Understanding the Care Ecologies of Veterans with PTSD

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ABSTRACT

Post-traumatic stress disorder (PTSD) disproportionately affects United States veterans, yet they may be reluctant to seek or engage in care. We interview 21 participants, including veterans with PTSD, clinicians who treat veterans and friends and family that support veterans through mental health ordeals. We investigate the military identity these veterans share. We explore how this may add to their reluctance in care-seeking behaviors. We also explore the roles of human and non-human intermediaries in ecologies of care and the potential for enhancing patient empowerment in current clinical treatment contexts. We discuss how military culture can be utilized in clinical care, how multiple perspectives can be leveraged to create a more holistic view of the patient, and finally, how veterans can be empowered during treatment. We conclude with recommendations for the design of sociotechnical systems that prioritize the above in support of the mental well-being of veterans with PTSD.

Author Keywords

PTSD, mental health, veteran care, therapy, treatment, care ecologies

INTRODUCTION

Human-Computer Interaction (HCI) research increasingly targets improved provision and uptake of healthcare [31]. Much of this work occurs in large-scale clinical systems that require collaboration across multiple stakeholders from disparate backgrounds. This includes doctors, patients, families, and institutions, among others (*e.g.* [46, 64, 36]). A growing focus emphasizes *patient empowerment*, foregrounding patients' perspectives amid these complex ecologies of care. It also requires close scrutiny of the various (human and non-human) intermediaries that play a role in facilitating care (*e.g.,* [62, 63, 64, 12, 36]). Our research extends this scholarship to US military veterans with post-traumatic stress disorder (PTSD).

PTSD is a trauma- and stressor-related disorder characterized by trauma re-experiencing (*e.g.,* intrusive memories and nightmares); avoidance of trauma-related situations, thoughts, and

feelings; negative alterations in thoughts and mood; and hyper-arousal [10]. US veterans are disproportionately affected by PTSD as compared to the US population, 16 percent to 6 percent respectively [4]. Among veterans, PTSD frequently co-occurs with other conditions that interfere with treatment engagement (*e.g.,* substance abuse [6], domestic violence [45], and medical illnesses [50, 27]).

Recovery from PTSD is possible, but treatment entails an intensive process. [76]. Veteran must revisit and engage with the traumatic event. Prolonged exposure (PE) therapy [76] and cognitive behavioral therapy (CBT) [2] are commonly utilized to treat PTSD in veterans. These therapies are delivered by clinicians through outpatient, intensive outpatient, and inpatient programs. They require guided work in the clinical setting as well as homework assignments in real-world contexts. Despite the proven effectiveness of PE and CBT only 50 percent of veterans with PTSD seek care [1]

Our research builds upon the work of [54] and [18], who have identified opportunities to design technology for PTSD. We provide an enriched understanding of the gap between care-seeking behaviors and care delivery for veterans with PTSD. We focus on barriers to therapeutic care and what role technology can play in enhancing patient empowerment. To do so, we interviewed veterans with PTSD, veteran-trusted others, and civilian-trusted others, as well as clinicians. This afforded us a rich understanding of informal and formal care-seeking and caregiving practices of US veterans with PTSD. Additionally, we investigated the role that military identity plays in veterans' care ecologies, their relationships and interactions with various actors in their environments [17, 48, 9], as they seek and engage with clinical treatment for PTSD.

Our analysis draws inspiration from Haraway's seminal work on *situated knowledges* [39, 38], building on recent HCI research that argues for the inclusion of partial and frequently conflicting perspectives in healthcare interventions [46]. Our findings indicate that military culture, poor matches between veteran and clinician, and institutionally mediated care discourage care-seeking. We discuss how military identities and caring perspectives can be leveraged. We also make technology design recommendations to facilitate patient empowerment. Our study focuses on overcoming barriers to care-seeking and identifying opportunities for patient empowerment in the veteran's ecology of care. Our primary contribution to HCI is that we examine the impact of military identity in the therapeutic context, making recommendations for the design of technology-mediated care systems for veterans with PTSD.

RELATED WORK

Below, we highlight the influence that military identity plays on veterans' care-seeking practices. Next, we explore the role of partial perspectives in ecologies of care. Finally, we discuss how our research extends a growing body of work on patient empowerment. These concepts are interwoven in the context of veterans with PTSD who are undergoing clinical treatment. We explore how patient information is generated and shared, as well as barriers that veterans faced in the treatment process.

Military Culture's Impact on Veteran Care

US veterans belong to a subculture of American society shaped by unique norms, conditions, and belief systems associated with the military. [23, 22, 37, 52]. They have a warrior mindset and collectivist identity [23, 74]. In adopting a warrior mindset, military personnel learn to value honor, fearlessness, restraint, and readiness for battle [37, 74]. Embracing a collectivist identity allows military personnel to learn to prioritize the mission and well-being of the group over themselves [23, 74, 80]. Veteran identity is associated with attributes such as stoicism [80], denial of weakness or illness, and secrecy [92]. These attributes pose challenges in seeking care and support [23, 80]. Veterans often dismiss their own reactions to trauma as a normal consequence to abnormal incidents from their military service [54, 80].

Psychotherapies such as PE [32], require for veterans to re-engage with traumatic memories under clinical guidance [54]. However, some veterans are reticent to disclose mental health needs to civilian clinicians [23]. Other veterans may emote in a restrained manner to maintain their military identity [23, 34].Clinicians may also be faced with knowledge gaps due to a limited understanding of military culture [23, 37, 52]. These embedded barriers may lead veterans to engage support networks outside clinical settings [54].

Support networks are critical during stressful times. This is the case when veterans leave the military and must put their military identity aside. Veterans who re-adjusting to civilian life may feel disconnected from their social groups [52, 80]. To regain a sense of control, they reach out to fellow veterans on social media [20, 81, 80]. These online forums connect veterans to a familiar culture and have notable communication features that include: disclosure strategies, self-censorship, judiciously sharing, and abstaining from posting to maintain individual anonymity [80]. Our study extends this work by examining the role military identity plays in care-seeking behavior in the context of clinical therapy and how veterans' real-world support networks affect mental health care.

