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To cite this article: Victoria Williamson, Emily J. Pearson, Mark Shevlin, Thanos Karatzias, Dierdre Macmanus & Dominic Murphy (2020): Experiences of Veterans with ICD-11 Complex PTSD in Engaging with Services, *Journal of Loss and Trauma*, DOI: [10.1080/15325024.2020.1749784](https://doi.org/10.1080/15325024.2020.1749784)

To link to this article: <https://doi.org/10.1080/15325024.2020.1749784>

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 Published online: 15 Apr 2020.

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Experiences of Veterans with ICD-11 Complex PTSD in Engaging with Services

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ABSTRACT

This study aimed to examine how UK military veterans with complex post-traumatic stress disorder (CPTSD) engage with psychological services. Qualitative interviews were conducted with eight veterans with CPTSD. Data were analyzed using thematic analysis. UK veterans with CPTSD were found to experience a number of barriers in accessing and engaging with mental health services. That certain CPTSD symptoms (e.g., negative self-concept) may act as a deterrent to help-seeking warrants further exploration in future help-seeking initiatives to ensure that those with CPTSD are able to access appropriate care.

ARTICLE HISTORY

Received 29 February 2020
Accepted 27 March 2020

KEYWORDS

Complex PTSD; CPTSD; trauma; veterans; ICD-11; stigma; mental health

In 2018 the 11th edition of the *International Classification of Diseases and Related Health Problems* (World Health Organisation, 2018) recognized both posttraumatic stress disorder (PTSD) and Complex PTSD (CPTSD) as trauma disorders. CPTSD can develop following experiences of recurrent or chronic trauma, such as childhood abuse, slavery, severe domestic violence or exposure to torture. In the ICD-11, CPTSD includes the three PTSD clusters (i.e., re-experience, avoidance, sense of threat) as well as three additional clusters that reflect “disturbances in self-organization” (DSO); affect dysregulation, negative self-concept and interpersonal difficulties (World Health Organisation, 2018).

Evidence suggests that CPTSD may be more prevalent than PTSD in the UK and US population-based research (Cloitre et al., 2019; Karatzias et al., 2019). Further, research has also found CPTSD to be more prevalent than PTSD in clinical samples of veterans (Murphy et al., 2020). At the same time, veterans have been found to underuse mental health services, with

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 Supplementary data for this article is available online at [publisher's website](#).

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only half of those who were experiencing mental health problems accessing medical support (Stevellink et al., 2019). Many barriers to help-seeking and treatment have been found in trauma-exposed military samples, including access difficulties (e.g., long waiting times for appointments, difficulty getting time off work) and concerns about mental health-related stigma (e.g., a mental health problem will detrimentally affect one's career, cause others to see you as weak [Iversen et al., 2011]). Military personnel with PTSD have been found to report greater barriers to care and internalized stigma (e.g. feeling "weak" for having a mental illness) than those with other disorders, such as alcohol misuse (Williamson et al., 2019) with higher levels of PTSD symptoms associated with increased internal stigma (Hoge et al., 2004).

Given the recency of CPTSD as a formal diagnosis, little is known about the experiences of veterans with CPTSD regarding their perceptions of mental health-related stigma, barriers to care, and engagement with psychological services. Military populations with PTSD often have relatively high non-response rates and patients drop out and it is possible that it is those with CPTSD may particularly struggle to access and engage with treatment. Furthermore, whether the barriers to help-seeking reported by veterans with PTSD are similar to those reported by veterans with CPTSD is unclear. It is possible that other barriers are more salient in cases of CPTSD, particularly given the DSO related symptoms. The pervasive psychological disturbances characteristic of CPTSD, such as persistent feelings of worthlessness, heightened emotional reactivity and difficulties sustaining interpersonal relationships, may influence how and when individuals with CPTSD seek formal psychological help. Addressing such barriers may improve access to clinical care and enable recovery. Therefore, the aim of this study was to carry out the first examination of how UK military veterans with CPTSD engage with mental health services and their experiences of barriers to treatment.

Method

The study was approved by the Edinburgh Napier Research Ethics Committees (SHSC0030).

