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ICD-11 Complex Post Traumatic Stress Disorder (CPTSD) in parents with perinatal bereavement: Implications for treatment and care

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Abstract

The 11th revision of the WHO International Classification of Diseases (ICD-11) has identified Complex PTSD (CPTSD) as a new condition.

Aim: To explore whether the new diagnosis of CPTSD (ICD11) is relevant to women who have experienced perinatal bereavement and to advance knowledge about the acceptability, feasibility and perceived impact of delivering an innovative flexible *Compassionate Focused Therapy (CFT) informed treatment package* to alleviate symptoms of this condition.

Methods: A mixed methods study using survey and interviews was conducted. Participants first completed the *International Trauma Questionnaire* (ITQ) to assess if they met the criteria for PTSD or CPTSD (n=72), and subsequent semi-structured interviews (n=12) identified participants' views about different treatment approaches.

Participants: A convenience sample of women who had experienced perinatal bereavement were recruited from one geographical region in Scotland.

Data collection: Information was gathered about trauma experiences related to perinatal bereavement; participants' levels of PTSD or CPTSD using the ITQ; and views regarding the features of treatment options. In-depth interviews with women (n=12) and a focus group with staff (n=5) were also conducted.

Findings: Of 74 participants (n=74) who fully completed the ITQ, 10.8% (n=8) met the criteria for PTSD and 29.7% (n=22) for CPTSD, equating to a total of 40.5% of participants experiencing traumatic stress. Results suggest that CPTSD is a more common condition than PTSD in people with perinatal bereavement, with qualitative data suggesting that CFT and EMDR can be useful and acceptable interventions for this population group.

Conclusion: A feasibility study is recommended next to evaluate acceptability of trial processes in preparation for a definitive randomised controlled trial of a new flexible *CFT informed treatment package* to address PTSD and CPTSD in people with perinatal bereavement.

Recommendations for practice: Routine assessment of ICD-11 CPTSD is recommended in this population group.

Key words: PTSD, Complex PTSD, midwives, perinatal bereavement, treatment

ICD-11 Complex Post Traumatic Stress Disorder (CPTSD) in parents with perinatal bereavement: Implications for treatment and care

Introduction

In the UK, 3,500 women experience trauma from perinatal bereavement each year (ONS, 2017), with examples including miscarriage, stillbirth, and neonatal death. The physical act of giving birth to a stillborn baby not only leads to natural forms of bereavement, but also can create more serious long-term mental health issues (Christiansen, 2017). In a systematic review by Christiansen et al. (2017), up to 39% of women who experienced perinatal bereavement went on to develop Post Traumatic Stress Disorder (PTSD), which can have devastating effects upon wellbeing and relationships with partner, family, and other children in the family. Despite the serious effects from developing PTSD post perinatal bereavement, currently there is lack of an NHS strategy to detect and treat the condition in this population group. As a consequence, many thousands of women experience ongoing symptoms from perinatal trauma (NICE, 2014, Brockington et al., 2017). Also, and of great importance, is the recent publication of the 11th revision of the WHO International Classification of Diseases (ICD-11) (WHO, 2018), which included a new condition called Complex PTSD (CPTSD) (Karatzias et al., 2019a). Acknowledging CPTSD as a new condition, our team identified the need to find out whether this new diagnosis is more common than PTSD amongst women who have experienced perinatal bereavement, before exploring whether CFT would be an acceptable and appropriate treatment in this context.

PTSD involves devastating responses to the perinatal trauma experienced, which can include behavioural changes, suicidal thoughts, replay of distressing memories**,** nightmares, and flashbacks**.** Together, these features can cause the woman to become irritable, socially avoidant, and easily startled, which can have profound effects on family members (Bromley et al., 2017). To add, a meta-analysis by Burden et al. (2016) analysed 144 studies about parental grief and concluded that loss from miscarriage, stillbirth, termination of pregnancy due to fetal anomaly, and neonatal death can create feelings of guilt, disenfranchisement, betrayal by one's body, and envy of others. As part of process, parents lose expectancy of future moments they visualised sharing with their baby (Michon et al., 2003), with few mementoes, none or few pictures, and a very short narrative (Flint, 2001), all of which can lower self-esteem (Wonch, 2017). What is clear, is

that PTSD co-existing with perinatal bereavement concludes in high rates of distress psychologically, emotionally, physiologically, and existentially (Hvidtjørn, 2018).