Partial Caring Perspectives of Human and Non-Human Intermediaries

Haraway, among others, has underscored the need for including a variety of perspectives [38]. She argues these situated knowledges are disparate, rational, and incomplete but critical to constructing our understanding and are valid to varying degrees. These *situated knowledges* also compel us to question what we know (or do not know) by adopting a certain point of view and argues that we must strive toward understanding a variety of such perspectives.

Caring for individuals with physical or mental health problems is a collaborative process [65] and involves human intermediaries, such as trusted others. These are informal caregivers who support patients with some aspect of care [62, 18]. They may be friends, family, or peers and have been shown to play crucial roles for supporting health outcomes [19] for a variety of conditions, including cancer [47], dementia [33], autism [51, 43], and trauma [18]. The same is true for PTSD care. It involves the individual experiencing PTSD, clinical staff, and also other human and non-human intermediaries. Trusted others see the individual experiencing PTSD in real-world settings, understand their own experiences with the individual, identify actions to be taken [73], collaborate with the person receiving care [97], and aid in the overall health care of the individual [66].

Previous studies have examined the inclusion of trusted others in clinical care for PTSD in veterans. One study acknowledged a significant correlation between veterans' self-report and observer ratings for pathology and distress in a PTSD therapy program [41]. Another found that spousal partners were able to acknowledge and estimate veterans' combat-related PTSD severity in terms of observable symptoms such as anger, anxiety [72], and avoidance [78]. However, as these informants may be directly impacted by the veterans' actions, they are likely to rate any observed problems at a higher rate of severity than clinicians [72].

In addition to human intermediaries, there are also non-human intermediaries that play a role in supporting veterans' care. Machine learning analyses of electronic health records (EHR) [71] and Twitter data [15] have effectively predicted suicidality within PTSD samples. Biochip technology has been explored for more effectively diagnosing the stage and severity of PTSD [55]. Virtual reality has been employed to create realistic virtual environments for therapy sessions in veterans [75]. In *A Cyborg Manifesto* [39], Haraway argues that non-human perspectives have a strong role to play in understanding identity and lived experiences. In fact, Haraway makes no distinction between the roles of man and machine in her work.

Our research builds on prior scholarship related to partial knowledges in complex healthcare ecologies [46] by examining the perspectives that both human and non-human intermediaries might contribute. We aim to understand the role these human and non-human relations play in support of the mental well-being of veterans with PTSD.

Patient Empowerment in Stigmatized Contexts

The World Health Organization describes patient empowerment as, "*a process in which patients understand their role, are given the knowledge and skills by their health-care provider to perform a task in an environment that recognizes community and cultural differences, and encourages patient participation [14].*" Patient empowerment is critical for chronic care management [69, 70], including mental health conditions [30], to enhance patient well-being. The HCI community has recognized the value of patient empowerment and subsequently, has explored how to incorporate this notion for a variety of health conditions [59, 44, 88] and technologies [99, 94]. Various design considerations have been noted, including a need

for information sharing, visualization of treatment progress [21], and eliciting patient reflections to place at the center of care [86, 59, 58]. However, technologies focused on patient empowerment have been criticized for neglecting individual needs and even disempowering patients by placing too great an emphasis on treatment compliance [83].

Patient empowerment may be especially difficult in stigmatized contexts [46]. Stigma occurs when a person is viewed in a negative way for a perceived or real quality (e.g. mental health condition) [34, 21, 69, 30]. Individuals may stigmatize themselves through negative thoughts and emotions [26, 77]. Stigma negatively characterizes the out group, which causes segregation between *us* and *them*. Some people with mental health disorders avoid help-seeking behavior because they fear being stigmatized and discriminated against [40, 77, 79]. They may also believe they are not worthy of receiving clinical help, that treatment will not improve their condition [25], or that seeking help from their social networks will be burdensome [25].

Previous research has examined how to empower stigmatized patients to seek and manage care through a variety of technologies. These may empower individuals to control the visibility of the condition [13] or build upon existing social behaviors and technologies to cope [29]. They may also empower stigmatized individuals by incorporating their ideas and perspectives into the design process. For example, Marcu *et al.* utilized participatory design to empower HIV-positive youth to design a technology to improve medication adherence and fostered adoption and usage of an intuitive technology [60]. While some technology is designed to reduce the impact of stigma, all must appreciate the potential of further stigmatizing the population or exacerbating vulnerabilities [57, 89].

We extend the scholarship of patient empowerment to veterans with PTSD. They are a vulnerable population with a stigmatized condition, where information exchange may be especially challenging because of their military identity. We consider how to engage veterans on their own terms and follow WHO recommendations [28, 80] by incorporating community and cultural differences.

METHODS

We conducted semi-structured interviews with multiple stakeholders, including veterans with PTSD, clinicians, veteran-trusted others, and civilian-trusted others.

Recruitment

All aspects of the study protocol were authorized by our university's Institutional Review Board (IRB). Recruitment occurred through three primary means. First, we reached out to about 50 personal contacts associated with veterans, including veterans themselves, clinicians, and friends and family of veterans. We used snowball sampling to recruit additional participants [35]. Second, we posted messages about our study on 75 social media channels, such as Reddit, NextDoor, and Facebook, to attract participants. Despite these outreach efforts, we struggled to secure interviews from veterans and trusted others. Finally, we reached out to clinicians who worked with veterans through private messages via LinkedIn and email. In utilizing

a market-model compensation scheme [95], clinicians were not compensated, but all other participants were entered into a $50 gift card raffle for their participation.