Participants

Veterans who had participated in an associated psychometric study on CPTSD assessment were recruited (Murphy et al., 2019). Participants were invited to take part if they screened positively for CPTSD using the International Trauma Questionnaire (ITQ; Cloitre et al., 2018). To be considered eligible for the study, participants had to be aged 18 years or more,

have served in the UK Armed Forces and received an offer for treatment for their psychological difficulties from Combat Stress.

The sample size was selected *a priori*. Eligible participants who had opted into the previous study [redacted for review] and were experiencing CPTSD symptoms were each given randomly allocated numbers which were ordered from high to low and then approached sequentially until eight participants were recruited. The collection of data from our sample of eight veterans resulted in thematic saturation which was determined by the research team when no additional themes were found from the reviewing of successive data.

Qualitative interview schedule and procedure

A semi-structured interview schedule was developed based on the existing literature and the research aims. The interview schedule included items relating to current help-seeking and challenges accessing support (e.g. when did you first seek help from a mental health service; how long were you having difficulties before you sought help; what were the biggest challenges of accessing support; what could have been done differently to help you; [Supplementary Table 1](#)). The interviews lasted an average of 45 min. Interviews were audio-recorded with consent and transcribed verbatim. Demographic information was also collected from participants.

Data analysis

Data were analyzed using the thematic analysis guidelines (Braun & Clarke, 2006). The researcher (EP) familiarized themselves with the transcripts, produced codes, searched for and developed emerging themes, revised and refined themes, and determined connections between the themes which, where applicable, were grouped together under superordinate themes. To ensure reliability, all codes and themes were independently reviewed by a second author (VW). A reflexive journal was kept during data analysis to acknowledge the influence of the researcher's prior experiences, thoughts, and expectations and avoid potentially biased interpretations of the data. Peer debriefing to enhance the credibility of the findings was conducted and discussions about the data interpretation and analysis were held with coauthors DM, TK, DM, MS who have experience with qualitative research and military mental health.

Results

Descriptive information

The majority of the sample were male ($n = 7$, 87.5%), married ($n = 5$, 62.5%) and had served in the British Army ($n = 7$, 87.5%). Half of the sample had

been deployed in a combat role ($n = 4$, 50.0%). All participants indicated that they had been exposed to experiences that met the criteria for trauma on the ICD-11. The mean age of participants was 64.3 years (SD 5.5) and the average length of military service was 23 years (SD 16.91; range 4–43 years; see Table 1).

At the time of the interview, five participants were no longer actively receiving support from mental health service, while others were receiving group therapy ($n = 1$, 12.5%) or outpatient therapy ($n = 2$, 25.0%). The majority of participants were taking one or more medications for their mental health difficulties ($n = 6$, 75%). One of the participants reported having first sought support between 1–5 years previously, three participants between 5–10 years previously and four participants stated that they first accessed mental health services 10 or more years previously. This suggests that the majority of the participants had been struggling with mental health difficulties for at least 5 years.

Qualitative results

Three key superordinate themes emerged following the thematic analysis: experiences of stigma influencing help-seeking, psychological factors influencing help-seeking, and organizational barriers to treatment. Excerpts have been anonymized to preserve confidentiality, with pseudonyms assigned by the researcher.

Experiences of stigma in help-seeking

One superordinate theme that emerged in relation to help-seeking was the experience of stigma and stigma-related barriers to care regarding their own and others' mental health difficulties. Different types of stigma and barriers were experienced both within and outside of the military setting, including career concerns, perceived stigma from others, limited awareness of support for mental health problems and issues relating to confidentiality.

The majority of veterans with CPTSD described that it was not acceptable to show any weakness or emotions because, as (ex-) military personnel, they should always be a pillar of strength. Compounding this effect was concerns that the disclosure of a mental health problem would negatively impact one's career and future professional progress. In particular, veterans described concerns that disclosure would lead others to think less of them, that they were not fit to perform their duties and may be a risk to colleagues. Given the potential impact on one's career, disclosing a mental health problem and seeking formal help was thought by some veterans to possibly have adverse knock-on effects on their family's finances and emotional wellbeing. These concerns hampered support seeking, with veterans

Table 1. Socio-demographic information for interview participants.