In the UK there is no current direct strategy for detecting and treating women who are experiencing PTSD or CPTSD post perinatal bereavement. Although there is a bereavement pathway in the majority of UK maternity units, care provision continues to be patchy and does not include screening for PTSD or CPTSD using the recommended *International Trauma Questionnaire* (ITQ) (Cloitre et al., 2018). The NHS Perinatal Institute (www.perinatal.nhs.uk/bereavement/standards.htm) currently promote that 5 standards should be followed:

(1) Each maternity unit exceeding 3000 births per year should have a trained Bereavement Support Specialist (BSS) dedicated to perinatal bereavement.

(2) Ongoing training for all staff involved in perinatal care.

(3) A dedicated room in the maternity unit should be available for bereaved parents.

(4) An information booklet should be provided to parents.

(5) Protocols/guidelines for bereavement care should be provided within maternity units.

In addition and at present, NHS commissioners across the UK do not provide specialist therapies for women who develop PTSD or CPTSD post death of their baby.

Women may need psychological therapy when grief is seriously interfering with their ability to manage everyday life. Examples of interventions may include person centred therapy, Cognitive Behavioural Therapy (CBT), Complicated Grief Therapy (CGT), psychotherapy, mindfulness, or straightforward skilled listening. There is a dearth of research that has evaluated effectiveness of treatments for PTSD and CPTSD post perinatal bereavement, probably because there are few organised detection and referral systems. Huberty et al. (2020) showed a significant decrease in PTSD symptoms post delivering online yoga to reduce PTSD in women who had experienced stillbirth. Navidian et al. (2017) found a statistically significant reduction in severity of PTSD symptoms in women who engaged with psychological grief counselling post stillbirth. No research reports on effectiveness of EMDR treatment for women diagnosed with PTSD post perinatal loss, and no studies have determined the effectiveness of *Compassion Focused Therapy (CFT)* to treat PTSD or CPTSD post perinatal bereavement. CFT is a new therapy, which has shown itself to be highly effective in other contexts, and therefore could also be successful for treating women with PTSD post perinatal bereavement.

What is CFT and why could it be an acceptable treatment for women experiencing PTSD or CPTSD post perinatal bereavement? CFT was founded by Paul Gilbert (2000) in response to the observation that many people, and in particular those high in shame and self-criticism, experience difficulties generating kind and self-supporting inner voices when engaging in traditional therapy. Gilbert observed that although these individuals were able to engage with cognitive and behavioural tasks, they often responded poorly to therapy (Rector et al. 2000, Bulmarsh et al., 2009). The CFT approach is based upon a growing body of neuroscientific evidence, which has demonstrated that motives and emotions have a major impact on self and affect regulation (Cozolino, 2002, Depue and Morrone-Strupinsky, 2005). CFT aims to redress imbalances between the threat and protection system, motivation and the self-soothing system in response to threat. In the situation of late miscarriage, stillbirth and neonatal death, women often blame themselves for their loss. In response, CFT aims to help the person respond to self-criticism with self-kindness and compassion, with the goal to improve psychological well-being. A key part of process is to help the person understand that many cognitive biases and distortions are built-in biological processes constructed by genetics and the environment (Gilbert, 2014). Systematic reviews about CFT have shown it to be effective as an intervention in reducing symptoms of PTSD and CPTSD in other populations (Ferrari et al., 2018, Leaviss and Uttley, 2015, Karatzias et al., 2019a, Kirby et al., 2017). Further, the evidence presented in the Leaviss and Uttley (2015), Kirby et al. (2017) and Ferrari et al. (2018) reviews support that a flexible phased CFT intervention could profoundly benefit women with PTSD and CPTSD post perinatal bereavement, provided that a definitive evaluation of effectiveness, acceptability and cost-effectiveness is successful.

