

Post-Traumatic Stress Disorder: Opportunities & Challenges for Computing Technology

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ABSTRACT

Post-Traumatic Stress Disorder (PTSD) is a condition in which a person responds to a traumatic event, such as war, a car accident, or physical abuse, with prolonged feelings of fear, helplessness, or horror. This disorder can have a significant detrimental impact on the lives of those affected by PTSD as well as their friends and family. In this paper, we outline the potential for computing technologies to assist with all aspects of the experience of Post-Traumatic Stress Disorder, including recognizing the pre-trauma disposition for PTSD, identifying the symptoms, helping with diagnosis, and aiding in the treatment and assessment of treatment. The content of this paper is based upon an extensive review of the literature and our consultations with domain experts and therapists who treat PTSD. We outline a number of opportunities for computing technologies to play a role in improving the lives of those with PTSD as well as challenges for working in this space. We also describe specific design considerations for computing technology designers.

Categories and Subject Descriptors

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous, K.4.2 Computers and Society: Social Issues, J.3 Life and Medical Sciences: Computer Applications

General Terms

Design, Human Factors

Keywords

Post-Traumatic Stress Disorder, PTSD, healthcare, mental health, mental disorders, trauma, veterans, mobile technologies, tele-health

1. INTRODUCTION

Recent work in the field of human-computer interaction and information science has looked to using technologies to help address some of the challenges associated with detecting, diagnosing, and treating mental health disorders. Tools for helping patients and therapists work together more effectively have been developed and used with success in patients ranging from young children to older adults. Many of these technologies have worked

in the general space of mental health, treating broad symptoms associated with depression [4], memory loss [2], or cognitive decline [2,54]. Although these types of tools can be applied to more specific disorders, others have carefully considered the intricacies of a particular disorder in order to design better tools. For example, working directly with the autism [16] or aphasia [30] communities has resulted in the design of specific tools for treating the specific symptoms, and studies have shown these tools to be successful and well-adopted.

We believe technology may be able to assist in the field of mental health by assisting with the treatment of Post-Traumatic Stress Disorder (PTSD). Patients with PTSD have experienced a traumatic event, such as war, a car accident, or physical abuse, and respond to the event with great fear or a sense of helplessness. These symptoms can greatly interfere with the lives of the patient and can often lead to other health disorders such as depression or alcoholism. The impact of this condition on the lives of patients can result in family distress [13], loss of employment [13] or other negative effects, so it is important to diagnose and treat the disorder as quickly as possible. There is also a stigma or shame associated with the disorder, and treatment can be expensive and out of reach of many patients. Thus, seeking ways to anonymously receive help or make treatment more efficient can have a big impact on the conditions associated with PTSD.

The incidence of PTSD is increasing world-wide, especially amongst soldiers returning from war. In the United States, over 12% of veterans returning from Iraq and Afghanistan [19] and 30% returning from Vietnam develop symptoms of PTSD [26]. Among the general population, 50-90% of all people experience trauma, with approximately 7.8% of those developing PTSD, and women are twice as likely as men to develop PTSD [24]. Victims or witnesses to violent crimes, domestic violence, car accidents, or childhood abuse can all be affected with PTSD. There are also many therapists who specialize in treating PTSD and members of the military who must work with others suffering from the disorder. In the United States, the federal government has declared prevention and treatment of PTSD a high priority [20]. Thus, the impact of PTSD is significant, and any work to help lessen its impact will affect many people.

We believe that computing technology can help play a role in reducing the significance of PTSD. Other researchers have successfully used technology in treating mental disorders on a more general level and for specific disorders, but have not yet focused specifically on PTSD. By studying this disorder and designing for it specifically, we can produce technologies that will be well received and address the nuances of the disorder. By providing access to treatment remotely, helping patients and their

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families search for help, helping improve the tracking of symptoms and the effectiveness of therapy, and in aiding in the diagnosis of the disorder, technology can help minimize the impact of the disorder and improve the lives of patients. This paper seeks to provide background on PTSD, inspire other researchers in this space, and serve as guidelines for future work.

In this paper, we first provide an overview of PTSD, including its causes, symptoms, diagnosis and treatment. For each phase of the PTSD experience, we describe the challenges to designing for PTSD, followed by a discussion of opportunities for computing technology, including existing work in this space as well as new ideas. Finally, we provide a discussion of design recommendations and conclude the paper.

2. OVERVIEW OF PTSD

In this section, we provide an overview of PTSD including its diagnosis, symptoms, and treatment. We also introduce a diagram of the Post-Traumatic Stress Disorder experience (Figure 1) we have developed to serve as a framework for our discussion of challenges and opportunities for technologies designed for this space. This section is intended to serve as an overview for those who are not previously familiar with the disorder and to help organize the remainder of the paper.

