



CLINICAL RESEARCH ARTICLE



Having permission not to remember: perspectives on interventions for post-traumatic stress disorder in the absence of trauma memory

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ABSTRACT

Background: It is possible for people to have post-traumatic stress disorder (PTSD) without memory of the trauma event, such as in drug-facilitated sexual assault. However, there is little evidence available on treatment provision for this population.

Objective: This study aimed to address this gap by exploring the experiences of people who have had psychological intervention for PTSD without memories (PwM).

Method: Interpretative phenomenological analysis was used to explore the lived experience of nine women with PwM, who had sought psychological assessment/therapy. Participants were recruited via social media and completed semi-structured interviews online/via telephone.

Results: Identified themes concerned two broad areas: (i) the challenges of having therapy whilst lacking memories and (ii) what was helpful in therapy. Challenges included: delayed help-seeking; having emotional/sensory reactions in the absence of recognisable triggers; experiencing therapy as more applicable to remembered trauma (vs. unremembered); and difficulty discussing and processing unremembered trauma. However, participants also described helpful aspects of therapy including: feeling safe and supported; working with emotional and sensory forms of experience; having scientific explanations for trauma and memory; and having 'permission' from therapists not to remember.

Conclusions: Recommendations for clinicians included: being aware that clients with PwM may have more difficulty accessing treatment and perceive it as less applicable to them; focussing on clients' emotions and sensations (not cognitive memories) in therapy; and supporting clients to develop a more self-compassionate understanding of their experiences and lack of memory, thus supporting them to accept that not remembering is 'permitted'.

Tener permiso para no recordar: perspectivas sobre las intervenciones para el trastorno de estrés postraumático en ausencia de memoria traumática

Antecedentes: Es posible que las personas tengan un trastorno de estrés postraumático (TEPT) sin recordar el evento traumático, como en una agresión sexual facilitada por drogas. Sin embargo, hay poca evidencia disponible sobre la provisión de tratamiento para esta población. Objetivo: Este estudio tuvo como objetivo abordar esta brecha mediante la exploración de las experiencias de las personas que han tenido una intervención psicológica para TEPT sin recuerdos (PwM en su sigla en inglés).

Método: Se usó análisis fenomenológico interpretativo para explorar la experiencia vivida de nueve mujeres con PwM, quienes habían buscado una evaluación/terapia psicológica. Las participantes fueron reclutadas a través de redes sociales y completaron entrevistas semiestructuradas en línea o por teléfono.

Resultados: Los temas identificados se referían a dos grandes áreas: (i) los desafíos de tener terapia mientras se carece de memoria; y (ii) lo que fue útil en la terapia. Los desafíos incluyeron: búsqueda de ayuda retardada; tener reacciones emocionales/sensoriales en ausencia de desencadenantes reconocibles; experimentar la terapia como más aplicable al trauma recordado (frente no recordado); y dificultad en discutir y procesar el trauma no recordado. Sin embargo, los participantes tambien describieron aspectos útiles de la terapia incluidos: sentirse seguros y apoyados; trabajar con formas de experiencia emocional y sensorial; tener explicaciones científicas para el trauma y el recuerdo; y tener 'permiso' de los terapeutas para no recordar.

Conclusiones: Las recomendaciones para el clínico incluyeron: ser conscientes de que los clientes con PwM pueden tener más dificultades para acceder al tratamiento y percibirlo como menos aplicable a ellos; en la terapia centrarse en las emociones y sensaciones de los clientes (no en los recuerdos cognitivos); y apoyar a los clientes a desarrollar una comprensión más compasiva de sus experiencias y falta de recuerdos, apoyando así que acepten que no recordar está 'permitido'.

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KEYWORDS

PSTD; post-traumatic stress disorder; trauma; memory; therapy; interpretive phenomenological analysis; trauma-informed care

PALABRAS CLAVE

TEPT: trastorno de estrés postraumático; trauma; recuerdo; terapia; análisis fenomenológico interpretativo; cuidados informados en trauma

关键词

PSTD; 创伤后应激障碍; 创 伤;记忆;治疗;解释现象学 分析; 创伤知情护理。

HIGHLIGHTS

·Having therapy for unremembered trauma involves unique challenges, but aspects of therapy can still be helpful. •Suggested 'dos and don'ts' for therapists include recognising the additional barriers to treatment, focussing on emotions (not memories), and normalising memory loss.

允许记不住:在没有创伤记忆的情况下对创伤后应激障碍干预的观点

背景:人们可能患有创伤后应激障碍 (PTSD),而对创伤事件没有记忆,例如在药物诱发的性侵犯中。然而,几乎没有证据为这一人群提供治疗。

目的:本研究旨在通过探究对没有记忆的 PTSD (PwM) 进行心理干预的人的经历来解决这一差距。

方法: 解释性现象学分析用于探索9 名寻求心理评估/治疗的 PwM 女性的生活经历。参与者是通过社交媒体招募,并通过网络/电话完成了半结构化访谈。

结果:确定的主题涉及两个广泛的领域: (i)在缺乏记忆的情况下进行治疗的挑战; (ii) 什么对治疗有帮助。挑战包括:延迟寻求帮助;在没有可识别的触发因素的情况下有情绪/感官反应;体验更适用于记得住的创伤治疗(相较于记不住的创伤);难以讨论和处理不记得的创伤。然而,参与者也描述了治疗的有益方面,包括:感到安全和支持;处理情感和感官形式的体验;对创伤和记忆有科学的解释;并且得到治疗师对于记不住的'许可'。

结论: 对临床医生的建议包括:意识到 PwM 患者可能更难以获得治疗,并认为治疗对他们不太适用;在治疗中关注客户的情绪和感觉(不是认知记忆);支持来访者对他们的经历和记忆力缺乏产生更自我同情的理解,从而支持他们接受不记得是'被允许的'。

Diagnostic criteria acknowledge that a degree of memory loss or fragmentation is often a characterising feature of post-traumatic stress disorder (PTSD; American Psychiatric Association [APA], 2013, 5th ed.). However, the National Institute for Health and Care Excellence (NICE, 2018) states that interventions targeting PTSD should involve 'elaboration and processing of the trauma memories' (para. 1.6.17). The concept of reprocessing traumatic memories is also a core feature of the prevailing cognitive models of PTSD (Ehlers & Clark, 2000; Foa & Kozak, 1986). Thus, best practice guidance appears to require the presence of memory to effectively treat PTSD.