What does the evidence say about effectiveness of other treatments for PTSD in alternative contexts? Overall, previous meta-analyses have supported the efficacy of trauma-focused psychological treatments, such as Cognitive Behavioural Therapy (CBT) and Eye Movement Desensitisation and Reprocessing (EMDR), for the treatment of PTSD. CBT and EMDR target patients' memories of their traumatic events and the personal meanings of the trauma and typically include repeated in vivo and/or imaginal exposure to the trauma, reappraisal of the meaning of the trauma and its consequences, or some combination of these techniques (Bisson et al., 2013). Despite potential promise of EMDR for the treatment for PTSD, problems exist in relation to its delivery post perinatal bereavement. Firstly, given the unique nature of perinatal bereavement, it remains unclear whether EMDR therapy is an effective treatment. Secondly, from a service delivery

perspective it is unknown what proportions of patients experience PTSD and might benefit from this treatment. Thirdly, emerging evidence suggests that exposure interventions such as EMDR might not be suitable for treating CPTSD symptoms stemming from childhood trauma (Karatzias et al., 2019a). If bereaved parents are survivors of childhood trauma and have symptoms of CPTSD, then they are less likely to benefit from exposure-based therapies.

What are the differences between PTSD and the new diagnosis of CPTSD? The new addition to the ICD-11(WHO, 2018) defines PTSD (code6B40) and CPTSD (code6B41) as two distinct sibling conditions situated under one parent category of trauma related disorders. PTSD is comprised of three symptom clusters: (1) Re-experiencing of the trauma in the here and now, (2) Avoidance of traumatic reminders, and (3) Persistent sense of current threat manifested by exaggerated startle and hypervigilance. In addition, CPTSD includes the (1-3) aforementioned clusters and also has an additional three clusters which are best described as Disturbances in Self-Organisation (DSO) (Maercker et al., 2013); (4) Affect dysregulation, (5) Negative self-concept, and (6) Disturbances in relationships. Distinctions between PTSD and CPTSD symptomatology have been validated in a variety of trauma samples (Brewin et al., 2017), which includes participants who have experienced interpersonal violence (Cloitre et al., 2013); rape, domestic violence and traumatic bereavement (Elklit et al., 2014); and refugees (Hyland et al., 2018). One question we wanted to answer in this study, is whether CPTSD is a more common condition than PTSD amongst women who are experiencing perinatal bereavement, and to consider whether *Compassion Focused Therapy (CFT)* is an acceptable treatment?

First, it is appropriate to consider why *Compassion Focused Therapy (CFT)* could be a more appropriate and effective treatment than others for CPTSD post perinatal bereavement? The answer is because evidence suggests that multicomponent therapies can be promising for the treatment of CPTSD (Karatzias and Cloitre, 2019). Preliminary research has also showed that third wave interventions, such as CFT, might be useful for the treatment of CPTSD (Karatzias et al., 2019a&b). A systematic review of 14 studies by Leaviss and Uttley (2015) has showed promise for CFT as an intervention for mood disorders and particularly for clients high in self-criticism. In addition, a later meta-analysis of 21 trials by Kirby et al. (2017) also showed that CFT can be useful for improving compassion, self-compassion, mindfulness, depression, anxiety, psychological distress, and well-being, particularly when the person is experiencing self-blame, guilt, and shame.

It should be noted that self-blame, guilt, and shame are common in bereaved parents, with a systematic review by Duncan and Cacciatore (2015) evidencing that guilt and shame predict more intense grief reactions and that self-blame predicts posttraumatic symptomology, anxiety, and depression in bereaved parents. In response, Compassion Focused Therapy (CFT) has been developed by Paul Gilbert to treat those high in shame and self-criticism (Gilbert, 2000, 2014).

Acknowledging that additional complexities may coexist with a diagnosis of PTSD post perinatal bereavement, thus presenting as CPTSD (e.g., Post Natal Depression (PND), complicated grief, or anxiety disorder etc.), it is important for therapists to be adaptable with treatments. There is a clear need to advance knowledge about acceptability, feasibility, and perceived impact of delivering an innovative flexible *CFT informed treatment package* to alleviate CPTSD symptoms. Also, given the introduction of CPTSD as a new ICD-11 condition (WHO, 2018), there is further need to identify whether this new diagnosis is relevant for women who have experienced perinatal bereavement. Hence the two research questions asked in this study are:

(1) Is CPTSD a more common condition than PTSD amongst women who are experiencing perinatal bereavement?
(2) Is a *CFT informed treatment package* an acceptable treatment for women experiencing PTSD or CPTSD post perinatal bereavement?