Participant	Sex	Age (years)	Relationship status	Employment	Nationality	Service	Rank (officer or in ranks)	Main role	Years in military
P1	Male	71	Married	Retired	British	Army	Officer	Combat	22
P2	Male	59	Divorced	Not working due to ill health	British	Army	Officer	Combat	21
P3	Male	63	Married	Not working due to ill health	British	Army	Officer	Combat	43
P4	Male	62	Married	Seeking employment	British	Army	Officer	Logistics/supply	40
P5	Male	65	Married	Retired	British	Royal Air Force	Officer	Military police	8
P6	Male	60	Widowed	Not working due to ill health	British	Army	Officer	Logistics/supply	42
P7	Female	60	Divorced	Not working due to ill health	British	Army	Ranks	Communications	4
P8	Male	74	Married	Retired	British	Army	Ranks	Combat	4

describing waiting until a crisis point was reached before seeking formal help.

As soon as they saw anyone reaching out for any support, their career immediately ended. There's a derogatory term, you're on a biff chit. I was a diver and engineer so if I had been put on any medication or seek any psychological support, I would have lost both.

When formal help was felt to be needed, many veterans described not knowing where to access support and did not feel that they had been adequately signposted to mental health services on leaving the Armed Forces. The limited awareness of the treatment options available may, in part, explain why several veterans described a pervasive fear that if they disclosed their mental health problems they would be "taken away," such as being sectioned under the Mental Health Act and placed in psychiatric inpatient care. During military service, some veterans described that help-seeking from Ministry of Defense (MoD) services was not an option as this care was not thought to be anonymous or confidential, especially as the staff member's role as a mental health professional was well known in the community.

I know that, younger soldiers didn't want to see mental professionals in work because of the stigma. You go to book in and say, "Oh, I've come to see Carol or Jackie or Jim and of course everyone knows who Carol, Jackie or Jim are

I didn't really [seek help]. I knew [my problems] had something to do with the Army... you hear about it. I'll be in the loony bin or I'll get... put away... [get] sectioned or something like that and I was so frightened.

Psychological factors influencing help-seeking

A second superordinate theme was found relating to emotional or psychological factors that influenced help-seeking. Sub-themes included poor awareness or understanding of PTSD and feeling unworthy of support. At the same time, social support systems to overcome such barriers were felt to be very important.

Several veterans described being unaware that they were experiencing trauma-related mental health problems. Some veterans were able to maintain daily functioning using coping strategies and therefore did not consider themselves to have a problem. Others reported being unaware that trauma exposure could be the cause of their symptoms. As a result, they were reluctant to engage with formal support when others suggested they should seek help. Acknowledgment that they were struggling often took several years to develop. Reluctance to seek support was also fueled by a feeling of being unworthy or undeserving of formal help. Many veterans

thought that there were other people in greater need of treatment or support services given their serious injuries or exposure to more severe traumas. Moreover, as described in the previous section, mental health staff were often well known in the local community. A further psychological barrier to seeking help was veteran concerns that their disclosure of traumatic events experienced during military service may cause distress for the clinician.

In my head others deserved it more than me and as far as I was concerned, I was still able to cope. There's people that were far more deserving and injured than me.

Notably, a number of facilitators to help-seeking were also experienced. Speaking with veteran peers who had experienced similar circumstances was felt to be very helpful, not only in realizing that they were not alone in experiencing psychological difficulties but also by sharing information about available services. Family members were often considered an invaluable source of support by many veterans. Veterans described that their partners, in particular, often helped them to manage their symptoms (e.g., dissociation, nightmares, etc.) and encouraged them to access formal treatment. Nonetheless, in cases where formal help was not sought for many years, some veterans described that their post-trauma responses and behaviors had a detrimental effect on their family, with a number of veterans now estranged from family members.

You know, it was only after quite a significant event when I wanted to end my life and I told her that she said right, you know, we need some help. When we went online and saw the combat stress advert.

Organizational barriers to accessing and engaging with treatment

The majority of veterans described that once they had decided to seek treatment, accessing care could be challenging as services were often overstretched and had long waiting lists. If they were offered treatment, some veterans described being offered a small number of sessions (maximum of 6) with several weeks between appointments. This was felt to be an inadequate provision of care to address the complex needs of military personnel. By comparison, physical health care was thought to be more easily accessible than mental health care, especially for those living in rural areas.