Post-Traumatic Stress Disorder is diagnosed as a mental disorder based on the Diagnostic and Statistical Manual (DSM-IV-TR) [1] criteria when:

1. a person witnesses or experiences events that involve death or serious injury, and
2. the person's response is one of intense fear, helplessness, or horror.

The specific trauma a person experiences can be anything they find particularly fearful or scary, and often involves witnessing or being a victim to serious violence. Experiencing war or an act of terrorism is a common source of trauma, as well as being victim or witness to domestic violence, childhood abuse, homicide, or suicide. PTSD also often affects people who have been involved or have witnessed serious car crashes.

Symptoms of PTSD are categorized into three main classes including re-experiencing, avoidance, and hyper-arousal. Re-experiencing involves an intrusive recall of the traumatic event, sleep disturbance or nightmares related to the event, dissociative recall, or anger and anxiety when exposed to reminders of the traumatic event. Avoidance includes avoiding reminders, places, or people related to the event, feelings of detachment or estrangement from others, or a restrictive range of emotions (e.g., numbing). Finally, hyper-arousal includes sleep disturbances or nightmares, irritability, anger, impulsiveness, aggression, and an exaggerated startle response.

These symptoms must be present at least 30 days to be considered chronic for a PTSD diagnosis, otherwise they are known as acute stress disorder. Diagnosis can occur soon after the first appearance of the symptoms or may be delayed until many years after their first occurrence. If symptoms do not appear until 6 months after the event, it is known as delayed onset. Experts diagnose PTSD by collecting information from friends and family and through a battery of tests designed to identify the specific cause and track the specific symptoms. For example, the Clinician-Administered PTSD Scale [3] and the Post Traumatic Diagnostic Scale [10] are

patient-completed scales designed to determine the severity and frequency of the above described symptoms.

A number of treatments have been developed to address PTSD. Traditional psychotherapy, both individually and as groups, is common for patients with PTSD. Cognitive behavior therapy (CBT), which seeks to change patterns of thinking or behavior that cause the negative experiences, is the most common form of treatment. Exposure therapy involves exposing patients to the memories of the traumatic situation to help them overcome their responses to reliving the event. Cognitive restructuring or Cognitive Processing Therapy (CPT) focuses on challenging unreasonable beliefs patients develop about the world. For example, someone who experiences a life-threatening car accident may begin to believe anytime they leave the house they will experience a life-threatening car accident. Both exposure therapy and CPT can involve a writing component. In the former case, it is used to revisit the traumatic experience, whereas in the latter it is used to help the patient re-write his or her beliefs about the world. Finally, more experimental techniques, such as eye movement desensitization and reprocessing, are being explored. In addition to therapy, symptoms are often treated with medication, such as risperidone or amitriptyline [22].

To help better illustrate the experience of Post-Traumatic Stress Disorder, we have developed Figure 1 as a diagram of the experience of PTSD, including pre-trauma, exposure to trauma, assessment/diagnosis, treatment, and beyond. We also identified stakeholders that are impacted by PTSD. These include: professionals including therapists, the patient, and family and friends of the patient. For each stakeholder, we indicate the portions of the experience in which each is involved. We refer to this diagram throughout the rest of this paper to help organize the challenges and opportunities for technology to assist with Post-Traumatic Stress Disorder.

3. CHALLENGES & OPPORTUNITIES

There are a number of challenges associated with treating PTSD. These challenges span the extent of the PTSD experience (see Figure 1). From experiences prior to the traumatic event through completion of treatment, there are issues that impact the treatment of PTSD. In this section, we discuss the set of challenges associated with each aspect of the PTSD experience: from pre-trauma to treatment. We highlight prior work in health informatics directed at addressing these challenges and suggest opportunities for further advances in the field. While we do suggest ideas for computing technology that could support PTSD care, we do so only as a means to instigate and inspire deeper thought about the issues related to conducting research in this domain.

3.1 Exposure to Trauma

Prior to exposure to a traumatic event, certain factors impact the likelihood of developing PTSD. Certain people are vulnerable to developing mental trauma (PTSD included) due to their biological make-up. Others become more susceptible as a result of their environment and life experiences. Still others develop PTSD due to a lack of awareness of the disorder and the associated symptoms. A lack of awareness can lead to delayed diagnosis and treatment, which exacerbates the condition.