There are, however, situations in which people lack any memory of the traumatic event, yet still meet diagnostic criteria for PTSD. The symptoms of emotional numbing, physiological arousal and intrusion that characterise the disorder (APA, 2013, p. 5th ed.) are not contingent on memory and can occur in its absence (King, 2001; Russell & Curran, 2002; Turnbull, Campbell, & Swann, 2001). Examples include psychological trauma occurring in the context of traumatic brain injury (TBI; Bryant et al., 2009; McNeil, 1996), asphyxiation (Layton, Krikorian, Dori, Martin, & Wardi, 2006), drug-facilitated sexual assault (Fitzgerald & Riley, 2000; Gauntlett-Gilbert, Keegan, & Petrak, 2004) and intensive care treatment (Jones, Griffiths, Humphris, & Skirrow, 2001).

Furthermore, trauma occurring in early childhood is often unavailable to recall due to childhood amnesia, yet is still associated with PTSD (Bruce et al., 2005; Cordón, Pipe, Sayfan, Melinder, & Goodman, 2004). Survivors of trauma occurring after the typical period of amnesia may still experience memory impairments when the adverse experiences are chronic or multiple, due to repeated traumatisation in childhood increasing the likelihood of memory loss for some or all of these experiences (Brewin, 2012; Goodman, Gonzalves, & Wolpe, 2018). For example, Briere and Conte (1993) found that frequency and duration of childhood sexual

abuse were positively correlated with amnesia for the abusive experiences in adult survivors. Thus, it is important to consider how applicable existing interventions for PTSD might be for individuals without trauma memories.

1. How is it possible to have PTSD without trauma memories?

Intrusive re-experiencing of the trauma event is commonly described as a core feature of PTSD (Ehlers et al., 2002). However, intrusive, non-memory thoughts are also common in PTSD and may include evaluations of the consequences of the trauma and how it might have been prevented (Hackmann, Ehlers, Speckens, & Clark, 2004; Reynolds & Brewin, 1999). For example, an individual who has no memory of a drug-facilitated sexual assault may still be aware that an assault took place (e.g. due to physical evidence) and may ruminate on the causes and consequences of the assault.

Ehlers and Clark (2000) suggested that re-experiencing may also manifest as emotional or sensory reactions to trauma triggers, in the absence of cognitive memories. They termed this affect without recall and theorised that people may be unable to recognise this as a form of trauma memory. This was echoed by King (2001) who described 'affect without recollection' in TBI survivors presenting with PTSD. Similarly, Padmanabhanunni and Edwards (2013) describe 'somatic intrusions' (p. 374) in survivors of drug-facilitated sexual assault and suggested these represented non-visual intrusive memories.

Gauntlett-Gilbert et al. (2004) described challenges arising in the treatment of drug-facilitated sexual assault survivors who experienced distressing sensory memories (e.g. smells) and were often preoccupied with attempts to recover cognitive memories. Anecdotally, they report exposure techniques were ineffective

with these individuals and recommended targeting beliefs about memory.

There is a decades-old controversy regarding the notion that 'repressed' trauma memories can be recovered in therapy (see Crews, 1995), which is arguably still active today (see Otgaar et al., 2019 for a review). A full account of this debate is beyond the scope of this paper, and contrary to its aims. Based on the literature reviewed above, this study conceptualises the existence of PTSD without memories (PwM) as a phenomenon that occurs when individuals have experienced traumatic events which, due to a range of potential biological and developmental factors, they cannot recall or have only sensory remnants of. Awareness of the trauma, therefore, develops through experiencing the symptoms of PTSD, and potentially also from corroborating evidence (e.g. when people with TBI are aware they were involved in a traffic accident but can only remember the moments preceding the crash).

In summary, whilst there is evidence that PwM exists and some indicators that this phenomenon may require therapeutic adaptations (Gauntlett-Gilbert et al., 2004), no empirically based guidance exists on providing psychological treatment for individuals in this situation. Therefore, the current study aimed to use Interpretative Phenomenological Analysis (IPA) to answer the question:

How do adults experience assessment and/or therapy for symptoms of post-traumatic stress disorder when they lack memory of the trauma event?

2. Methodology

2.1. Ethics

Paid consultation was sought from a person with lived experience of PTSD who advised on trauma-sensitive ethical practice regarding the production of recruitment materials and the distress management plan. Ethical approval for the study was granted by the University of Bath Psychology Research Ethics Committee (PREC19-226) and by the NHS Health Research Authority and Research Ethics Committee (REC reference: 20/SC/0209; IRAS project ID: 270965). Participants were not paid for participation, out of concern this may incentivise people to participate in potentially distressing research against their best interests (Bentley & Thacker, 2004).

2.2. Participants

Adults were deemed eligible for the study if they: (a) had/previously had symptoms of PTSD (self-assessed based on a description of PTSD); (b) had no memory/only sensory memories for the trauma event (self-report); and (c) had received trauma-focussed

Table 1. Participant demographic and intervention data.

