Patient K, refugee group).

Eight patients mentioned the importance of *time* for recovery in psychotherapy, and those who took part in groups were particularly vocal about it not being long enough. Several mentioned that the traumatic events they had experienced in childhood had gone on for some years. Patient D. (women's group) said:

> The therapy has really helped, but I need more because I am just open, you know when you get that blast and you see that mushroom cloud, I am like the mushroom cloud it hasn't dissipated yet … my trauma happened when I was from the age of 5…so to not haven't spoken about that at all until the age I am now, I am in my fifties.

Patients also talked about the ending of therapy being very difficult for them and one participant was highly critical of the lack of follow-up support:

> When the therapy stops, poof, that's it! And it's my biggest bugbear with it because it's just like, don't worry, if you start feeling bad again, go to your GP and they'll do a referral. Some people, it's taken them years for them to go to their GP … they're bringing out this complex trauma, but don't just do it as therapy in a room or a one-to-one, expand people's opportunity to help themselves a bit more (Researcher 1, women's group).

Relationships in the community

While the research was directed at exploring patient views on psychotherapy for Complex PTSD, there was also an opportunity to comment on other activities in peer support groups.

Eight people talked about how they felt scared and suspicious, even "paranoid" about other people in general. Patients who had been subjected to life-threatening physical assaults had obvious difficulties with *trust* such as Patient Q (individual psychodynamic therapy): "Before I don't *trust* people and I feel I hate everybody. I'm so sorry. But now I started to be close to people, people they show me they are … not all bad, but some good".

Time was again an important theme for rebuilding wider relationships, based on initial gains in *trust* and confidence in group and/or individual psychotherapy. A 71-year-old man who had been maltreated as an infant, then tortured by a military government, described it like this:

> I still working to be better, but I think it needs to have more *time,* and the more *time* giving the group, with the art, the writing group, because in them we are a big family, we know each other, we know the problem we have brought before. And that is good for me (Researcher 5, individual NET therapy).

Anger and irritability with other people was an obstacle to recovery mentioned by six people. Two people identified an increase in their own confidence as enabling them to control *anger*:

> I feel like now I'm putting the *anger* and blame where it's supposed to be put so (laughs) how are my feelings towards other people? Well, maybe with some people it's more negative than others? But I think that's just part of the process, part of the healing and getting better. In terms of friendships I think that's improved because I'm now able to speak my mind, my opinions, lay down my boundaries, say no (Researcher 2, women's group).

Discussion

Patient views in the context of debate on CPTSD psychotherapy

Patients' views on psychotherapy in this study provide support for a theoretical understanding of CPTSD based on attachment theory (Bowlby, 1969; De Zulueta, 2006; Schore, 2003) because patients emphasised that rebuilding relationships based on trust was the crucial process in psychotherapy. Some participants made a causal link: such rebuilding was necessary because interpersonal trauma had caused CPTSD. Researcher 2 concluded: "It's all about someone

doing something to someone, and then maybe that's the way out. It's getting back in through others … " This finding may be a valuable contribution to evidence for treatment guidelines for CPTSD.

The finding affirms the critique of current APA guidelines on PTSD by numerous clinicians such as Norcross and Wampold (2019), who describe "a huge paradox" (p. 3) in trauma treatment because, they assert, research funding is mainly directed towards evaluating different treatment methods, although it is the relationship with the therapist, and his/her responsiveness, which is central to healing.

Regarding patient views on how rebuilding relationships might be accomplished, the participants said it was vital to have enough time in psychotherapy to help them overcome difficulties in trusting others. At least one year (allowing for breaks and illness) was felt to be necessary. This has been questioned in a recent ongoing study where a number of therapists rotate in offering short-term intensive treatment (Van Minnen et al., 2018). By contrast, our study found that talking about trauma can be healing in the context of established relationships of trust, and that not talking could be like continuing torture.

Reflections on research approach

As the first author was psychotherapist or co-therapist for 17 of the 24 participants, we consider here how the research process and findings were influenced by this. One likely dynamic was unequal power relations. The implementation of interviews by former patients with other patients was intended to address such inequality, as well as to elicit more authentic responses., as described by other researchers (Rose, 2003; Rose et al., 2006).

Some participants may have felt an obligation to take part in the research, particularly those who were refugees and others who had formed a strong transference relationship, seeing the therapist as a mother figure. This was a reason for stipulating that participants had finished therapy at least 12 weeks previously, to allow some time for therapy to be processed

The relationship between the psychotherapist and the researchers had further levels of complexity. At a practical level there was an overt exchange. Two researchers asked for help with housing, one needed a signature for her passport application and two others needed references for work. Such practical support had been agreed before the research began as it was one of the aims of the participatory approach that researchers would gain skills and capacity for recovery. Findings on this aspect of the study are reported elsewhere (Matheson & Weightman, 2019).

During training, the researchers were invited to contribute to design and decided that they would interview each other before going on to the other participants. Social desirability bias, where the participants may have felt obliged to give positive responses to researchers, was counteracted by training the researchers to ask open questions and elicit detailed responses (Bowling, 2014).

Considering the impact of the research relationships on findings, the most salient question is that of researcher bias: were the researchers influenced by the clinician in selection of themes? The clinician was explicit that the purpose of the study was to explore patients' views, and as a number of different kinds of therapy were on offer, she was expecting both negative and positive feedback. In fact, the researchers' selection of themes did not follow the professional agenda of the clinician, for example, whether a phased approach was useful in comparison to trauma-focused work alone. Although the findings contained much positive feedback, there were also criticisms about lack of follow-up and inadequate time for therapy (see pp. 11–12).

We argue therefore that the participatory design of the study was effective in privileging patients' views. There were also advantages for the research process in the pre-existing relationship of trust (Liamputtong, 2007).

Limitations and future research

As patients in the study viewed social networks as significant for recovery, community re-integration as treatment merits further research, particularly since attachment relationships are understood to be vital for mental health (Seager, 2006).

Although the community setting was intended to promote greater research-to-practise generalisability, it would be useful to extend the research to other locations and participants. For example, it would be interesting to investigate how CPTSD symptoms manifest in Sri Lanka itself and how a different cultural setting may evoke different responses and solutions to distress.

Conclusion: clinical implications

This study of patients' views provides evidence for CPTSD treatment guidelines: the prerequisite for recovery is to rebuild relationships, which may be done in individual therapy, group therapy and the wider community with peer support. Sufficient time was needed to achieve the necessary trust and a minimum of one year was proposed. These findings have been contested in the literature (De Jongh et al., 2016; Van Minnen et al., 2018) and have not been previously been demonstrated in empirical research on patient views.

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