Veteran-centered design of a Post-Traumatic Stress Disorder (PTSD) tool: Qualitative Analysis of Interviews with Veterans

Many veterans from recent wars are suffering from Post-Traumatic Stress Disorder (PTSD). Ideas for novel PTSD supportive technologies were explored through iterative semi-structured interviews with veterans diagnosed with PTSD. A qualitative analysis of transcribed interview data suggests emerging topics pertaining to veteran behaviors or attitudes, overall improvement opportunities in the current PTSD care, and functional and information requirements for PTSD-supportive technologies. Findings suggest hyperarousal triggers inhibit quality of life by encouraging avoidance, high perceived value of well-timed alerts, and a need for closing a disconnect between clinicians and their patients. Findings will inform the design of supportive solutions to connect patients to peers, report crucial information to clinicians between sessions, and leverage breathing or meditation exercises to encourage healthy refocus. Findings are expected to inform the process of designing novel PTSD treatment-supportive technologies and enable them to be better integrated with the current care system.

INTRODUCTION

Post-traumatic stress disorder (PTSD) is a mental health disorder or an anxiety-based psychiatric condition developed after witnessing or living through distressing events along with feelings of fear, helplessness and horror. Four main symptoms are associated with PTSD are re-experiencing the event (e.g. nightmares, flashbacks), avoidance of events similar to the traumatic event, negative feelings and thoughts, and arousal and reactivity related to the traumatic event (e.g. aggression, hyperarousal, difficulty to concentrate or sleep) (American Psychiatric Association, 2013). Symptoms need to be present for at least a month before diagnosis ("DSM-5 Criteria for PTSD - PTSD," n.d.).

PTSD is prevalent especially among veterans who have served in recent combats. Around 14-16% of deployed U.S. military personnel are associated with symptoms of PTSD (Hoge et al., 2004). According to Fulton et al. (2015), approximately 23 percent of veterans of recent wars in Iraq and Afghanistan suffer from this condition. This rate is far above the 7.8% estimated prevalence among general population (Kessler et al. 1995).

While several treatment options exist for PTSD, issues related to monetary concerns, scheduling conflicts, access to adequate healthcare clinics in close proximity prevent veterans from receiving appropriate treatment (Institute of Medicine, 2013). Other barriers include scheduling complications, redeployments for active duty personnel, high provider turnover, and poor-patient provider relationship (Chase et al., 2016). In addition, social stigmas may prevent veterans from seeking help for mental disorders, as this can sometimes be seen as a sign of weakness (Corrigan, 2004; Mittal et al., 2013). Such stigmas associated with PTSD can hamper treatment for a substantial subset (over 40%) of veterans (Kulesza et al, 2015).

The above-mentioned barriers negatively affect veterans' re-integration into society. Research shows that only about 40% of returning veterans from Iraq are interested in receiving help amongst those who screened positive for PTSD, depression or general anxiety disorder three months post deployment (Brown et al., 2011).

Completion of treatment as well as issues with pharmacotherapy vs. psychotherapy-based treatment have also been studied as factors contributing to poor treatment. A preventive approach that focuses on early intervention and treatment for PTSD and comorbid illnesses such as depression is needed to improve outcomes and reduce long-term medical care costs (Geiling & Rosen, 2012). An outcomes-based research and real-time epidemiology for tracking veterans' progress through the healthcare system could be implemented to guide therapies and preventive strategies. Early intervention and treatment may also reduce suicidal thoughts and avoid alcohol or tobacco abuse later on in life for veterans. This will also save costs arising from secondary complications associated with alcohol or tobacco such as alcoholic liver disease or a pulmonary complication (Geiling & Rosen, 2012).