Demographics	Sample $(n = 9)$
Gender	100% female (<i>n</i> = 9)
Country of residence	U.K. $(n = 8)$; U.S.A. $(n = 1)$
Age	Range: 22-54, mean age: 31
Ethnicity*	1× White Nordic
	3× White British
	1× White European
	1× White Norwegian/Welsh
Co-occurring occurring mental	n = 6 (including autism,
health/neurodevelopmental	depression, anxiety, DID,
conditions	trichotillomania, Tourette's
	syndrome, ADHD)
Intervention	Sample
Access route	Private (<i>n</i> = 5; four in the U.K., one in the U.S.A.)
	U.K. NHS $(n = 4)$
Intervention type**	Assessment $(n = 1)$
	Treatment $(n = 8)$
Treatment approach	Described as: 3× EMDR (2×
	treatment; I× assessment for
	treatment); 1× compassion-
	focused trauma therapy; 3×
	integrative trauma-focused
	therapy; $1 \times$ combination of CBT
	and narrative approaches; and
	1× psychodynamic
	psychotherapy

Note. ADHD = attention deficit hyperactivity disorder; ARFID = avoidant or restrictive food intake disorder; CBT = cognitive behavioural therapy; DID = dissociative identity disorder; EMDR = eye movement desensitisation and reprocessing; NHS = National Health Service; U.K. = United Kingdom; U.S.A. = United States of America.

*Due to researcher error, participant ethnicity was not recorded at initial data collection. Participants were invited to provide this information post-analysis when findings were emailed to them; however, only six responded leading to incomplete ethnicity data.

**All participants reported previous experiences of therapy prior to the most recent intervention. Therefore, whilst interviews were focussed on the most recent experience, participants also discussed previous treatment.

intervention finishing within the last 12 months. See Table 1 for demographic and intervention data.

2.2.1. Nature of participants' trauma memory

All participants had received assessment and/or psychological therapy for symptoms of PTSD. Importantly, all participants reported having a mixture of remembered and unremembered trauma, largely in the context of multiple or chronic traumas. For example, some participants had experienced prolonged abuse in childhood and had memories of the more recent traumas but not of earlier ones. With regards to the absent memories, one participant reported no memory at all; and eight participants reported sensory memories only. The nature of the traumatic experiences that had led to PTSD without memories included: sexual violence in adulthood; childhood sexual abuse; witnessing domestic violence/family breakdown in childhood; exposure to acute parental distress in childhood; coercive control/honour-based violence; and traumatic experiences whilst detained under the mental health act. Although this was not explicitly asked in interviews, five of the nine participants reported some factual knowledge of events due to: family informing (P5);

medical notes (P7); 'flashes' of emotion or memory from a similar time period (P4; P5); dissociated parts 'containing memories of abuse' (P6); or physical injuries (P1).

Again, although not requested, many participants explained how they had begun to consider there may be unremembered traumas. Sources included a sense that something was 'wrong' (P5; P7), that 'something' had happened (P8; P9) or that there were 'gaps' in their memory (P4; P5). Four participants described having 'body'/'somatic' memories (P2; P7; P6) or a 'slight visual and a smell' (P8).

2.3. Procedure

2.3.1. Recruitment

The onset of the global COVID-19 pandemic considerably hampered NHS recruitment and ultimately no participants were recruited through this route. Non-NHS recruitment took place via social media, using purpose-made video (https://t.co/ o4tUuqaVws?amp=1). Potential participants contacted the first author via email to express interest, whereupon they were emailed the information sheet and a list of screening questions. Ineligible participants were informed of the reasons why they could not be included.

2.3.2. Semi-structured interview

Semi-structured interview questions were devised by the first, second and fourth authors and used open, non-directive questions designed to illicit what was most significant to the individual about their experiences (Smith, Flowers, & Larkin, 2013). The first author piloted these questions with the third author.

Following interviews, feedback was elicited from each participant regarding the clarity and appropriateness of interview questions. The first author used supervision to consider the responses received and reflect on participants' understanding of the questions. This led to minor amendments to the phrasing of interview questions over time.

2.3.3. Data collection

Eligible, consenting participants were telephoned to collect additional demographic data and arrange interviews. In accordance with the distress management plan, participants were asked how they would like to be supported if they became distressed.

Due to the COVID-19 pandemic, all interviews took place via phone (n = 6) or Microsoft Teams/ Skype (n = 3). Personalised debrief sheets were sent via email, containing details of local and national services/organisations providing further support. Audiorecorded interview data were retained only until transcription had taken place, whereupon it was deleted.

2.3.4. Note on additional measure

It was initially planned to use a measure of autobiographical memory - the Memory Experiences Questionnaire (Sutin & Robins, 2007). However, this assesses a single memory and participants all reported multiple trauma memories. Most participants reported it was a poor representation of their experiences and therefore it was omitted.

2.3.5. Transcription and analysis

IPA was chosen to enable analysis of participants' lived experiences without reliance on pre-existing theory (Smith et al., 2013). IPA employs the principles of ideography, phenomenology and hermeneutics to understand the experiences of others. It is concerned with the individual rather than general experience (ideography) and attempts to recognise how people perceive events (phenomenology) via interpreting and translating their inner world (hermeneutics). IPA thus employs a dual translation process (or double hermeneutic) wherein the researcher attempts to make sense of how the participant has understood their experiences (Smith & Osborn, 2008).

The study followed the IPA procedures described in Smith et al. (2013). The first author transcribed and reread the interviews to become immersed in the data and the mood of the interviews (Pietkiewicz & Smith, 2014). Transcripts were analysed using NVivo 12 software. Initial noting (brief commentaries on the data) was done using the annotations feature of NVivo. Preliminary coding (labelling and organising of data) drew on both initial notes and the raw data and was captured via the creation of 'nodes' (NVivo term for codes). Emergent codes were then developed into themes, and similar themes were clustered, resulting in a list of superordinate themes, themes and subthemes. Wherever practical, participants' own words were incorporated into theme labels.