They are good at what they do, but the lady that I was seeing could only see me once every three or four weeks and she's going to give me a maximum of six sessions because of their funding, so I got six days therapy. About a half an hour a time, this wasn't enough to address my seven traumas.

The experience of making initial contact with a healthcare provider was especially salient. Some veterans felt poorly understood by healthcare

services. They perceived that, as a veteran, their post-trauma responses and symptoms were not commonly found in civilians given their unique exposure to combat trauma. Veterans reported that their General Practitioner (GP) did not recognize their symptoms as trauma symptoms and others felt that their psychological difficulties were dismissed by clinical care teams. Limited consideration was reportedly given for re-traumatisation and veterans described having to repeatedly state to different mental health services their reason for seeking help, the trauma(s) experienced and their current symptoms.

I'm sick of repeating everything. You know, it doesn't matter who you go to, I have to go back to the very beginning and explain everything.

Once support was accessed, difficulties building rapport with clinicians could be experienced. For example, if the clinician's gender or ethnicity was related to the trauma veterans were concerned that the clinician would be unable to effectively treat them as they would inadvertently trigger their trauma memory. Although, at the same time, many veterans identified several positive aspects of their treatment, including learning coping strategies to manage their symptoms, receiving advice about the support available from other veteran-affiliated organizations, and expectation management that their symptoms may never be "cured" but could be more effectively managed. Nonetheless, on discharge, some veterans felt that there was very limited follow-up care offered from mental health services and more regular contact following discharge would be beneficial.

I went into [removed]looking for a cure, my psychiatrist said to me, "Mate there is no cure. We can teach you ways of coping with it, but it will always be there. I can take it away, but I'll take half your life away with it. No happy memories, would you really want that?" And I said, "No."

Discussion

The aim of this study was to explore the experiences of UK military veterans with CPTSD engaging with mental health services and their perceptions of barriers to treatment. Our findings illustrate the considerable mental health stigma and organizational barriers to formal help-seeking that are experienced by this population, such as poor recognition of trauma-related symptoms by clinical care teams. Once care was accessed, treatment was often described as helpful in improving wellbeing and adaptive coping; although, these results also highlight the perceived inadequacies of the support currently offered to some veterans, with many describing long waiting times and limited follow up care.

Our findings detail how veterans meeting criteria for CPTSD can experience significant internalized mental health-related stigma. These results indicate that, despite efforts to reduce the stigma of mental illness and encourage open discussion in both the military and general population (Borschmann et al., 2014), considerable mental health-related stigma and barriers to care may continue to exist for those with CPTSD. Mental health-related stigma remains a key hurdle to formal help-seeking for CPTSD and this is consistent with recent studies of ongoing mental health-related stigma in military samples (Iversen et al., 2011; Jones et al., 2015). Notably, the present study found that veterans with CPTSD held concerns about being perceived as weak for having a psychological problem and felt unworthy of receiving formal treatment. Such internalized stigma beliefs are not uncommon amongst military personnel with mental health difficulties (Iversen et al., 2011). It is also possible that this may reflect DSO symptoms that are present in CPTSD, such as negative self-concept and worthlessness. This pattern is concerning and may also be relevant to younger veterans as previous studies with Afghanistan and Iraq war veterans have found that higher levels of emotional “toughness” (e.g., over self-reliance, suppression of displays of distress) to be significantly associated with poorer mental health (Jakupcak et al., 2014). In the present study, veterans also described concerns that if mental health difficulties were disclosed, then this could lead to their being sectioned under the Mental Health Act. This highlights potential areas to target in future mental health stigma campaigns; for example, publicizing positive patient testimonies that seeking help is a sign of self-awareness, that everyone is entitled to care and treatment often does not require inpatient care. A further concern of veterans with CPTSD was that their visit would not remain confidential or that others would know what they were visiting a particular clinician for. It is possible that incorporating clearer information about the tenets and limits of confidentiality as a central part of mental health stigma campaigns, as well as making this information more visible on service websites, may potentially be helpful in allaying this concern.