Method

A mixed methods approach was implemented. *Phase One* included a quantitative survey designed to explore rates of PTSD and CPTSD within a population of women who have experienced perinatal bereavement. *Phase Two* involved semi-structured interviews and a focus group. Ethical approval was sought and granted by Edinburgh Napier University ethics committee.

Participants and setting

A convenience sample of (n=500) women who had experienced perinatal bereavement and had registered with a perinatal bereavement charity were sent the survey. Participants who take help from this charity do so on an optional basis, with free counselling available to any woman, partner or family who is experiencing grief post perinatal bereavement. No inclusion or exclusion criteria was considered appropriate because of the nature of CPTSD, which includes dual mental health diagnosis. Information about the study was

given, with women participating totally on a voluntary basis. To provide public advocacy for the study, two people who had personally experienced a stillbirth provided feedback about worth of the study, diagnoses, methods, and treatments to the research team.

Data-collection

An online survey was sent to (n=500) families on the perinatal bereavement support group list, with data gathered between March-Sept 2019. Potential participants were provided with information from which they could decide whether or not they wished to participate in the study. Women who opted to take part in an interview were provided with informed choice prior to signing a consent form. All data pertaining to this study was managed in accordance with the UK Data Protection Act 2018 and the university security and data protection policies to ensure that participants' personal identifiable data and anonymised data were fully protected. As part of the survey, interviews, and focus group, the following topics were addressed:

Women and members of public who had experienced perinatal bereavement (interview):

- Their thoughts about acceptability, feasibility, and impact of treatments for PTSD or CPTSD. Participants were shown a 15-minute PowerPoint, which contained information about what flexible therapy could involve. For example, in addition to counselling, EMDR therapy was clearly outlined and the number of expected visits. Post viewing, an opportunity to ask questions was provided.

Women who had experienced perinatal bereavement (surveys and interviews).

- Their history and experience of perinatal bereavement.
- Symptoms of PTSD or CPTSD.
- Experience of support/care from *local* other voluntary and statutory services.
- Feelings about *random allocation* and attending *8 sessions of EMDR.*

Charity members and maternity staff (focus group):

- What would hinder/enable recruitment?
- Where do women go to (or are referred) for support following perinatal bereavement.

Phase One: The online survey was created using the system NOVI and was sent via *a local organisation* closed Facebook group and email list. Contents of the survey included

the valid and reliable ITQ (Cloitre et al., 2018). The survey also gathered demographic data and information about bereavement(s) and trauma experience; level of contact with the bereavement charity and any other bereavement services; participants' views regarding acceptability, feasibility and perceived impact of a *CFT informed treatment package* and Eye Movement Desensitisation and Reprocessing (EMDR)*;* and future trial design. Survey participants were also asked about their willingness to be interviewed in *Phase 2* of the study.

Phase Two: Willing survey participants who met the criteria for PTSD or CPTSD using the ITQ (Cloitre et al., 2018) were invited for a face-to-face interview at a venue of their choice. Post informed consent, (n=12) interviews and (n=1) focus group were carried out by the second author and were audio-recorded and transcribed. The focus group comprised of staff (n=5), who at the time worked with women experiencing perinatal bereavement. The PPI members (n=2) were interviewed in their home by JP and CJHM.

Data-analysis

Quantitative data were entered into spreadsheets and statistically analysed using SPSS. Qualitative data from the survey, interviews, focus group, and PPI participants were summarised and incorporated into a framework matrix, with names anonymised using numerical coding. Qualitative data were analysed using thematic analysis according to Gale and Heath (2013), which includes the following stages: (1) Transcription, (2) Familiarisation with the interview, (3) Coding, (4) Developing a working analytical framework, (5) Applying the analytical framework, (6) Charting data into the framework matrix, (7) Interpreting the data. Interviews were transcribed verbatim, with all transcripts read in their entirety to assist engagement and generate interpretation. The rationale was to identify preliminary codes, with short descriptive labels allocated to sections of the text, following which labels expressing similar concepts were grouped together to form themes (Charmaz, 2006). The selected quotes reflect themes that unravel the women's perceptions of the effects their perinatal bereavement had upon them and acceptability of potential treatments. Mixed methods of data collection permitted integration of both qualitative and quantitative data to ultimately produce study findings and recommendations. This sequential design included two phases: (1) an initial quantitative instrument phase, followed by (2) a qualitative data collection phase, in which the qualitative segment built directly upon the results from the quantitative stage. Sequential

data collection allowed viewing of data from multiple perspectives, which in this study included the views of women who have experienced perinatal bereavement and also the midwives who provide care.