The steps described above (reading, noting, coding and creating themes) outline how the data were approached; however, analysis was an iterative process wherein emergent codes/themes were repeatedly discussed with the other authors and refined over time. Therefore, these steps were revisited multiple times for each transcript. In recognition of how researchers' own values and experiences may shape interpretations (Smith et al., 2013), the first author kept a reflexive diary to document and bracket preconceived ideas and assumptions (Pietkiewicz & Smith, 2014). In meetings with the other authors, the main analyst was encouraged to reflect on how her identity and experience as a trainee psychologist was informing her understanding of the data.

When themes had been created for all transcripts, the first author worked across transcripts, amalgamating similar themes and trimming irrelevant ones to Interviews were transcribed by first author and then read and re-read during upload to NVivo.



Initial noting was done using the annotations feature of NVivo. Preliminary coding drew on initial notes and the raw data. Preliminary codes were revisited throughout theme development to explore different potential interpretations.



Emergent codes were developed into themes. Similar themes were clustered, resulting in a list of themes and superordinate themes. Themes were produced for each transcript before noting began on the next one. Themes from individual transcripts were revisited throughout the process of developing over-arching themes.



Cross-transcript coding. Similar themes were amalgamated and further refined to reflect the broader data source. Irrelevant themes were discarded. This resulted in a set of overarching themes and superordinate themes drawn from all transcripts.



Third author read through the initial set of overarching themes to check for plausibility. This led to less pertinent themes being de-emphasised in the final results.

Figure 1. Overview of analysis, audit and reflexivity procedures. Note. Circular arrows represent iterative analysis process and repetition of steps.

produce an overarching set of themes drawn from all transcripts. See Figure 1 for an overview.

The third researcher (who had no part in datahandling until this point) then read themes from a top-down perspective, to enhance plausibility. Initial analysis had produced a sizeable data set and this feedback led to a de-emphasis on less pertinent topics as these diluted the focus on key findings.

3. Results

3.1. Themes

The analysis led to the creation of two superordinate themes: The challenges of having therapy/assessment for PTSD without memories (referred to henceforth as 'Challenges') and What helps (in therapy). Each superordinate theme contained eight themes. See Figure 2 for an overview.

3.2. Superordinate theme 1: challenges

the superordinate theme 'Challenges' Within (Figure 3), eight themes were identified and are presented below in an order which broadly reflects participants' journey through accessing and receiving treatment/assessment. Additional quotes supporting these themes are shown in Table 2.

Throughout each stage of analysis the first author kept reflexive logs to track decision-making and aid in bracketing off pre-existing assumptions. Emergent codes and themes were regularly discussed with co-authors who queried and challenged initial interpretations to encourage further reflexivity.

Theme 1. Delay in recognising PTSD and accessing support. Three participants (P1, P2 and P7) explicitly linked their lack of memory to a disruption in recognising and seeking help for their PTSD. One stated that lacking memories 'was a huge part of a delay in getting support' (P7); another reported 'maybe I would have mentioned it earlier [if I remembered]' (P1).

Theme 2. I've got no proof it was real. Three participants reported questioning whether their unremembered traumas really happened: 'it's like knowing something that happened, but half feeling like "was that just something that I read or heard? Or was it completely real?" (P8). Two participants worried that professionals might not believe them: 'No one's gonna believe me [...] I've got no proof that any of it was real' (P1).

Indeed, two other participants, reported experiences where their lack of memory appeared to be disbelieved or denied: 'This therapist was like "nothing ever happened to you, I can come up with a thousand reasons why X, Y or Z you might be experiencing" (P6).

Theme 3. How do you talk about something you can't remember? Three participants expressed the challenge inherent in not being able to reliably 'recognise' (P3) or 'talk about' (P5) traumatic material, particularly in the context of 'fluctuating' (P1) memories. Two participants had therefore questioned 'what's the point?' (P5) in trying to work on unremembered

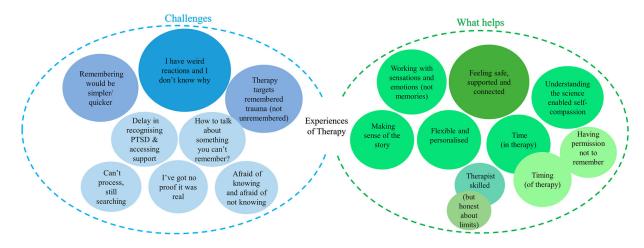


Figure 2. Overview of superordinate themes and themes (N = 9).

Note. Size of bubbles is indicative of number of participants endorsing each theme. Overlapping bubbles represent instances where highly related but distinct themes were combined.

trauma, when 'you can only speculate' (P3) about what happened.

Theme 4. I have weird reactions and I don't know why. Six participants reported how lacking memories resulted in them experiencing triggers or emotional responses they couldn't understand or account for:

There's so many other things that I know create a trauma response in me but I don't know what they are. So like, things that happen in life on a day to day life, that I'll just have this really flip, this weird reaction to. And I don't know why! (P3)

Theme 5. Can't process, still searching. Three participants reported that lack of memory prevented them being able to 'process' and 'make sense of' (P3) their trauma. For two participants, this led to a lingering feeling of still 'searching for' (P3) the gaps in memory.

Theme 6. Therapy targets remembered trauma (but not unremembered). Four participants described how their therapy had been focussed on (and therefore effective for) the traumatic material they did recall, but had not addressed absent memories:

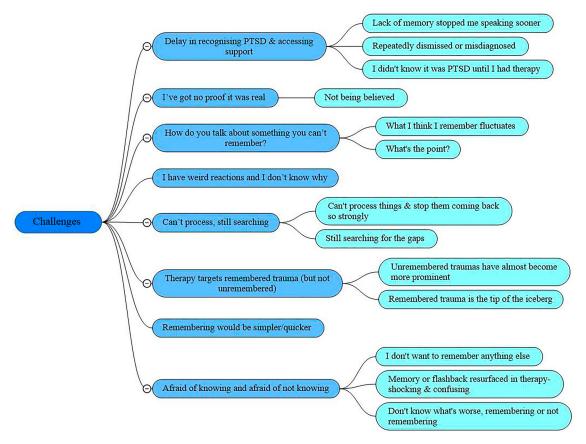


Figure 3. Mindmap showing themes and subthemes for the superordinate theme challenges.