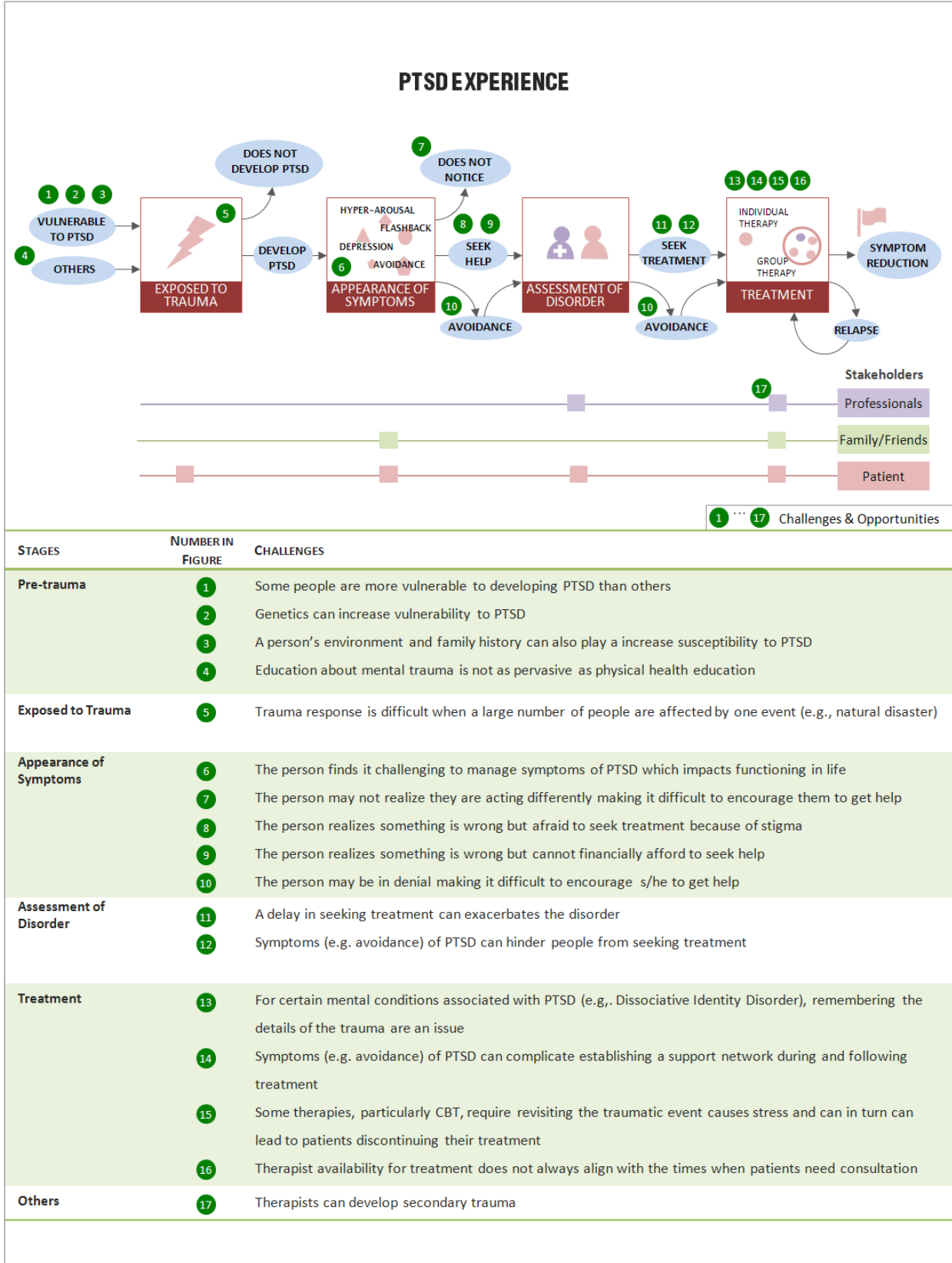


Figure 1: Diagram of the PTSD experience and the corresponding challenges at each stage

3.1.1 Challenges

Studies have shown women to be more susceptible to developing PTSD than men in some cases [23]. Genetic history also plays a role in PTSD susceptibility [45,49]. Additionally, a history of family mental illness increases the chances PTSD will develop following a traumatic event [28,44,45,48]. In addition to genetics, susceptibility to PTSD can be increased by environmental conditions. Muller et al. found in a study of adults who experienced childhood abuse that a negative view of self is strongly correlated with symptoms of PTSD [33]. Ullman and Filipas found a relationship between PTSD symptoms and low education level, greater perceived life threat and negative social reactions to a report of sexual assault [48]. LeardMann et al. discovered people with low physical or mental health state were more likely to develop PTSD as well [28].