Technological interventions have been discussed as viable treatment alternatives in the recent literature (Henderson, Davis, Smith, & King, 2014; Majerowicz & Tracy, 2010). Mobile health (mHealth) apps have seen a surge in recent years, especially to manage chronic conditions, such as diabetes (Ciemins, Coon, & Sorli, 2010), and mental health disorders (Luxton, McCann, Bush, Mishkind, & Reger, 2011). Although mHealth apps offer several advantages over more traditional methods, including the option of location tracking, keeping notes, and discreteness (Becker et al., 2014), the evidence suggesting the adoption of user-centered design and evaluation approaches is largely absent. Systematic investigation of user's need, expectations, and past experiences is essential to ensure sustained usability of mHealth apps (McCurdie et al., 2012). In addition, apps need to be validated to ensure proper treatment and improvement in the patients. While there are hundreds of apps available for PTSD, only a few have been validated using formal human factors and usability engineering methods and integration into clinicians' work remains an overall gap (Rodriguez-Paras et al., 2017).

The overall scarcity of literature on PTSD-supportive technologies or tools can be traced back to the complexity of PTSD care and lack of a systems perspective and user-centered design approaches. With a combination of coordinated and ad hoc efforts to meet the demands, the current PTSD care system has naturally evolved into a highly complex socio-technical system with multiple stakeholders. To design a tool to fit in the existing care system, it is imperative to first address the system's complexity from the perspectives of both end-users,

i.e., healthcare providers and veterans with PTSD. The lack of systems perspective in currently available tools which could lead to a loss of potential opportunities for improvement is partly due to the absence of clear understanding of the current PTSD care system for veterans to inform the design of such tools (Moon et al., 2017).

As an initial effort to address such a research gap, this paper investigates *veterans' perspective* on improvement areas in the current PTSD care system and how these areas can be addressed with potential technologies or tools. Recent interviews with clinicians have led to a model of PTSD care that include six phases: quick screening, screening & diagnosis, prescription, treatment, in-between sessions, and follow-up & diagnostic re-assessment (Moon et al. 2017). Moon et al.'s (2017) findings suggest that the current system lacks consideration of the unique characteristics of veterans with PTSD and lacks treatment control in-between sessions. Building on these findings, this research aims at understanding the unique behavioral and attitudinal characteristics of veterans with PTSD, identifying improvement opportunities in overall PTSD care processes or pathways (especially in-between sessions), and deriving functional requirements for PTSD treatment-supportive technologies or tools.

This paper documents our findings from an iterative qualitative data analysis (QDA) of semi-structured veteran interviews to inform our current research and development of a sensor-enabled smartwatch tool for remote monitoring of PTSD patients.

METHODS

Qualitative Data Collection

To investigate *veterans' perspective* on improvement areas in the current PTSD care system and how we can tackle them with potential technologies or tools, semi-structured subject matter expert (SME) interviews were conducted with 20 veterans who are diagnosed with PTSD. All of interviews were combat veterans who are receiving or have received PTSD treatments (i.e., psychotherapy and/or medications) from VA and/or non-VA providers. A snowball sampling method was used to recruit participants through bulk emails sent to several veterans' organizations in South Texas. A convenient sample was also used to recruit veterans who participated in Project Hero's (a non-profit organization that organizes bicycle riding activities for veterans and first responders suffering from PTSD) various events. The study received Institutional Review Board (IRB) approval from the authors' institution. Participants received a $50 Amazon gift certificate after completion of the interview. In case of any discomfort, mental stress, or frustration that a participant could experience during an interview, the research team prepared phone numbers for support or help from related organizations including veteran crisis line and campus psychology clinic.

To reach a level of knowledge saturation, semi-structured interviews were conducted iteratively based on a predefined list of questions that changed subtly as the project progressed. Interviews took about 30 to 45 minutes.

Qualitative Data Analysis

Interviews were transcribed, coded, and analyzed by two coders using MAXQDA-12. The general thematic analysis approach we use mimics the Corbin and Strauss approach in that it contains three phases of sense-making which seek to refine themes and model relationships among interviewee responses (Bryman, 2015; Corbin & Strauss, 2015). This general thematic analysis approach proceeded from an understanding that inquiry could yield *inductive* or *deductive* results. Therefore, the coding and QDA process was arranged into three stages: (1) Initial Coding, (2) Focused Coding, and (3) Modeling Relationships.