Table 2. Quotes illustrating themes from 'Challenges'.

Theme	Participant quotes
Delay in recognising PTSD and accessing support	'Initially, I was like "I haven't experienced trauma so I don't know why I'm having trauma therapy"'. (P2)
2) I've got no proof it was real	'I had this worry of it not being real and that maybe somehow my therapist would tell me I was making it up'. (P5)
	'This psychiatrist [] put down in the letter [] that there was no evidence that I experienced any childhood trauma'. (P9)
3) How do you talk about something you can't remember?	'If on one day I said "nothing ever happened" or "this happened" and then [] another day I'm like "no I think this happened" and it's totally different [] Then what happens if people take that on face value?. (P1)
4) I have weird reactions and I don't know why	'I remember trying to piece together a certain problem I have in supermarkets [] and being able to express exactly what I experience when I'm in a supermarket but not being really able to um, put that down to a very specific memory.' (P5)
5) Can't process, still searching	'Um, there's huge, huge gaps where I imagine quite a lot of stuff happened. And then a very concentrated area where like everything happened all at the same time. Yeah, so I feel like I'm sort of searching for that actually'. (P3)
	'It feels a little bit like everything is a hunt to unearth a secret. A secret you're keeping from yourself'. (P6)
6) Therapy targets remembered trauma (but not unremembered)	'I had very specific TFCBT [trauma-focused CBT] for one particular incident, I no longer have scary memories of that [] But I can't generalise it to [] any of the other very similar issues in my life – I don't know why'. (P1)
7) Remembering would be simpler/quicker	'I think in therapy and in life I would make much faster progress towards whatever is next'. (P6) 'I think if I'd been able to work on them because I'd remembered them, they'd also be mostly resolved'. (P8)
8) Afraid of knowing and afraid of not knowing	'you're afraid of knowing and you're afraid of not knowing'. (P6) 'If like the one thing I got out of therapy was clearer memories of things I don't want, I really wouldn't like to remember then, I'd probably give it a miss to be honest!'. (P1)

It was kind of like "ok you've got those memories you can work with that" [...] Um, and that was really really frustrating cos it's like well actually, yes, there's that little bit but that's kinda the tip of the iceberg. (P3)

Nor had they been effective in resolving them: 'The traumas that I can remember, like most of those now are highly desensitised. [...] But then the ones I can't remember have almost become a little bit more prominent as a result' (P8).

Theme 7. Remembering would be simpler/quicker. Five participants expressed their views that having memories would have made therapy 'more straightforward' (P4); 'linear' (P2); 'simpler' (P1).

Theme 8. Afraid of knowing and afraid of not knowing. Interestingly given the above themes, some participants also reported ambivalence about recovering memories. Two had recalled additional memories through flashbacks in therapy and described being 'terrified' (P6; P9) by the experience. Both participants seemed to express a conflicted view on whether getting trauma memories back would be helpful: 'when I started therapy, the thing I kept saying to [mum] every day was "I don't know what's worse: remembering or not remembering" (P9); 'you're afraid of knowing and you're afraid of not knowing' (P6). These reactions seem to be compounded by therapist responses that were perceived as unhelpful: 'And I told [therapist] about this, and it went nowhere' (P6).

3.3. Superordinate theme 2: what was helpful in therapy

This superordinate theme included a further eight themes (Figure 4) which are presented in our

suggested order of least to most specific, in terms of their application to PwM (as opposed to 'typical' PTSD). Additional quotes supporting these themes are shown in Table 3.

Theme 9. Time and timing. Two participants valued having enough time to go 'at my pace' (P5) in private therapy (NHS treatment tends to be more time limited). Four participants also endorsed the importance of interventions being offered/ received at the right time, when they were 'ready to talk' (P4).

Theme 10. Feeling safe, supported and connected. Seven participants endorsed the significance of safety and trust in therapy. Seven participants reported a sense of being in 'connection' (P2) or collaboration with their therapist: 'it just felt like a discovery process together and we were a team'. (P7). Two participants reported the positive impact of therapists who showed 'an interest in my life beyond the trauma' (P8).

Theme 11. Making sense of the story. Five participants valued having a chance to make sense of their experiences through talking in therapy: 'I think I'd missed [pre-therapy] a really important [...] thing that's protective, which is the ability to just say your story and make sense of it' (P7). Two participants who felt unable to speak freely about their experiences professionals during assessment/therapy reported additional difficulty/'frustration': (P1).

Theme 12. Flexible and personalised. Five participants highlighted their appreciation of therapists offering 'flexibility' (P6) in treatment and that there wasn't pressure to comply with a pre-existing idea of trauma therapy: 'There was no [...] 'we've got to make it look like this' thing' (P7). Two participants appreciated how therapists adapted therapy to them

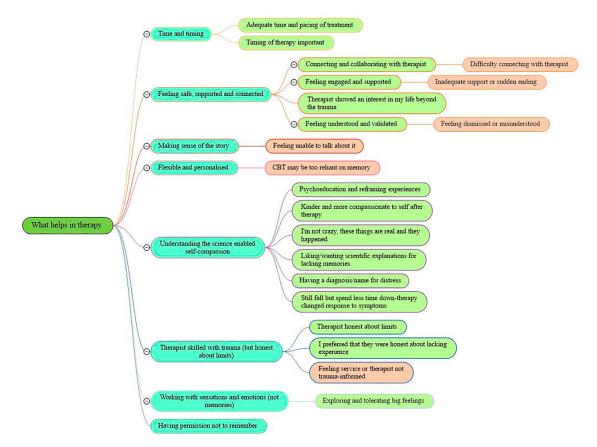


Figure 4. Mindmap showing themes and subthemes for the superordinate what helps (in therapy). Note. Bubbles in orange represent factors that were unhelpful.

specifically, through 'use of language' (P4) and 'drawing and painting alongside the therapy' (P8).