Participants

All participants provided signed consent via paper or electronic forms before proceeding with the study. We interviewed 21 participants for our study, including 10 clinicians (C; one clinician is also a veteran and labeled CV), 5 veterans with PTSD (V), 4 veterans who are trusted others (VT), and 2 civilians who are trusted others (CT). No veteran or civilian participants had relationships with clinician participants. Two trusted others had relationships with two of the veterans with PTSD who participated in our study. Names of participants have been changed to protect their identities. An additional 10 potential participants chose not to proceed after reading the IRB consent form (8 did not respond after receiving the form, while 2 explained that they were not inclined to sign a consent form). All the clinicians interviewed had treated veterans with PTSD. They have worked in both the Veteran Administration (VA) and private institutions through outpatient and intensive outpatient programs. While the majority of the clinicians delivered therapy in person within a clinical setting, one clinician provided in-home treatment and another offered telehealth services. Clinicians were located throughout the United States. Additional details about the participants can be found in Table 1.

Among the veterans we interviewed with PTSD, four identified as male and one as female. These individuals had served as enlisted members of the Army or Marines. All of these individuals have received treatment for PTSD through inpatient and/or outpatient programs through a variety of institutions in various locations in the Northeastern and Southeastern United States. Finally, we interviewed trusted others, who are friends or family members who act as caregivers to veterans with PTSD. This included four fellow military veterans and two civilians. The military veterans represented the Army, Air Force, Navy, and Marines. Each of these individuals has had relationships with veterans suffering from PTSD, in which they interacted with the person three or more times per week. One veteran was the mother of a veteran with PTSD, whereas another veteran participant had several friends who were veterans with PTSD. Two were military officers who are still involved in the veteran community. Both civilian-trusted others were women who had long-term romantic partnerships with veterans with PTSD.

Data Collection and Analysis

All semi-structured interviews were conducted by the first author over a period of 12 months. Interview questions focused on understanding the therapy experience, technology usage, data collection practices, involvement of trusted others, and ways participants believed technology could support the therapy experience for each stakeholder group. Questions in each category were tailored to veterans, trusted others, and clinicians. For example, when asking about trusted other involvement, veterans were asked about the nature of their relationships with trusted others and in what ways these individuals were involved, if at all, in their care. Trusted others

Table 1. Background information regarding 21 participants (clinicians, veteran patients, and trusted others) in the study.

Name	Role	Location	Apprx Age, Gender	Mode	Base Diagnosis	Treatment Type Received or Provided	Military Branch	Years in Military
V1	Veteran with PTSD	NC	30-39, M	Email	PTSD with severe anxiety and depression	Attempted therapy but it was too stressful	Not disclosed	Not disclosed
V2	Veteran with PTSD	GA	20-29, F	Phone	PTSD, General Anxiety Disorder, Panic Disorder, Depression	Outpatient	Marines	6 years
V3	Veteran with PTSD	GA	70-79, M	In person	PTSD	Inpatient, Outpatient	Air Force	Not disclosed
V4	Veteran with PTSD	NY	20-29, M	Phone	PTSD, TBI	Outpatient	Army	5 years
V5	Veteran with PTSD	MA	60-69, M	Phone	PTSD	Inpatient, Outpatient	Marines, Army	10 years
VT1	Trusted Other, Veteran	VA	60-69 , M	Phone	-	N/A	Navy	21 years
VT2	Trusted Other, Veteran	AL	60-69, M	Phone	-	N/A	Army	37.5 years
VT3	Trusted Other, Veteran	AL	20-29, M	Phone	-	N/A	Marines	4 years
VT4	Trusted Other, Veteran	GA	40-49, F	Phone	-	N/A	Marines	-
CT1	Trusted Other, Civilian	GA	40-49, F	In person	-	N/A	N/A	-
CT2	Trusted Other, Civilian	GA	60-69, F	In person	-	N/A	N/A	-
CV1	Clinician, Veteran	GA	40-49, F	Phone	-	Intensive Outpatient	Navy	5 years
C2	Clinician	GA	30-39, F	Phone	-	Intensive Outpatient	-	-
C3	Clinician	IL	30-39, M	Phone	-	Intensive Outpatient, Outpatient	-	-
C4	Clinician	GA	30-39, F	Phone	-	Intensive Outpatient	-	-
C5	Clinician	GA	40-49, F	Phone	-	Intensive Outpatient	-	-
C6	Clinician	GA	30-39, F	Phone	-	Intensive Outpatient	-	-
C7	Clinician	NY	40-49, F	Phone	-	Outpatient	-	-
C8	Clinician	CA	30-39, F	Phone	-	Outpatient	-	-
C9	Clinician	IL	30-39, F	Phone	-	Intensive Outpatient, Outpatient	-	-
C10	Clinician	PA	30-39, F	Email	-	Intensive Outpatient	-	-

were asked about the nature of their relationships with veterans and how they perceived their role in that veteran's care. Clinicians were asked about involving trusted others in their clinical practice.

Interviews lasted from 30 to 90 minutes. 2 were conducted in person, 15 over the phone, and 3 via email. Choice for interview format was based on participant preference, which reduced participant burden while also limiting selection bias. Despite interview format, all participants answered the same set of questions (*e.g.,* for veterans: "What information do you provide to clinicians?", "What technologies, if any, do you use to to manage your condition?"). Email participants submitted written responses to these questions. In one case, the researcher sent a second email to a participant so that the participant would elaborate on their responses.

The interviews were analyzed by four of the authors using thematic analysis [16]. First, we conducted an inductive thematic coding analysis of relevant literature on themes of military culture, care-seeking, and patient empowerment highlighting the terms "Privacy," "Veteran Identity," and "Trusted Others in Treatment." The first and second authors independently coded the interview data from the bottom-up and developed a set of twenty axial codes across all participants. Using this initial code book, two authors again independently coded the interview transcripts from the top-down. The entire team met to review, debate, and refine the code book. We defined five overarching themes derived from the initial twenty axial codes to explore care ecologies as well as the behaviors and interactions that affect participants during care interactions. The themes of *care seeking, participation in care, treatment progression, trusted others opportunities, and future ideas for patient engagement* are referenced in the next section.

FINDINGS

We outline the complexities of engaging care ecologies of US veterans in clinical treatment for PTSD across three sections. The first section highlights how military identity shapes care-seeking activity based on themes related to *care-seeking*. The second section includes insights into human and non-human intermediaries role in care delivery to inform *participation in care* and leverage *trusted others opportunities*. The third outlines technology use in treatment based on the themes of *treatment progression* and *future ideas for patient engagement* according to veterans and clinicians.