Initial Coding accounted for *deductive* themes constructed from predefined interview questions, while *inductive* themes "emerged" from tangential conversation made possible by the semi-structured nature of the interviews. In *Focused Coding,* entropy among responses was reduced by combining like responses among the inductive and deductive themes. Finally, in *Modeling Relationships*, we explain findings in the context of relationship to other findings.

Inter-coder reliability check was intermittently performed, facilitated by the visual and statistical tools within MAXQDA-12. More specifically, each person coded the transcripts by categorizing question responses. The coding outcomes of multiple coders were compared using MAXQDA. The dispersed and sometimes conflicting responses were finally synthesized by resolving these conflicts until a consensus was reached between the two coders.

RESULTS

A highlight of findings is presented in alignment with the intent of our QDA: (1) to understand behaviors and attitudes, (2) to identify opportunities in the "overall PTSD care process", and (3) to develop functional requirements for potential supportive technologies. Together, these categories comprise a set to begin defining our space of PTSD care opportunities.

Unique Behaviors or Attitudes of Veterans with PTSD

Design solutions that are compatible with veteran world-outlooks and daily lives require understanding their behaviors and attitudes. They are described in no particular order.

Topic 1 emerged among responses regarding the greatest struggle between therapy sessions. *Topics 2 and 3* represent the most frequent responses regarding how a veteran resolves their physiological symptoms following a hyperarousal onset. Note that despite the implicit frequentist nature of these interpretations, an effort to acknowledge miscellaneous categories has been demonstrated throughout the study.

Topic 1: Social Isolation. Over half of the participants described a sense of societal disconnect or their own perceived debilitating isolation. Indeed, our language is not hyperbole:

"I slip off into self-isolating behaviors and negative behaviors where I just stay at home and don't get anything done and let my mind go back to things I don't want to think about but I can't stop myself from thinking

about them so that can be debilitating and to get out of that I ride my bicycle…"

Topic 2: Avoid/Leave Situation. The social isolation may be partly explained by one's effort to minimize exposure to PTSD hyperarousal triggers. About half of the participants mentioned their tendency to avoid or leave situations where there are or may be triggers, of which at least half of those reported include "large crowds", "public places", or "unexpected sounds".

"Avoidance. That's the main thing to avoiding the symptoms or whatever the trigger was. I don't go out. Of course, I live in Killeen where its all military so you don't go out on the first and the fifteenth, you don't go out anytime during those. So, you know you go out in the middle of the afternoon or on a workday off pay day weekends crowds are reduced. And so, avoidance is the best thing I do. A lot of time I just go, and I haven't done that in a while, probably couple times this year but I would just go lock myself in my bathroom for an hour, like, so, and just sit and be quiet."

Topic 3: Breathe and Calm (Refocus). More significantly, a majority of the participants reported breathing exercises, meditation, or other mind-calming techniques for resolving hyperarousal states. From modeling these relationships, it seems there is a mode of behavior developing around the trigger events in how veterans avoid them (short term avoidance and long term isolation) as well as how they choose to resolve them (deep breathing and refocus exercises, or leaving the situation). One particular participant summarizes this succinctly:

"I try to avoid the situation to begin with but if I can't and I am in it I try to remove myself from the situation. Get out of the environment which I am in. If my wife is there, she will normally sense what is going on and she will pull my hand or hold my hand and just try to keep me calm… I've done yoga in the past so the deep breathing from yoga definitely helps me bring myself down. I try to think about something else. I call it meditation. I try to focus on something specific as opposed to all this other stuff which is going on..."

Improvement Opportunities in the Current PTSD Care

Interviews led to some holistic observations regarding opportunities in the "overall PTSD care process". Findings can be categorized into two groups: those pertaining to a veteran's regular psychotherapy appointment (i.e. "treatment"), and those during times and places *between* these appointments. *Topic 4* emerged after asking the participants about general challenges in receiving treatment while *Topic 5* represents the most significant challenges during the time between sessions with a therapist or doctor.

Topic 4: Disconnect from the Therapist. The majority of responses involve some frustration at systemic issues related to entering and maintaining treatment with the same doctor within the military healthcare system (namely, those resources offered by the VA). Specifically, the limited frequency of visits and high turnover rate of therapists inhibit the development of a relationship between doctors and patients.