Theme 13. Understanding the 'science' enabled selfcompassion. Five participants expressed the importance of having trauma-related or 'psychoeducational'

(P7) explanations for their trauma-related distress. For three, this enabled different understandings of their symptoms:

I have a lot of like checking behaviours at night which have been perceived over the years as

Theme	Participant quotes
9) Time and timing	'It might take you six sessions to even try and, not necessarily recall a memory but to try and pinpoint exactly what's happening'. (P3)
10) Feeling safe, supported and connected	'I was safe whatever I was going to say'. (P4)
11) Making sense of the story	'I think just kind of getting me to talk about things more, getting me to kind of, yeah just be willing to tal about things'. (P9)
	'I think (pause) just by me being able to talk, and sometimes I didn't even really know what I was talking about'. (P3)
12) Flexible and personalised	'I've really appreciated [therapist's] ability to bring together different approaches, um. So, flexibility is good'. (P6)
13) Understanding the 'science' enabled self-compassion	'Understanding the science a bit more about how when, sometimes things happen you might not remember and that sometimes you do that to try and protect yourself from what's happening. And understanding that that is something that really does happen, um, and that it's not pretend. And that you're not totally crazy or making things up'. (P5)
	'In the past [] I would even tell myself that I was being stupid or dramatic and I needed to pull mysel together. Um but leaving therapy with an understanding that maybe that's not as easy for me [] ha allowed me to take myself seriously and give myself the time I need to feel better'. (P5)
14) Therapist skilled (but honest about limits)	'He was really honest about (pause) and I really appreciated that, that there isn't really a roadmap'. (P7
15) Working with sensations and emotions (not memories)	'We'd go into like, like checking on those emotions. And then sometimes that would open up a door insidme, and this part of me that had been traumatised for whatever reason, and it didn't really matter what the reason was or what the cause was, that whatever it was that was inside me had needed to get out (P2)
16) Having permission not to remember	'There was something very important about the permission for it [memory] to be broken [] and we also talked about the fact that it might be that I never remember bits [] there might have been a bit where was thinking you know, I want this memory to come back or to be in a neater way or to be more organised. And now [] I can look back in a much kinder way [] It's my whirlwind of a broken kind of time (laughs). And that's ok' (P7)

bordering on obsessive-compulsive. And he [therapist] was like "I just think that you're carrying out extensive safety measures but that's in response to the fear of violence which is a very real fear that people can have when they've experienced things like you have". (P8)

Such explanations were 'healing' (P7); enabled them to 'be compassionate towards the, the parts that aren't (sighs) able to function at the moment as well as possible' (P2) and 'legitimised what I was experiencing in my head' (P5).

Significantly, some participants said this knowledge enabled them to alter their responses to trauma symptoms. Whilst all eight participants who had received therapy referenced that they were still living with the impact of trauma in some form, four of these reported having 'better strategies' (P9).

Theme 14. Therapist skilled (but honest about limits). Three participants described how their therapist's expertise in trauma was 'important' (P7) and helped them feel 'reassured' (P4). In addition, two participants appreciated when therapists were 'transparent [about] not knowing that much about working with people who don't remember what's happened'. (P8).

Theme 15. Working with sensations and emotions (not memories). Six participants described how they had worked with 'somatic realities' (P6) and emotions in therapy, rather than focussing on memories: 'What I've learnt over the years in terms of therapy is that maybe it doesn't matter that I don't have all these exact memories, but actually what I do have are feelings. Um, which I probably can work on'. (P3).

Theme 16. Having permission not to remember. Four participants remarked on the helpfulness of therapists who normalised their experiences of lacking memories and having incomplete narratives:

I would say that a lot of it came down to permission. [...] And being told that just because you can't quite fully remember something doesn't mean it didn't traumatise you, doesn't mean it's not valid or real, um, is what therapy did for me. (P5)

These participants also felt that they received a message that having memories was not actually necessary for recovery: 'I think that the model that my therapist had [...] that I didn't need to know the full story in order to heal, is a really important message for other people who are going through it' (P2).

4. Discussion

Overall, 16 themes in two superordinate themes were identified from interviews with nine participants about their experience of assessment/therapy for PTSD without memories (PwM). Participants identified that they *did* experience additional challenges (superordinate Theme 1) due to lacking memory, and reflected on ways in which therapy for PwM is experienced as more or less helpful (superordinate Theme 2).

Although participants were not asked how they became aware of trauma, some volunteered this information: mostly describing somatic or felt forms of memory/knowledge, and sometimes corroborating evidence. Interestingly, all participants reported having a combination of remembered and unremembered trauma, usually in the context of chronic or repeated adverse experiences. This raises a question regarding how the cumulative impact of multiple/enduring traumas influenced participants' experience of PwM and suggests that, for some participants, their PTSD symptoms may be linked to multiple events (both remembered and not). This seems consistent with Gauntlett-Gilbert et al. (2004), who describe one drug-facilitated sexual assault survivor with total amnesia (they became aware of the assault by external means), whilst others had periods of amnesia interspersed with fragmentary memories. It, therefore, seems apparent that people with PwM/PTSD may have a mixture of remembered and unremembered trauma.

4.1. Challenges

Findings suggested that lack of memory constituted a barrier to both accessing and utilising timely PTSD intervention. Participants explicitly linked PwM to delayed help-seeking, with some doubting their own experiences and fearful of being disbelieved by professionals. That two participants did in fact encounter disbelief highlights that such fears are not unfounded. This is significant in light of evidence that delayed or reluctant trauma disclosure predicts PTSD (Mueller, Moergeli, & Maercker, 2008), as does negative reactions from disclosure-recipients (Ullman, 2003).