We call attention to three main participant groups in the care ecology—civilian (CT) and veteran (VT) trusted others, veterans with PTSD (V), and civilian (C) and veteran (CV) clinicians. Veterans with PTSD offer perspectives on their care experience with emphasis on the roles of clinicians and trusted others in supporting such care. Trusted others provide insights on veteran behavior, as well as their own involvement in treatment. Finally, clinicians offer perspectives on their practices, the experience of treating veterans with PTSD, and the inclusion of trusted others in the clinical process.

Military Identity Shapes Care-Seeking Activity

Below, we discuss how veterans are reticent to seek clinical attention for their mental health issues. We detail the impact of military identity both as a barrier to care and its significance in the clinician-veteran matching process.

Veteran Military Identity Acts as Barrier to Care

Military training brings veterans to adopt a military identity that favors hyper-masculine behaviors such as strength [23, 80, 24], stoicism [80], and secrecy [92] and poses challenges to seeking and receiving care [23, 80]. Veterans assume this

identity after they undergo training in a branch of the US military. They reflect an identity aligned to the culture of the specific military branch. It is not gender-specific and seeks to unify under a common identity, as VT4, a veteran-trusted other participant, detailed in her experience as a US Marine:

> *"You know how Christians can be born again? Well, we kind of feel like we're born again in the Marine Corps. It's a new you, it's a better you. When you become a Marine, you have a new family; you're born into this family and you have brothers and sisters. We'll die for each other."-VT4*

Clinicians, veterans, and trusted others explained that veterans often sought care after PTSD symptoms could no longer be ignored. V1 shared the experience that brought him to admit he had a problem:

> *"...my wife attempted to wake me very abruptly and I sent her to the hospital. As this was unintentional, I did see that my PTSD was so severe that I checked myself into the VA that day to get treatment."-V1*

Other participants explained that military identities may discourage veterans from seeking care. VT1, a veteran-trusted other participant, shared the following experience. He was a contractor for the Department of Defense after the Gulf War, and his job was to encourage fellow veterans to enroll in health care treatment at the VA. He explained how difficult it could be to spur care-seeking behavior in veterans. He lamented the challenges he faced in his role:

> *"[These veterans] weren't ready to admit anything, to get them to 'fess up to having some kind of mental [health condition]... and get professional help. You couldn't get [them] to go to the hospital if they were physically ill. There is a culture that is built into the military: you will push on no matter what. You will not be a malingerer because you're part of a team and you never want to leave your teammates hanging. " -VT1*

Clinician Exposure to Military Culture Impacts Care
Veterans face an additional challenge when seeking care based on their clinicians' understanding of military culture. Clinicians C7, C3, and CV1 emphasized the need for breaking down the hyper-masculine shield and connecting with other veterans to deliver effective treatment. C7 reported that a solid match leads to developing rapport and ultimately, allows the veteran to share experiences more openly with their clinician. V4, a veteran with PTSD, explained why it was easier to connect with another veteran rather than a civilian:

> *"You're not as open with personal problems, especially things that revolve around military service. Civilians don't have those experiences, backgrounds, and issues." -V4*

Our interviews illustrated further that a strong match between the clinician and the veteran-patient (this term refers to veterans who have or are receiving clinical treatment) was critical not only at the initial stage but also for treatment adherence, engagement, and success. CV1, a clinician and veteran, said that because of a shared military identity, she was able to quickly

overcome barriers many non-veteran clinicians faced in encouraging patient vulnerability. C3 suggested that clinicians may encourage vulnerability in veterans by demonstrating their success with veterans or veterans with attributes similar to the patient.

Despite the clear need for cohesive matching, mismatches between clinicians and veteran-patients are somewhat commonplace. Three veteran participants diagnosed with PTSD had experienced a poor pairing with a clinician at the VA. They explained that these clinicians had not taken time to listen or understand their background and experiences. This caused V2, V3, and V5 to stop receiving care for a period of time before seeking a new clinician at the VA or in the private sector. CT1, a civilian-trusted informant, said that her ex-boyfriend had also experienced a mismatch at the VA. He had not wished to be medicated, was marked as defiant, and ultimately quit treatment with the VA. She described his experience:

> *"He didn't like that he was labeled volatile because...he didn't want to take medication for PTSD. They didn't offer him any other kind of therapy, like exposure therapy or anything like that. They just said, take medication...he decided not to finish [treatment]."-CT1*

Human & Non-Human Intermediaries Inform Care Delivery
In this section, we report the limitations and opportunities of incorporating two types of partial perspectives in veteran care. First, we examine human intermediaries, including the current role of self-report data in clinical care, dependence on veteran-veteran networks both in treatment and their daily lives, and the importance of trusted others in providing real-world observations of veteran behavior to clinicians. Second, we describe clinician and patient technology use to understand the role of non-human intermediaries in PTSD care.

Veteran Self-Report: a Primary, Problematic, and Partial Data Source in PTSD Care
Evidence-based PTSD therapies are reliant on veteran self-report [7]. For example, in session, veterans complete standardized assessments (*e.g.,* PHQ-9 [53], PTSD Checklist [91]), exposure-based homework assignments in which they record subjective units of distress (SUDs), and in-person exposure-based exercises alone or in a group under the guidance of clinicians [76]. Self-report is limited as it is inherently biased. As such, we have labeled veteran self-report as a 'human intermediary' as they may intentionally or unintentionally mediate what is reported during therapy and provide a particular perspective to the therapeutic context by doing so. Our data show that self-report is particularly problematic for veterans with PTSD who are likely to also suffer from traumatic brain injury (TBI) [3]. V1 said:

> *"Unfortunately, with all of my stress from lack of sleep and anxiety, my memory tends to really be short-term." -V1*

To improve recall, veterans in our study implemented strategies to record activities to share during clinical sessions. V4 and V2 were instructed to write down their nightmares by clinicians. Yet, they would only do this if they remembered or

felt motivated. Four clinicians instructed their patients to use the PE Coach mobile application's [5] recording functions to track homework.