A lack of awareness of PTSD and its symptoms can also impact the onset of it. While the disorder is gaining more attention in the United States as a problem resulting from ongoing combat in the Middle East, PTSD is also a problem in the general population. PTSD is much more than a war-related disorder. In either case, being aware of what the symptoms is an important first step to seeking a diagnosis and treatment. Unfortunately, education on mental health is not promoted as generally as education on physical health in schools and in the public at large [31,47]. The lack of education about PTSD only further perpetuates the stigma associated with it and leads to delays in treatment.

Without an awareness of the symptoms of PTSD, it is difficult for those who develop symptoms to recognize the need to seek treatment. Furthermore, those around the affected person may not be able to, or may be unwilling to make the connection between changes in behavior and mental illness. Education on mental trauma can improve negative attitudes toward PTSD as well as increase the likelihood persons affected by the disorder (or family and friends) can identify the symptoms [51].

Once exposed to a trauma, the research on PTSD shifts to determining how to prevent it from developing. Some researchers find promise in the use of psychological debriefing to hinder the development of PTSD; however, studies of debriefing have yet to produce significant evidence of its effectiveness [6]. For mass trauma (an event that affects a large number of people such as a hurricane), Hobfoll et al. recommend “promoting a sense of safety, calming, a sense of self- and community efficacy, connectedness, and hope” [17]. Ensuring that a large group of people receives this type of support is a magnanimous task requiring multiple teams of crisis responders. However, without immediate intervention, stress from the trauma could develop into PTSD.

3.1.2 Opportunities

Given the propensity for certain persons to develop PTSD following a traumatic event, an opportunity exists to develop technologies that help assess the likelihood someone might develop PTSD. Trauma researchers have already initiated efforts to predict vulnerability. Shalev et al. explored the use of a combination of questionnaires and scales to predict the development of PTSD [44].

Computing technology research aimed at determining the susceptibility of a person to PTSD could have a substantial impact. Particularly, research in automated diagnostic tools for assessing the risk of developing PTSD could make a significant

contribution in situations where a person’s occupation might require them to work in high stress and potentially traumatizing situations (e.g., firefighting or military combat). Such a technology might provide digital versions of PTSD assessment scales and make suggestions about the level of action the user should take. For example, users with strong indicators of PTSD may be referred to a therapist based on the results while less serious cases could be provided with educational resources and helpful techniques to address the residual effects of a stressful situation.

Whether online or through a stand-alone device, diagnostic tools that help assess risk can help provide the information needed to help both health professionals and people themselves gauge the likelihood PTSD could develop. With this information, all interested stakeholders could determine what sort of support might be needed prior to placement in a stressful situation (e.g., combat).

Moving from risk to intervention following a trauma, research efforts might explore providing trauma preparedness kits through computing technology. Such kits might take the form of a smartphone application, which includes tools that help users find a safe place and then step the user through stress management techniques. The kit might also allow users to connect to a communication stream (e.g., via social networking, email or phone) through which they could receive directions from first responders about the appropriate actions to take. The kit might also connect the user to other people (or the broader community for mass trauma) to combat feelings of loneliness. This could be useful for individual trauma as well as mass trauma. The user’s existing social network might be leveraged or an ad-hoc social network might be generated to support people who are experiencing a mass trauma. Telemedicine might also be used to intervene and provide assistance until local assistance can be obtained. Psychotherapists could become first responders alongside emergency medical personnel and provide individuals and even groups with counseling and support to help mentally stabilize the victims of trauma.

3.2 Appearance of Symptoms

According to the DSM-IV-TR, the longer a person waits to receive treatment, the worse PTSD becomes. Treatment just after the traumatic event can eliminate the risk of developing PTSD. The longer the delay in treatment, the more likely PTSD goes from being acute to chronic. Unfortunately, the stigma associated with PTSD, denial, and financial considerations comprise some of the reasons people refrain from seeking treatment.

3.2.1 Challenges

An often-cited barrier to seeking treatment is the stigma associated with PTSD and mental illnesses in general. This stigma is particularly challenging in the United States military where mental illness is sometimes considered a sign of weakness. Unfortunately, these are the people who are placed in situations that are likely to cause them trauma (e.g., active combat). Though the main causes of trauma in the general population (excluding the military) are not war-related (e.g., childhood abuse, sexual trauma, natural and man-made disasters, etc.), a stigma surrounding mental illness still exists. Overcoming this stigma is necessary to treat PTSD at its onset. In some cases, an early intervention can prevent PTSD from developing at all. Without immediate help, an acute condition could become chronic, which

can have negative financial and social implications in the long term.