Case-based PwM research has identified that belief in trauma memories as essential for positive outcomes can negatively impact therapy due to excessive rumination in an attempt to recover them (Gauntlett-Gilbert et al., 2004; Padmanabhanunni & Edwards, 2013). This is consistent with our findings, wherein some participants described 'searching' for memories and endorsed beliefs that memory would simplify treatment. Approaches to PTSD treatment may inadvertently reinforce these beliefs. For example, a study published whilst this research was in-progress found that not writing a therapeutic trauma narrative resulted in greater maintenance of positive outcomes for survivors of drug-facilitated sexual assault (Jaffe, Kaysen, Smith, Galovski, & Resick, 2021). They suggest that recall-focussed therapy may unintentionally highlight amnesia-related stuck points in PwM and maintain symptoms. Such evidence may partially

Table 4. Recommendations for practitioners treating PTSD without memories (PwM).

Do be aware that people with PwM may perceive therapy as less suited to or helpful for them and may believe that trauma memories are necessary for

good outcomes.

Do collaboratively develop goals for therapy, that are not reliant on memory recovery/recall but incorporate building a self-compassionate understanding and approach to experiences.

Do be aware that clients with PwM are likely to find therapy more challenging due to: a more difficult journey towards accessing appropriate support; fear of (and possibly experience of) being disbelieved by services due to lack of 'proof'; uncertainty regarding how to discuss their experiences.

Do be aware that clients with PwM experience emotional and sensory forms of recall in the absence of cognitive trauma memories. This can include trigger responses, even if the triggers themselves cannot be identified or explained.

Do continue to apply core features of trauma-focussed care for people with PwM, including: timely and sufficient access to care; promoting safety and collaboration; building a trusting therapeutic relationship; opportunities to make sense of personal narratives; and psychoeducation.

Do use personalised and flexible approaches to PTSD formulation and treatment that incorporate the unique features of PwM. Combine existing evidence-based interventions with clinical knowledge, stay up to date with emergent literature (which may be in the form of case studies rather than large trials) and seek supervision and consultation from more experienced clinicians.

Do remember that every client's experience with PTSD/PwM will be different. Collaboratively develop an idiosyncratic understanding of their unique experience, whilst continually updating your own knowledge.

Do offer scientifically informed explanations of how memory and trauma interact to support clients exploring alternative understandings for their experiences. Explicitly normalise memory loss and promote selfcompassion. Focus on sensory and emotional experiences during treatment.

Do not assume that memory recovery is desirable (or necessary for positive client outcomes). People with PwM may feel conflicted about the possibility of memory recovery in therapy.

Do not make it an aim of therapy to recover memory as this may be unrealistic and unachievable.

Do not invalidate clients' accounts, even if they seem contradictory or incoherent. People with PTSD may have a mixture of remembered and unremembered trauma.

Do not assume that clients are unaffected by trauma just because they cannot cognitively recall it.

Do not underestimate the length of time that may be needed to build a trusting relationship with clients with PwM, and to collaboratively understand and begin to work with the trauma.

Do not assume that standardised PTSD treatment protocols alone will be sufficient in PwM

Do not feel you need to be an expert in PwM, however also do not hesitate to seek further advice and support if there are gaps in your own understanding of PwM.

Do not advise clients that memory is necessary for successful outcomes in PTSD therapy.

Note. PTSD = post-traumatic stress disorder; PwM = PTSD without memories.

account for why participants in this study found treatment less effective for unremembered trauma. However, not addressing memory gaps was also reported as unhelpful by participants - which is consistent with trauma-informed care principles emphasising the importance of recognising traumatic experiences (Substance Abuse and Mental Health Services Administration, 2014).

A prominent theme in *Challenges* concerned participants' emotional and/or sensory responses resulting from PwM, unconnected to cognitive memory. This seems congruent with Ehlers and Clark's (2000) description of affect without recall. Since our study was designed, Woodward (2020) has provided

Table 5. Recommendations for future research.

Recommendations

- Research is required to further define, describe and measure PwM in order to determine its core features and reliably differentiate it from classic PTSD. This will also enable clinicians to correctly recognise and identify PwM in clinical practice.
- Further confirmatory qualitative research with people with PwM who access therapy.
- Future studies should aim to collect data from participants from diverse demographic groups in order to develop a culturally sensitive understanding of how PwM presents and how best to treat it.
- · When the empirical literature is further developed, controlled trials of PTSD interventions utilising the adaptations recommended by this and other studies should be conducted with PwM populations to determine efficacy and suitability for clinical delivery.

Note. PTSD = post-traumatic stress disorder; PwM = PTSD without memories.

preliminary evidence of this formerly theoretical concept and concluded that affect without recall may represent a form of perceptual memory where dislocated trauma reactions occur in the absence of memory. This aligns with accounts in our findings, wherein participants recognised 'weird' reactions as trauma responses but did not know what was causing them.

Furthermore, Woodward (2020) suggests that the increased fear and confusion associated with affect without recall may lead to negative interpretations such as 'I'm going mad' (p. 44) and greater difficulty predicting triggers. They hypothesise this could make PwM more likely to maintain over time and harder to treat. Indeed, Jaffe et al. (2021) found more lingering PTSD symptoms in drug-facilitated sexual assault survivors six months post-therapy, compared to survivors of non-drug-facilitated sexual assault (who recalled the assault). This seems consistent with our study, wherein participants reportedly found therapy more effective for remembered traumas than PwM.

Despite describing additional difficulties associated with PwM, three participants also expressed ambivalence regarding memory recovery. People seeking PTSD treatment often report fear of reliving remembered traumas (Shearing, Lee, & Clohessy, 2011), suggesting that people with PwM may be in the uncomfortable position of both wanting and not wanting to recover trauma memories. This bears

Table 6. Key messages for people experiencing PTSD without memories (PwM).

Key messages for people with PwM

We summarised the key things that participants as a whole have told us about their experiences of having therapy for PwM. You may or may not find these helpful in your own life.