"I think it is a very difficult system because of the volume of patients. That, I have gone sometimes to the VA because I feel stressed out. I feel

like things are very difficult in life and I kind of don't have an answer so I'm just going to go talk to a counselor. You can't, I don't make an appointment I just drive there and someone will see me but it is very informal. There is no follow up and it's just me on a distressed situation. I have in my own personal experience, I can't tell you that I have never gone through a whole…. I can say I have never seen the same doctor twice."

Topic 5: Hyperarousal Triggers. Over half of the interviewees mentioned triggers and their subsequent hyperarousal onsets as significant challenges between therapy sessions. Most of these discussed loud, unexpected noises and crowded, public spaces as particular stimuli for the onset of hyperarousal states, although a notable many specifically mentioned scents and imagery associated with burns, fireworks, the fourth of July holiday, or war. Recall how the perception of these trigger stimuli is such that a person may prefer isolation or avoidance over risking encounters. One participant's comment exemplifies all these observations:

"Crowds, definitely crowds, are bad. Unexpected noises, like for example, Fourth of July, I know there are going to be fireworks… There's some smells sometimes, people burning trash, gives me flashbacks of certain places. I really avoid watching the news, and I really try to avoid movies that military variety, I just enjoy them but usually whenever I watch them I have nightmares of stuff..."

Functional Requirements for Potential PTSD Treatment-Supportive Technologies or Tools

Veteran feedback was used to explore *functional* requirements for PTSD treatment-supportive technologies. The word "functional" demonstrates our pursuit of an objective assessment that reveals "solution-neutral" functions, thereby informing design decisions about *how* systems or solutions can fulfill these functions. The following topics represent veteran responses to direct inquiries about what functions may be useful in a supportive technology.

Topic 6: Warn/ Intervene for Hyperarousal Onset. Over half of the veterans imagined a device capable of buzzing, alarming, preventing, or otherwise intervening in the onset of a hyperarousal state following trigger stimuli. This was complemented by a notion of continuous objective monitoring of some useful biometric.

"I know it's pretty hard but I wished there was a way that somehow you could give me a heads up that I was about to have a trigger, I don't even know if that possible, if I knew I was about to have a trigger, that way I could start focusing and get myself out of that situation and prevent it."

Topic 7: Peer-to-Peer (P2P) Connection. P2P connection was a function that had been predetermined to have some value due to previous conversations with clinicians and veterans outside of the study. It involves connecting veterans to other veterans, or perhaps even family members, via a support community. The sentiments around this feature are largely mixed. It seems the appeal depends largely on the personality and social circle of the veteran.

"... I just need something so I can manage it myself. I just want to get to a point where I don't need someone to help me manage my issues"
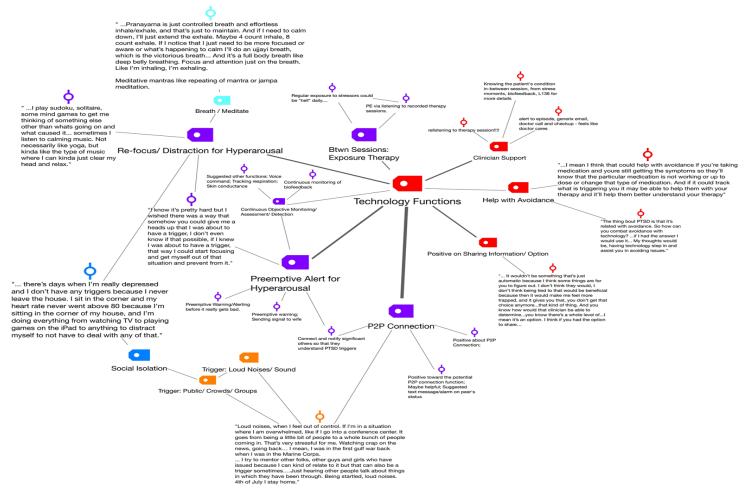
Figure 1. Relationships between responses and code categories illustrate the design space

"... you want someone who is trustworthy and who has been there and understand what you have been through. Not someone who doesn't understand what you are going through, who hasn't seen it. Getting someone who is compatible with someone. That makes that person comfortable. The shoe's gotta fit."