Results

Quantitative findings:

Out of the (n=500) participants who were sent the survey, (n=92) responded, with (n=74) fully completing the ITQ (Cloitre et al., 2018); corresponding to a response of 14.8%. A total of (n=8; 10.8%) participants met the criteria for PTSD and (n=22; 29.7%) for CPTSD.

Demographic data

Those who completed the ITQ were on average aged 37 (ranging from 25-60 years), with 89% white British, 82% living with a partner, 23% suffering three or more perinatal losses, and 50% of losses occurring before 24 weeks gestation. Of the losses experienced by participants, 49% occurred between 1-5 years prior to study participation, and 15% occurred within the 12-months prior to taking part (*Table 1*).

TABLE 1

Qualitative findings: Four themes were clustered from the qualitative data, which included (1) Perinatal bereavement is shocking, (2) Participants perceptions of support and therapy, (3) Views about developing therapy and its delivery, and (4) A CFT informed treatment package is considered acceptable. To view quotes see *Table 2.*

TABLE 2

(1) *Perinatal bereavement is shocking*

Perinatal bereavement has longstanding impact that often persists for years.

Many participants articulated negative feelings about themselves as women and mothers, with some experiencing guilt, shame, and feeling let down by their bodies. Some held negative feelings about their partners who often wanted to move on from their loss. For some, their loss left them living with ‘blackness’ and ‘faking it’ to cover numbness (see Table 2). The following quote examples one participant’s numbness:

> *"Numb without any colour in my life for four years (…) I’m walking about empty and have been doing it for years (…) I’ve been numb inside and pretending since then, a long*

time now (…) I'm still fake, I'm still pretending" (Justine).

(2) *Participants perceptions of support provision*

Women highly valued support offered by the bereavement charity, which helped them feel welcome, as if they belonged, safe, and understood. For many participants, the non-trauma focussed counselling did not 'touch' their traumatic experiences of perinatal bereavement, which were described by one participant as '*trying to heat up the North Sea with a hot water bottle'.* Women who have experienced perinatal bereavement often feel isolated and forgotten by the system, with access to ongoing care varying according to geographical location. Post-bereavement, information is often issued early and at a time when it is difficult to assimilate. Also, currently there is no proactive follow-up provided by the NHS, with women expected to seek out help for themselves. Many described finding access to psychological care challenging, with it being sought out only when desperate. In addition, access to care was often limited by gestation at time of loss, with fewer options available when the pregnancy ended before 24 weeks. What is evident from the quotes in *Table 2*, is that there is a real need to improve referral for support and improve the effectiveness of therapy for this vulnerable group.

(3) *Views about developing therapy and its delivery*

The quotes clearly show that there is room for improvement in both the perinatal bereavement services provided and delivery of therapeutic interventions (see *Table 2*). When participants were asked about testing of therapeutic interventions, the survey, interviews, focus group, and public involvement data confirmed that future research to test out new trauma treatments is highly relevant and welcome. Interviewees were delighted that care provision was being progressed and expressed gratitude that there was an interest in improving treatments for trauma experienced post perinatal bereavement. In relation to a future trial, there were mixed reactions to the process of randomisation, with disappointment expressed if not selected to be part of the active treatment group. Nevertheless, the majority (80%) of the interviewed women expressed willingness to participate in anything that would help others in their situation. As such, randomisation was not a deterrent to participating in a future trial designed to treat PTSD and CPTSD, compared with a control condition. Attending up to eight separate treatment sessions was considered acceptable, with women asking for the schedule to be tailored around their work and childcare commitments, which would work towards improving study retention. There was some hesitancy surrounding EMDR therapy, with an expressed need to

understand more about treatments and possibly liaising with someone who had personal experience of the therapy.

(4) *CFT informed treatment package considered acceptable*

All of the participating women recognised the need for design of a future study to measure the effects of a *CFT informed treatment package* for PTSD and the new diagnosis of CPTSD (ICD11) (WHO, 2018). However, many did not like the use of the terms PTSD or CPTSD, instead preferring a description of key symptoms to prevent labelling of mental health issues. Members of the study steering group also recognised that a proactive consecutive recruitment strategy from a wider setting requires to be developed, which includes NHS and primary care referrals.