Overall, participants suggested there might be challenges associated with PwM

- Just because you can't remember your trauma doesn't mean it won't affect you.
- You may never remember what happened and the story may never fully make sense.
- You might have emotional and sensory/body reactions to things that are hard to explain or predict.
- You may find accessing therapy harder due to worries about not being believed, or not knowing how to talk about your experiences.
- You might feel that you need memories for therapy to work well, that therapy would be easier if you remembered the trauma or that you're still
- You may also be unsure about whether you want your memories back or not, and feel worried about both of these options.

... But there are things that can help

- It's ok not to remember your trauma or fully understand what happened to you. This happens sometimes and it's real.
- You don't need memories in order to get better- there are other things you can work on in therapy that can help.
- Having a chance to talk through your story (even if it doesn't fully make sense or there are gaps) can be supportive.
- Understanding more about how trauma impacts your body, emotions and memory may help you be kinder/more compassionate towards yourself when things are difficult.
- You may find you can work with your emotions and body sensations instead of memories in therapy. These may actually be a different type of memory.
- You may feel you need longer to be able to work on unremembered trauma in therapy.
- Having a therapist with whom you feel safe, supported and understood is important and can make a difference.

If you are having therapy or thinking about having therapy in the future, we recommend you talk to your therapist about your concerns around PwM. If it feels helpful, you could discuss this research and show them the findings to help you agree how you will work together.

recognising if, as suggested by one participant in our study, people with PwM might avoid treatment due to beliefs it could trigger recall.

4.2. What helps

It is worth considering which of the factors described as helpful by participants might constitute 'standard' aspects of trauma-related therapy. A safe and supportive space; accessing timely and sufficient treatment; the chance to make sense of one's story and to have scientific explanations for symptoms are all features that would likely characterise typical PTSD treatment (Ehlers & Clark, 2000; Ehlers, Clark, Hackmann, McManus, & Fennell, 2005; Sweeney, Clement, Filson, & Kennedy, 2016). Less consistently provided (dependent on setting and therapist skill/experience) might be: flexible and personalised interventions; therapists acknowledging the challenges of treating PwM; explicit and permissive acknowledgement and explanation of unremembered trauma; and a focus on sensations and emotions as opposed to memory content.

Having reported both desire for and ambivalence about recovering memories, participants in our study seemed to find 'permission' to accept nonrecovery of trauma memories was most helpful. Furthermore, having explanations for why they might lack memories enabled some to become less preoccupied with recall and develop more helpful and selfcompassionate coping strategies. This concurs with findings showing that psychoeducation can successfully challenge unhelpful interpretations of memory gaps in PwM (Padmanabhanunni & Edwards, 2013; Woodward, 2020).

Participants in our study suggested that alternative therapeutic work might usefully focus on their emotional/somatic trauma experiences - or affect without recall (Ehlers and Clark 2000). That they experienced this as helpful reflects recommendations that AwR should be proactively addressed and acknowledged as an important aspect of trauma presentation in PwM (Padmanabhanunni & Edwards, 2013; Woodward, 2020). Learning to accept emotional responses without resistance or further distress is associated with lesser PTSD severity (Tull, Barrett, McMillan, & Roemer, 2007), which further explains why participants in this study reported being positively impacted by emotional processing without any change in recall.

5. Implications

These findings lead to the development of recommendations for clinicians working with PTSD without memories (PwM; Table 4) and for future research (Table 5). In collaboration with a person with lived experience of PTSD, an accessible version of the findings was produced, including key messages for people with PwM (Table 6).\

Although it did not constitute a theme in the current data, the experience reported by one participant of being unable to find a therapist who understood her experience of honour-based violence highlights the importance of cultural competence in trauma therapy. It is crucial that clinicians working with PwM/PTSD develop an awareness of how their own cultural norms impact their interpretation of trauma symptoms, whilst also recognising that cultural diversity may influence the presentation of trauma



symptoms and the meaning that clients attribute to them (Schnyder et al., 2016).

6. Limitations

Participants were all social media users who put themselves forward for participation, thus self-selection bias was inherent in recruitment. The sample is biased towards Western and English-speaking cultures. That the sample consisted solely of women may reflect the greater lifetime prevalence of PTSD in women (Olff, 2017) however, the experiences of men/people of other gender identities are not represented. Participant ethnicity was not obtained for all participants; thus, the study fails to capture potentially influential intersectional factors relating to race and culture.

As the Memory Experiences Questionnaire (Sutin and Robins) proved a poor fit for participants' experiences of multiple/repeated trauma, the self-reported categories of 'no memory' or 'only sensory memory' are not objectively defined. It is therefore unclear how homogenous the sample was in terms of the quality of their trauma memories. Participants reported a variety of different trauma events leading to them having PTSD without memories, some of which (e.g. early life and sexual trauma) are thought to have particularly great impact on survivors (Olff, 2017) and might therefore have influenced therapy experiences.

Conducting interviews remotely may have influenced participants' willingness to divulge personal information and limited researchers' ability to capture non-verbal communications.

Finally, the researchers are all qualified/trainee psychologists with experience of providing therapy, and the second and fourth authors have significant expertise regarding the impact of trauma. That this knowledge and experience will impact upon data interpretation is not necessarily a weakness of this fundamentally subjective methodology, considering the efforts taken to be transparent and reflexive during analysis and write up (Smith et al., 2013); however, it must be acknowledged.

7. Conclusion

People with unremembered trauma, who have received psychological assessment and/or therapy, have reported significant challenges and barriers to accessing and utilising these interventions for PTSD and attributed this, at least in part, to their lack of trauma memory. Based on these findings, providers and researchers need to consider how to improve equity of access, acceptability, appropriateness, experience of and outcomes from PTSD therapy for this client group, considering the recommendations above as a starting point.

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Data availability statement

Data available on request due to privacy/ethical restrictions.

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