Clinicians utilize their intuition to navigate and extrapolate from veteran's self-report [7]. Clinicians explained that during therapy sessions, they probed veterans' experiences more deeply to better understand how veterans cope and manage their lives. They stated this is critical as veterans may over-report symptoms to receive government care or compensation, just as they may under-report to maintain a strong image and avoid stigma[84].

Fellow Military Veterans are Peer-Support Systems
Veterans utilize veteran-veteran networks for support whilst in clinical therapy. Notably, this phenomenon of peer support via collective identity has also been identified in managing stigmatized illnesses in online communities [11, 100]. Participants explained that this reliance was learned during their military service when they were expected to rely on one another for mental health support. Veteran-trusted others VT1, VT2, and VT4 said active duty officers and enlisted ranks kept a close eye for aberrant behavior, and if the situation was serious enough, they willingly divulged information to officers or chaplains in order for that individual to receive appropriate care. VT4 said that this was critical as the hyper-masculine attitude of the military could prevent individuals from seeking out treatment. It is noteworthy that VT1 and VT2 both received formal mental health training during their service, while VT4 did not. VT2 described his readiness to care for a fellow veteran as such:

> *"We are trained to take care of one another, to watch each other's moods, to be sensitive to personal issues that are being raised, and to know of anything anybody was suffering from."-VT2*

The experience of VT4 showcased the relevance of formalized training in health received in the military. However, regardless of formal or informal training received by veterans, there was a clear sense of interdependence among veterans interviewed, regardless of military branch and rank.

Veteran-participants relied on one another for mental health support while in clinical care. They were able to note changes in each other's behaviors. For example, V2 and her veteran friends texted regularly and were able to detect issues through changes in texting patterns, noting the number and type of words used, tone, and speed at which the texts are exchanged. Veteran V3 regularly checked in via text or call with 58 other veterans he had met through PTSD treatment. If he didn't receive a response from one of these veterans, he would check in with other members of the network who may have had information regarding the well-being of the veteran in question. These veteran-veteran mental health support networks are close-knit and provide an outlet for genuine conversation. Veteran V4 noted:

> *"[My veteran buddies and I] have experienced some of these traumatic things, and we're able to comfortably get into these hard conversations." -V4*

It is important to highlight that not all support networks are positive. V3 was the only veteran to report a negative mental health relationship with other veterans. He noted that in his inpatient treatment experience, shortly after Vietnam, he and fellow veterans would congregate to smoke marijuana and drink heavily. He explained that at the time he did not view this as negative, but retrospectively noted that these interactions were not positive for his health. When he stopped drinking and smoking, the relationships with these veterans faded away.

Clinicians further utilize informal veteran-veteran networks in formal treatment during group therapy sessions. They said that veterans shared a cultural bond with one another which promoted exchanges. Clinicians also leveraged intricacies of sub-cultures between branches, generations, genders, ranks, and races. Clinician C7, who treated many African-American veterans, explained that care had to be tailored for cultural values and their years of service in the military. Clinicians C6 and C9, explained how important understanding these intricacies was for developing a cohesive, functional group therapy environment. Clinician C6 said that groups spoke more freely when formed according to age and service generation. For example, veterans of the same war typically related well to one another, but if gender was not balanced (*e.g.,* 1 woman to 9 men), the minority group was not likely to participate. Clinician C9 described how group dynamics could be affected if the military rank of the members were not considered:

> *"We have specific dynamics that we're aware of in the group setting. For example, maybe [some veterans] had bad experiences with leadership in the military and we have officers who are participating in the group. So we try to remain aware of any sort of interpersonal concerns or anything that could affect cohesion or kind of a smooth group process."-C9*

Trusted Others Provide Perspectives to Veteran Behavior
Our findings revealed that veterans relied on trusted others such as friends and family for support in real-world settings. Three veteran participants (V5, V1, and V3) were dependent upon their partners for health care such as taking medication, scheduling appointments, and managing symptoms. Two veterans (V2 and V4) relied less heavily upon trusted others but knew they could lean on their friends and family members if required. One veteran (V3) described having a negative, abusive relationship with a partner in the past. V3 stated that he could not and did not want to rely upon her for support.

Seven of ten clinicians incorporated trusted others into treatment in some form as they had clear access to observing the veteran in real world contexts. C3 and C5 only included trusted others in an educational session on PTSD (when appropriate). C7 conducted therapy sessions in the homes of veterans, and as a result, often interacted with and incorporated family members for education or included their perspectives with the permission of the veteran. C9, C10, C4, and C8 collected information from trusted others. This could be in cases where the veteran suffered from memory loss or was open to including an additional perspective. C4 believed that this was helpful, as veterans may not understand how their behavior affects others. The inclusion of trusted other perspectives as

described by C8 provides additional insight and understanding of both veterans and clinicians.

> *"One of the best sources of data is the collateral data that I get from family caregivers and friends that inter-act with the veteran on a day-to-day basis. That can be really telling and can affirm someone's story. It also provides another perspective which can be very power-ful in treatment, helping the veteran gain insight into their behaviors and the impact they're having in their environment."-C8*

Clinicians explained, however, that trusted others' perspectives were subjective. They may under- or over-report behaviors and attitudes as they directly impact their own lives. Further-more, clinicians shared that relationships between veterans and trusted others could be delicate. Two clinicians noted that including trusted other perspectives might worsen violence, aggression, or cause damage to an already fragile relation-ship. Clinician C3, who treats veterans through an intensive program, described the nuances of involving trusted others in treatment:

> *"We bring [a trusted other] in for only a week [for edu-cational purposes]. Ripping off that Band Aid—I don't know what's going to be in there. It could be a little cut or it could be open heart surgery. Opening up that can of worms in a very short time wouldn't work."-C3*