Discussion

In relation to the first research question, which asked whether CPTSD a more common condition than PTSD amongst women who are experiencing perinatal bereavement? Results from using the ITQ (Cloitre et al., 2018) survey instrument found that 40.5% of participants experienced trauma symptoms post perinatal bereavement, which is a similar result to the Christiansen (2017) systematic review, which reported that up to 39% go on to develop PTSD (Christiansen, 2017). Despite the serious effects from developing PTSD or CPTSD post perinatal bereavement, there is currently lack of an NHS strategy to detect and treat these conditions. As a consequence, many thousands of women experience ongoing symptoms from perinatal trauma (NICE, 201, Brockington et al., 2017). Quotes from the qualitative data support how harrowing experiencing trauma symptoms can be:

> *"I didn't want to be in my body anymore…acute feeling of being very uneasy and uncomfortable in my skin...overwhelmed by these feelings...just feeling enveloped in blackness" (Kelly).*

People with PTSD experience a number of distressing persistent symptoms, which include re-experiencing trauma repeatedly through flashbacks and nightmares, emotional numbness, sleep problems, difficulties in relationships, sudden anger, and drug and alcohol misuse (ICD-11) (WHO, 2018), which supports the need to routinely offer support and therapy. Further qualitative quotes from participants illustrated benefits from receiving support:

"Having (the bereavement charity) come then was amazing and knowing that they're there (…) it's like a safety blanket" (Justine).

Also, clearly there is need to develop a pathway that recognises, diagnoses, and treats PTSD and CPTSD post perinatal bereavement (Aiyelaagbe et al., 2017), with the following quote supporting this assertion:

"I got referred to (another charity) and they said they couldn't help me because I lived (outside zone)" (Patricia).

Participants also perceived a need to develop style of interventions to meet their personal wants and individualised needs:

(Referred for therapy) *"I really didn't want to do a group thing, I'd rather get one-one, but she says you have to do this. This is the way we do it now, if you don't go you get taken off" (Mary).*

All participants interviewed supported that flexible therapies require to be developed to alleviate complex trauma symptoms.

In relation to the second research question, which asked if a flexible *CFT informed treatment package* would be an acceptable treatment for trauma symptoms. Even though there were difficulties in fully grasping the concept, the participants agreed that more effective treatments require to be developed:

"I'm unsure...just if it would work. I mean how it works even (…) but I think given the opportunity I would give it a go to see if it would help" (Helen).

Post discussion about delivery, participants agreed that there was potential for it to be a useful intervention for perinatal bereavement related symptoms of PTSD and CPTSD. There was some hesitancy surrounding EMDR therapy, with an expressed need to understand more about treatments and possibly liaising with someone who had personal experience of the therapy:

"I'm unsure...just if it would work. I mean how it works even (…) but I think given the opportunity I would give it a go to see if it would help" (Helen).

Clearly, the qualitative themes support need for developing a flexible *CFT informed treatment package* to treat women with PTSD and CPTSD post perinatal bereavement. The survey, interviews, focus group, and public involvement data confirmed that future

research to test out new trauma treatments is highly relevant and welcome. Interviewees were strongly in support of care provision being progressed and expressed gratitude that there was an interest in improving treatments for trauma experienced post perinatal bereavement.

Limitations

A limitation of this study is that it focussed on one geographical area of Scotland that is relatively more affluent than other parts of the country. This area consists of one large urban area, as well as more outlying rural areas and less affluent towns, and so future research should consider the added impact of social gradient. Additionally, a future feasibility study would need to widen recruitment to include the NHS services and provide consecutive assessment of need and estimates of referral rates for definitive trials of treatments. Also, participants consisted of those women who are motivated to seek out help for their symptoms, which requires consideration.

Directions for future research

Karatzias and Cloitre (2019) suggested that further research is required that builds upon the success of prior interventions. CFT seems to be a promising existing intervention for this population group and a feasibility study followed by an RCT on the effectiveness and acceptability of this intervention is now urgently required.