Another key theme found was the range of logistic or organizational barriers to accessing and engaging with treatment reported by veterans with CPTSD. Many veterans described having limited awareness of where to seek help and poor recognition of CPTSD symptomology by their GP. If formal help was sought, they encountered a long wait for treatment due to overstretched services, an insufficient number of treatment sessions and little follow up after discharge. It is possible that this, in part, reflects the fact that veterans participating in the present study first sought help prior to the introduction of the TILS (transition, intervention and liaison service) (National Health Service, 2017) which purports to offer veterans an initial

appointment within two weeks. Nonetheless, our results highlight the current lack of resources within mental health services and the resulting disrupted care systems. Our findings illustrate the continued need to ensure that veterans who wish to access care know how to do so, that GP's and other gatekeepers have the appropriate knowledge and skill in the identification, diagnosis, and management of individuals with trauma-related mental health difficulties, and that the latter is aware of the psychology services and specialist veteran mental health services in their locality. Greater awareness and understanding of the Armed Forces Covenant (Taylor, 2011) is needed to advocate for priority treatment of injuries sustained as a result of military service, such as CPTSD. As the demand for mental health services continues to grow, there is increased pressure on the UK Government to narrow the gap in funding between physical and mental health. However, Government health budgets are increasingly limited and therefore remote or online treatments may be a potential solution to facilitate early access to evidence-based care for those with CPTSD. Cost-effective online treatments have been developed to address several mental health problems, including non-complex PTSD, alcohol misuse, depression and anxiety (Kuhn et al., 2017; Leightley et al., 2018) and the development of a similar frontline approach for CPTSD may be especially beneficial given the pervasive impact CPTSD can have on wellbeing. Nevertheless, finding appropriate treatments for CPTSD remains a research priority in the area of psychotraumatology (Karatzias et al., 2019).

Furthermore, a key finding of this study was that veterans with CPTSD experienced social support to be particularly beneficial. Veteran peers were found to be especially helpful in normalizing experiences of mental health problems as well as signposting to available services. Family members and spouses were also considered a key source of support in helping veterans with CPTSD manage their distress. These findings are consistent with previous studies that social support is associated with improved outcomes post-trauma as well as better responses to treatment (Clapp & Gayle Beck, 2009; Gros et al., 2016). However, participating veterans also described that their psychological difficulties, if left untreated for several years, could contribute toward a break down in family relationships. This finding is consistent with previous research in both military and civilian families that mental health problems can disrupt family functioning as well as contribute toward poorer adjustment for spouses and children (Leen-Feldner et al., 2011). These results suggest the need for mental health services to not only consider the impact of CPTSD on veteran wellbeing but also the needs of their family unit and ensure that appropriate familial guidance and support is readily available. These results also suggest that early identification and treatment of CPTSD will be beneficial for veterans and relatives.

This study has several limitations. First, it is possible that the emergent themes are restricted by the limited demographic diversity of the veteran sample. For example, many of the veterans participating in the study were of, or nearing, retirement age (mean age 64.3 years) and it is possible that their views may not be generalizable to younger veterans. Future studies could include the perspectives of wider demographic diversity. Second, although all participants appeared to speak candidly about their experiences during the interviews, it is important to reflect on the potential influence of researcher and participant characteristics (e.g., social desirability) on the data collected. In an attempt to counter this, all participants were informed that participation was anonymous, confidential and they could withdraw from the study at any time. Finally, given the qualitative nature of the study, a large-scale quantitative investigation exploring help-seeking patterns in veterans with CPTSD and their experiences of help-seeking and treatment would be useful in determining the generalisability of the findings and how they compare across other clinical settings.

Conclusions

This is the first study exploring experiences of veterans with CPTSD and the difficulties they face in engaging with mental health services. While many personal, economic and political factors may act as barriers to care, this study suggests stigma may impair formal help-seeking, which is especially important for those suffering from a form of PTSD which has avoidance as one of its core symptoms. That CPTSD DSO symptoms, such as negative self-concept and worthlessness, may also act as a salient barrier to help-seeking for those with CPTSD warrants further exploration and consideration in future help-seeking initiatives to ensure that military personnel and veterans with CPTSD are able to access appropriate care. There is a need for better recognition of CPTSD symptoms by health care professionals as early identification and intervention can have a positive impact for both veterans and their families.

Funding

This research was funded by the Forces in Mind Trust.

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