Trusted others such as CT1, CT2, and VT4 had limited partici-pation in clinical treatment but were able to see a variety of symptoms in real-world settings. Each had attended therapy sessions with a veteran with PTSD in the past and had provided information regarding real-world behaviors, as they were ea-ger to support them. CT1 described how she could recognize her ex-boyfriend's triggers, such as bags on the side of the road or children crying. She actively watched for triggers and sought to help her ex-boyfriend both in the therapy sessions she attended and in real-world settings. She explained:

> *"I'm no therapist. I've never taken any sort of psychology classes… it's not like that. I just think that [it's impor-tant] somebody that cares, that's an advocate almost for you but is also involved and wants to help in connection with other human beings."-CT1*

As a result of their informal caregiving in the real world, trusted others demonstrated a genuine desire to play a role in the therapeutic journey, as explained by CT1. Another partic-ipant, VT4, became involved with her adult daughter's care after she had had a serious mental health episode and the fam-ily began to suspect a mental health misdiagnosis. Her daugh-ter requested her assistance in contacting her regular mental health care clinician while she resided in an inpatient facil-ity. Veteran trusted-other VT4 explained how she provided information to the clinician ("her" refers to VT4's daughter) :

> *"I knew how important it was to mentally take images and audio recordings [about the incident] ... I don't want to downplay it and I don't want to, you know, amplify it; I want [the clinician] to know exactly what it was. So I showed [the clinician] how her body was moving... how*

> *she was talking. I explained how I went to her house to clean up the blood that was all in the kitchen. And so I knew that she had taken her hands and fingers and smeared the blood around on the floor because I could see the swirly pattern where she had painted with her [own] blood. -CT1"*

Trusted others, like VT4, were able to give the clinicians information that would otherwise be unavailable. In VT4's case, the daughter had no memory of the entire incident. Not all trusted others interviewed were eager to disclose such information. VT3, explained it would be difficult to decide what was appropriate to share. He did not wish to betray the trust or privacy of his fellow veteran.

Non-Human Intermediaries and Veteran-Patient Privacy
Veterans have access to a variety of non-human intermediaries (*i.e.,* technologies) to support PTSD care, including PE Coach [5], DOD Veteran Link [85], and social networking sites for veteran-veteran communication [80, 81], among others. Addi-tionally, various technological advances in the medical field have provided veterans with access to clinically sponsored technologies, such as electronic health records (EHR) and fitness wearables.

Despite such options, clinicians explained that only a small portion of the data assessed about veterans from session to session is collected in an EHR. Only past medical records, standardized assessments, and high-level notes recorded by the clinician are formally logged. They explained that detailed descriptions of conversations, exercises, or reactions to exer-cises (e.g., subjective unites of distress, SUDs) are noted by clinicians in separate, personal files. If trusted other perspec-tives are collected, these were not formally logged. Clinicians stated they they typically spent approximately 10-15 minutes reviewing the patient case in the EHR file prior to the patient appointment. In addition, clinicians said that veterans main-tain their own homework and SUDs in paper files or through mobile applications such as PE Coach [5]. Clinicians C3 and C9 both provided intensive outpatient care that included giving each veteran a wearable fitness tracker. They explained that veterans maintained their own quantified-self records from these devices and would verbally share sleep and exercise activity unprompted.

According to clinicians, the disjointed nature of patient data is due in large part to privacy concerns around potential misuse of the data. The patient EHR file is a legal document that can be accessed by the patient and potentially other parties. Clinicians include only what is medically and legally required to protect themselves and the veterans they treat. Clinicians explained that they would not want a veteran or another party to misunderstand or misuse detailed notes they took. C5 said:

> *"[The medical record has potential to be used negatively]. I tend to think about it in a legalistic way, so I put in things in the medical record that relate to safety concerns and risk. I'm making sure that the plan for the patients' continued course of treatment is in there. Whatever comes up in therapy sessions is not meant to be documented in a*

medical record. I don't need to write that my patient got in a fight with her husband over doing the dishes." -C5

Clinicians noted that concerns of privacy are normal for anyone who is disclosing health-related information. This is especially true for veterans. In our sample, all but one of the veterans expressed some mistrust of the government. For example, V4 explained that he received treatment at the VA but only revealed as much as necessary in order to receive financial benefits. He felt a loss of agency because in exchange for these benefits, V4 signed away his rights to talk about his experiences related to trauma outside of therapy; he cannot write a book or publicize what he saw or experienced. He said:

"The government's not entitled to your data. I just don't trust them enough to have it in their hands and have the best interest for the individual."-V4

Accessing Data to Empower Veterans during Treatment
Individuals with mental health conditions struggle to believe that treatment will improve their condition [25]. This is exacerbated for veterans who, as a result of military culture, have a tendency to be more self-reliant [28, 80]. In this section, we report veterans' understanding of their own progress during treatment and their expressed need for information access.

Noting Progress is Critical for Patient Engagement
Veteran participants expressed that a feeling of progress while undergoing treatment was critical for continued participation in PTSD therapies. One veteran, V1, lacked an understanding of how treatment had a positive impact on his life. He explained that facing the traumatic memories session after session was too overwhelming to feel like any progress was being made. He eventually quit treatment. V2, on the other hand, felt that treatment progression was clear over the first several sessions but that progress became more difficult to perceive as sessions continued:

"Some weeks [treatment] doesn't feel like it's effective. When I first started, every session had some sort of marked improvement because I was just a wreck. Everything was so hard, simple things like doing the dishes or going to work or just putting on shoes or showering."-V2

Clinicians indicated that demonstrating treatment progress was both motivational and informative for veterans. Clinicians devised the means to engage veterans in making sense of the data collected in accessible ways. Once veterans had gone through several treatment sessions, clinicians demonstrated progress by creating visual graphs of SUDs via Microsoft Excel or self-report measures through the EHR system. Clinician C9 encouraged veterans to create line graphs on paper despite having digitized data available, saying *"We keep their scores in an Excel spreadsheet and can easily print it out. I encourage them to track it themselves on paper for ownership of the process."* This exercise by C9 provided veterans ownership over data and an understanding of treatment progress.