Conclusion

This study has indicated that CPTSD is a more common condition than PTSD within a population of women with perinatal bereavement. Clearly and in relation to any additional complexities that may coexist with a diagnosis of PTSD, which represent as CPTSD, there are wider unmet needs, which may include for example PND, complicated grief, and/or anxiety disorder. Participants in this study recognised the need for new trauma interventions, with supportive counselling alone perceived inadequate as a standalone treatment. It is worth investigating further the efficacy and acceptability of a flexible *CFT informed treatment package* to address PTSD and CPTSD.

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Table 1: Demographic Data

Ethnicity	**No. (%) women** (n=73 women provided this information)
White British	65 (89.1%)
White European	5 (6.8%)
White Other *(American, not stated)*	2 (2.7%)
Other Ethnic Group *(Japanese)*	1 (1.4%)
Living situation	**No. (%) women** (n=74 women provided this information)
Lives alone	4 (5.4%)
Lives with spouse/partner	61 (82.4%)
Lives with family/friends	8 (10.8%)
Other	1 (1.4%)
No. of losses (Total no. losses reported = 109)	**No. (%) women reporting this level of loss** (n=74 women provided this information)
1	37 (50.0%)
2	20 (27.0%)
3	8 (10.8 %)
4	3 (4.1%)
5 or more	6 (8.1%)
Timing of loss (n= 94 Timings of loss reported)	**No. (%) women reporting this timing**
< 24 weeks gestation	47 (50.0%)
>= 24 weeks gestation	26 (27.7%)
During labour and birth	5 (5.3 %)
<= 1 month of age	14 (14.9 %)
> 1 month of age	2 (2.1%)
Time since loss occurred (n= 94 Time since loss reported)	**No. (%) women reporting this timing**
< 1 month	1 (1.1%)
1-6 months	5 (5.3%)
>6 and <12 months	8 (8.5%)
1-5 years	46 (48.9%)
>5 and <10 years	19 (20.2%)
10-18 years	16 (17.0%)

Table 2: Participant's quotes	**Themes**
"I was trying to rip my skin off my body 'I don't like this body' I felt like it would let me down…I couldn't get pregnant and I'd lost two babies" (Mary). *"I didn't want to be in my body anymore…acute feeling of being very uneasy and uncomfortable in my skin...overwhelmed by these feelings...just feeling enveloped in blackness" (Kelly).* *"Numb without any colour in my life for four years (…) I'm walking about empty and have been doing it for years (…) I've been numb inside and pretending since then, a long time now (…) I'm still fake, I'm still pretending" (Justine).*	(1) Perinatal bereavement is shocking
"I felt like it was a huge weight actually off my shoulders just having somebody that understood" (Helen). *"Having (the bereavement charity) come then was amazing and knowing that they're there (…) it's like a safety blanket" (Justine).* *"The place I felt safest was among people that understood in the early, early days" (Gemma).*	(2) Participants perceptions of support provision
(General counselling) "*found helpful right till the end...I kind of like I felt judged...she's a really nice lady...didn't like to let her know she'd upset me...didn't go to follow-up (…) we had a good rapport and then all of a sudden she judged me" (Mary).* *"Basically turned away* (from a different charity) *'sorry your loss isn't late enough for us to help you'* (miscarriage before 16 weeks)" (*Mary).* *"Six month waiting list for counselling" (Gemma).* (Referred for therapy) *"I really didn't want to do a group thing, I'd rather get one-one, but she says you have to do this. This is the way we do it now, if you don't go you get taken off" (Mary).* *"I got referred to (another charity) and they said they couldn't help me because I lived (outside zone)" (Patricia).*	(3) Views about developing therapy and its delivery
"Okay yeah. ...at a time of day that would be suitable for me then yeah that'd be fine...and hour or an hour and a half per week is okay" (Helen). *"That would be fine. But just as long as it would be around peoples work schedule…an hours not long to get a babysitter (…) as long as it works around people" (Jane).* *"I'm unsure...just if it would work. I mean how it works even (…) but I think given the opportunity I would give it a go to see if it would help" (Helen).* *"I'm very sceptical, but I would recommend anyone to try anything that would help" (Jane).* *"I would like to have the treatment endorsed by someone who has used it and to know it can work" (PPI participant Dan).* *"How many people actually know much about it, I'm not sure (…) I suppose it's just how accessible it is and what people understand of it" (Gemma).*	(4) CFT informed treatment package considered acceptable