Topic 8: Clinician Support Function. Half of the veterans commented, when asked directly, that they would be okay with sharing their information with clinicians. This specifically pertains to health information between sessions, if it were made easily available. The range of this information could vary, but participants expressed a desire to shift into a more proactive relationship with their doctor.

"... you want [the doctor] to read your file before you go in, and it seems like every time you go they don't read your file, so I would like the doctor to be more active with the process, like in between session maybe get in touch with you via email or send or submit different exercises or something to do so that way it's both sided so instead of having me wear this thing and feel like I'm being monitored or watched all the time."

To this end, we think of the final phase of our QDA, *Modeling Relationships*, as a powerful visual tool for modeling and understanding the design space. Figure 1 illustrates this preliminary qualitative modeling of relationships among topic 6, 7, and 8, i.e., three functions of technologies/tools that veterans would appreciate the most. The width of links to a code or the size of a code shows how frequently the code was brought

up and emerged during interviews. For instance, topic 6 (Warn/ Intervene for Hyperarousal Onset) is explained primarily with two codes, i.e., 'Preemptive Alert for Hyperarousal' and 'Re-focus/ Distraction for Hyperarousal'. With hyperarousal onset, veterans wanted a preemptive alert and re-focus/ distraction intervention. Figure 1 shows that these two codes of topic 6 are interlinked with each other, as well as with topic 7 (Peer-to-Peer or P2P Connection). This qualitative modeling of relationships enables a genesis of narrative storytelling from veterans' perspective.

DISCUSSION

The QDA topics synthesize veteran responses to interview questions and offer some valuable insight into their lives. In addition to their direct feedback about some previously explored design functions (e.g. P2P), the exploration of behaviors and attitudes through modeling relationships between their responses allows creative insights to emerge. QDA in this way can identify potential avenues for follow-up questions or refreshing new perspectives. This opens the design space beyond the boundaries of our requests for direct feedback.

For example, Topic 6 synthesizes many requests for a subtle buzzing mechanism attached via wrist or elsewhere that can seek to halt panic in the early moments of a trigger event. This direct feedback from veterans has informed the design of

an interactive, continuous monitoring tool that utilizes biosensing and machine learning to detect PTSD triggers and provide timely intervention. However, no veteran requested a virtual environment for exploring and making extinct these very same trigger stimuli, unsurprising, since the set of possibilities from the QDA would be strictly limited by those understood by our participants. Indeed elsewhere Difede, Cukor, Wyka, Olden, Hoffman, Lee, and Altemus (2014) studied the presence of D-cycloserine in Virtual Reality Exposure Therapy (VRET). Building on their understanding of PTSD as a disorder of emotional learning, the details of sensory stimuli (Topic 5) are more than enough to create a generic yet effective virtual scenario that seeks to *eliminate* the fear response associated with these trigger events. Consumer VR systems (e.g. Vive or Oculus) are now to the point that they may be (relatively) easily adopted at home to accommodate isolated tendencies.

On the other hand, it remains difficult to generalize whether a design solution that encourages or discourages some behavior would, in the long run, improve perceived quality of life. For example, it may not be wise to "distract" a participant from their trigger stimuli; there may be elements of meditative, breathing, or so-called mind/body solutions that are preferable in working *through* the trigger rather than mentally *avoiding* or *reliving* the trauma. The overwhelming number of participants currently employing these mind/body strategies suggests that we must understand how the physical and psychological practice complements or conflicts with other intervention techniques. Similarly, an at-home VRET solution for working through anxiety associated with public places may not be preferable to actually venturing to public spaces, as the former actually encourages isolation while targeting the user's *perceived* isolation through experiences in a virtual world with virtual actors. While the findings documented in this paper contribute to further understanding of how to design solutions for those veterans afflicted with PTSD, future work must go towards exploring how these insights can be operationalized and evaluated.

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