Including Data Sources Can Help Verify Patient Progress
Clinicians suggested that current methods of demonstrating progress could be supported by collecting and displaying ad-

ditional subjective and objective data. In terms of subjective data, clinicians sought information about behavior outside the clinical office setting, including more timely veteran self-report and outside perspectives from third parties (*e.g.,* trusted others). Three clinicians desired objective, bio-sensing data to demonstrate the body's physiological progress during treatment. C10 said:

"[I wish we could have] something that could provide evidence of improvement through biological measures. We administer symptom checklists, which allows clients to see their positive growth on the chart, but if they were able to see an actual decrease in heart rate or skin response or even cortisol levels, that may reinforce the hard work of trauma treatment."-C10

Inclusion of biological measures, as described by C10, served to provide an additional, objective perspective for clinician consideration in treatment decisions and veteran understanding of progress. Though desired, the prospect of additional data to demonstrate progress was daunting for already time-strapped clinicians reviewing multiple data sources. However, both clinicians and patients agreed that demonstrating progress was critical for continued engagement.

DISCUSSION
We have investigated various aspects of the care ecologies of veterans with PTSD. First, we explored how military identity shapes the veteran experience as they seek and encounter clinical treatment. Next, we detailed the various partial perspectives of human and non-human intermediaries that contribute to the veteran's care ecology. Finally, we shared current information practices which are used to engage and empower veterans as they undergo clinical care.

Our research adds to the growing HCI literature on how ecologies of care can inform progress in patient healthcare (e.g., [49, 42, 19, 96, 87, 56] and design of appropriate technology [48, 9].) In particular, we focused on how this perspective can help overcome care-seeking barriers and can highlight opportunities for patient empowerment. It also confirms findings from recent studies that advocate for the integration of trusted others, into the clinical-care workflow, in the wake of trauma [18, 54, 80, 81]. We contribute to emerging insights on the integration of collective data practices in personal informatics [73] with a focus on mental health conditions [67]. Below, we discuss our findings in the therapeutic context and make recommendations for the design of technology-mediated care systems for veterans with PTSD. We outline how future technology design can enhance veteran-patient engagement with evidence-based PTSD treatments through affirmation of military culture, as well as leveraging the partial perspectives from multiple intermediaries.

Implications for Embracing Military Identity in PTSD Care
Military identities promote attributes such as self-reliance, stoicism, and strength [23, 80, 24, 92], whereas PTSD therapies demand connection, expression, and vulnerability. Our findings add to existing research [18, 54] that show how technology leveraging strong, communal identities of veterans can empower their treatment journey [101]. Accordingly, our

findings have demonstrated that military identity shapes the veteran care experience. Often, the military identity is seen as a barrier to care, preventing veterans from engaging in treatment. Clinicians must break down this barrier by attempting to understand the experiences of military veterans. This lends itself to more successful matching between clinicians and patients, which results in more effective treatment. Based on our findings, we outline three approaches to leverage military culture in technology design.

Embrace the Individual's Military Identity
Military identities cannot be separated from the veteran. Future technologies can leverage military identity to empower veterans. For example, technologies may serve individual veterans with personalized progress measures by visualizing qualities consistent with military identities, such as acts that demonstrate strength. This can aid in empowering patients by demonstrating progress in their preferred terms while expanding the military-related lexicon of the clinician during treatment. This is akin to adopting an assets-based approach [61] when designing technology for holistic care.

Design to Bridge Civilian and Military Cross-Cultural Barriers
We found that when clinicians in our study showed consideration for military identities and experiences, they were more likely to develop rapport with the veterans in their care. When this did not occur, veterans were more likely to disengage with treatment. Future designs may be able to guide and educate clinicians in cross-cultural competency with military identity. Interfaces may provide conversational prompts which serve to establish understanding between civilians and veterans.

Predictive Matching as An Affirmation of Military Identity
Furthermore, future designs may also consider taking a personalized approach by incorporating predictive profiles for clinician-patient matching. Such technologies may offer concise overviews of successful outcomes across clinician and patient archetypes. Veterans would be able to articulate their military identity. In parallel, clinicians could be provided with insights about veteran's expectations to guide interactions. This would also allow technology to highlight patterns of successes and areas for improvement across treatments and provide support systems to strengthen the dyadic clinician-patient relationship.

Implications for Leveraging Multiple Perspectives in Ecologies of Care

A variety of human and non-human intermediaries provide partial perspectives to veteran care ecologies. Our findings describe contributions of three human intermediaries to the care ecology. First, we described how veterans' self-reporting ability may be impacted by their military experience. Second, we detailed the interdependence of veterans in care. Third, we explained how trusted others can participate in care.

Facilitating Self-Report
Veterans regularly contribute self-report data in clinical sessions. However, this group is disproportionately affected by issues of memory lapses due to the high chance of co-morbid conditions such as traumatic brain injury or alcoholism. Already, clinicians suggest that veterans implement strategies

to improve their recall by utilizing apps such as PE Coach or recording their thoughts or dreams on paper or mobile notebooks. Future designs may consider the collection or more timely and accurate self-report data by utilizing smartphones. First, ecological momentary assessments (EMAs) might be utilized to collect data regarding the veteran's mood and activities throughout the day to obtain information on behaviors outside the clinical context to be shared with clinicians. Furthermore, smartphone sensor data and wearables may be able to provide additional information on physical well-being and sleep, as well as application usage. For example, when veterans are instructed to use PE Coach to complete therapeutic homework assignments, passive data sensing (e.g. application usage, location) may be able to provide clinicians with a sense of patient engagement and focus on the task at hand. Such data can also be visualized and presented to patients too [82].

Capitalize on Veteran Interdependence
Clinicians shared that they capitalize on veterans' shared culture in group therapy sessions. They carefully formed groups to enhance the dynamics between sub-cultures, allowing veterans to connect over the basis of shared experiences. While there are toxic relationships inherent to the in- and out-group mentality, military identity seeks to unify groups through habitual exposure. Studies show that veterans find support in online communities [81]. Our findings reveal that veterans are able to identify aberrant behavior via in-person and virtual contexts (e.g. texting). In a similar vein, technology could be designed to support military identities in a group setting, leveraging the existing camaraderie among groups of veterans, as peer support has been shown to address gaps in care for mental health [68]. Other platforms include mobile applications (e.g. VA DoD Veteran Link [85]) that can prioritize peer coaches to support veterans in navigating the PTSD treatment journey. Such technologies can create connections between veterans in similar stages of treatment, facilitate positive interactions through culturally appropriate guided conversations, and assist in creating online or virtual events. However, the privacy and confidentiality of veteran-patients needs to be foregrounded in the design of such online communities.

Incorporating and Educating Trusted Other Perspectives
Our findings demonstrate that trusted others are able to identify real-world data about veteran behaviors and, in some cases, to provide this collateral information to clinicians. Several clinicians in our study already include the trusted other's perspectives into the PTSD treatment process. These findings emphasize allowing veterans to pick the trusted others to be included as part of their care. They also reinforce the importance of adequate screening along with a flexible inclusion of multiple trusted others. EMAs can also be used to collect relevant information at regular, timely intervals in the real world. A second opportunity for future technology is to educate trusted others on what symptoms, behaviors, and attitudes are useful to report and in what manner. This is important because this knowledge is something that is otherwise gained through the personal experience of individuals suffering from PTSD.

Balancing Multiple Perspectives for Review
Our findings indicate a variety of human and non-human perspectives contribute to the care ecology of veterans with PTSD. For example, clinicians selectively utilize EHR data, their own notes, collateral information from trusted others, and biometric data from wearables (*e.g.,* heart rate, stress level) to supplement patient self-report. Should these data sources be incorporated into future technology, designers must attend to common barriers identified in using patient-generated data within a clinical setting [93]. Technology can coalesce patient data, including individuals' session-to-session progress, cohort progression, and analysis of EHR data through machine learning and data visualization to improve clinician reviews. This would facilitate reconciling disparate data sources to effectively synthesize patient health data for decision-making. Attempts have been made to take into consideration clinicians' need to streamline workflow. However, there need to be new systems that allow access to the data by both patients and clinicians [82]. The inclusion of such perspectives might provide more informed participation in treatment.For example, it can be easily visualized to track progress. Technology must consider how to weigh and display data from each of these subjective, partial perspectives [38] of human and non-human intermediaries in the care ecology. It must consider how to maintain or enhance veteran engagement and empowerment at the center of the care ecology.

Implications for Veteran Empowerment

Understanding of patient empowerment in HCI is steadily growing (*e.g.,* [68, 67, 45, 21, 66, 13, 74]). However, patient empowerment in stigmatized contexts is less understood. Technologies may be employed to help individuals seek out and manage care [29]. They can also stigmatize or exacerbate vulnerabilities in these populations [57, 89]. In our study, veterans feared Government misuse of their mental health data to negatively affect benefits. Clinicians noted this was possible and subsequently, limited data input.

Veteran Control of Data
For veterans to feel empowered, they must have access to monitor and utilize their own mental health data. They should be provided with a transparent understanding of how the data might be used and opt in or out of logging certain information in clear, common language. Research has already explored how such variables can prompt reflection through patient-facing interfaces [86, 59, 58]. However, further research is needed to explore customization of technology to integrate relevant patient-centered presentation of data for PTSD care.

Supporting Ephemeral, Non-Institutionalized Data Solutions
Another barrier to data collection during treatment is the veteran-patients' mistrust of institutional authorities contributing to feelings of mistrust and surveillance reported in similar health research [98]. We provide two design implications. First, future designs might be created by non-institutional authorities. At this juncture, much research and technology development for veterans is conducted by the DoD and VA. Second, we suggest that disparate data points collection use ephemeral media to display particularly sensitive information.

Patients can define such measures to demonstrate and deconstruct treatment progress through measures that cannot be permanently linked to a veteran's records. For example, this type of ephemeral mechanism has been made popular by social media platform, SnapChat [8]. This could be reformatted for medical purposes to utilize data and engage patients.

The Challenge of Veteran Participation for Future Design
HCI researchers who intend to work with this audience must be sensitive to possible reticence on the part of veteran-patients. Research methods such as co-design and participatory design rely on group dynamics that may be hidden or become invisible when recruitment of participants is approached through institutional authorities. Future research and design can investigate how to generate a more holistic picture of veteran health while maintaining or enhancing patient empowerment. While it is optimal to partner with the veteran in the design process, a more pragmatic approach is to seek user feedback over time.

LIMITATIONS AND FUTURE WORK

Conducting research with individuals from vulnerable and stigmatized populations introduces a set of challenges. First and foremost is the difficulty in accessing participants [90]. In this study, targeted participants were very hard to reach despite extensive recruiting schemes. Informed consent further constricted the participant pool. One option was to simplify the consent procedure; however, we did not choose this option because simplified consent would significantly limit the type of questions we could ask. Future research could investigate if forgoing signed consent leads to enhanced recruitment and, by extension, different findings. Future studies might also aim to have a sample that resembles military demographics. This could allow us to investigate designing for under-represented military veterans such as women and racial and ethnic minorities. Another area that requires attention is the role that the source of PTSD (combat versus military sexual trauma, MST) plays in shaping care-seeking behaviors. Furthermore, our research examines a narrow part of the veteran's PTSD experience: the therapeutic context. As past studies have acknowledged [80, 28], additional research is needed outside of the clinical setting. This may include designing technologies for PTSD management in daily life that leverages military culture to support veteran mental health.

CONCLUSION

HCI is increasingly investigating complex ecologies of care and the importance of patient empowerment. We extended this work by focusing on barriers to therapeutic care among veterans with PTSD and exploring what role technology might play in enhancing empowerment. Drawing on qualitative research inquiry, we uncovered the challenges and opportunities in care-seeking for veterans with PTSD. We discussed how the veterans' military identity might lead us to enriched design opportunities. Future design would likely benefit from leveraging the presence of partial caring perspectives owing to additional human and non-human intermediaries, with the understanding that the veteran must be at the center of the design activity.

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