Beyond the stigma, persons affected by PTSD can go into denial about their symptoms [5]. Denial prevents people affected by PTSD from seeking treatment because they simply do not believe they have a problem. It is also the case, particularly in the military, that the affected believe that they are only experiencing a normal reaction to an abnormal event. For some, this is true, however, in those that do develop PTSD, denial can increase the severity of the condition. Without treatment, the disorder can have a negative impact on the affected person and those with whom the person comes into contact.

For some people, financial considerations are the primary challenge to addressing their symptoms. Treatment for mental illness is costly and is not always covered by insurance policies. This is further complicated by the fact that some people do not meet all of the qualifications for a PTSD diagnosis although the impact on their lives is commensurate with those having an official diagnosis. As a result, they cannot receive coverage by their insurance for treatment. Again, what might have been treated before evolving into a more serious condition is allowed to become more severe.

3.2.2 Opportunities

Denial can lead to a delay in seeking treatment. It can also make the experience of family and friends more difficult. To help the affected recognize their change in behavior, ubiquitous capture and access technologies might record evidence of PTSD symptoms to help caregivers convince the affected of the need to seek help. The technology could capture video of the affected person before and after the traumatic event and highlight contrasting behaviors (e.g., difference in temperament). The recorded differences in behavior could then be presented to the affected person from a third person perspective to help them see changes in his or her own behavior.

Even if affected persons recognize the symptoms of PTSD, the cost of therapy can be prohibitive. Computing might fill the gap by providing training systems to help loved ones of the affected provide care until the assistance of a professional can be obtained. Such systems could help family and friends understand the disorder and learn about useful techniques to help with providing and managing care overall. While training family members or friends might help, it should only be explored in terms of an option that can be used until professional help is available and affordable.

Even with access to a therapist, typically the patient only sees the therapist for an hour, once a week. Between sessions, patients can still experience symptoms and need help with functioning in everyday life. As a complement to therapy sessions, technology can remind patients about the coping mechanisms they have learned in therapy and guide them through the techniques provided by the therapist.

3.3 Assessment of Disorder

Once the symptoms of Post-Traumatic Stress Disorder are detected either by the patient or their family members, the next step is determining whether the symptoms are strong enough for a diagnosis. Having a diagnosis allows therapists to assess how to treat the patient as well, because PTSD may be handled differently than just anxiety. In addition, a diagnosis may be required for some medical insurance companies to cover

treatment. Although diagnosis of PTSD is relatively straightforward, once symptoms are noticed and the patient has sought professional help, there are still some challenges to and opportunities for improving this process.

3.3.1 Challenges

Diagnosis of PTSD happens when a trained therapist or specialist interviews and/or observes the patient and determines the extent of the disorder. Nearly all therapists use the DSM-IV-TR criteria to make the diagnosis described in Section 2. Many experienced therapists can make the assessment of the criteria during a single visit with a patient who can describe their condition well, but for others, more information may need to be collected. For example, gaining access to family members or co-workers may be necessary to gather details about the extent of the symptoms a patient may be too embarrassed to admit, or information about other co-morbidities, such as alcohol abuse or depression.

Clinicians often use standardized measures for diagnosis, such as the Clinician-Administered PTSD scale (CAPS) [3]. While these scales are found to be highly reliable [52], therapists may have some challenge in getting patients to provide the appropriate responses. Others use scales that are completed by the patient, such as the Impact of Event Scale [53]. One challenge related to this version is having the patient agree to take the test in the first place. The scales may also need to be modified to be appropriate based on the type of trauma (e.g., war vs. a car accident), population (e.g., younger children or older adults), or language (e.g., translations to Spanish or German). Finally, since both types of scales need to be validated for each change or modification made, researchers need to obtain a large number of responses to assess the validity for each version of the scale.

Overall, the assessment of PTSD may also be fairly subjective, and there is a possibility that the information provided by patients may not be accurate, either due to avoidance or due to exaggeration of symptoms. Finally, once the diagnosis is made, the next steps may be a bit daunting. Even with a diagnosis, patients may be reluctant to seek care due to avoidance or be overwhelmed with the decision of what to do next.

3.3.2 Opportunities

Technology may be useful in helping to gather some of the information needed by therapists, especially when they need to reply on other people. Allowing therapists to query a person's social network about their symptoms or behaviors, with great care given to confidentiality, may help in providing a broader picture of the patients' symptoms. In addition, tools that may help a therapist assess a person's symptoms in a more naturalistic manner may be helpful in making more objective assessments and determining the severity of the disorder. Tools that allow a patient to record their symptoms and a therapist to review their frequency or severity may help therapists make more informed decisions about the DSM-IV-TR criteria. Determining ways of distributing patient-completed scales more widely and/or anonymously online may help in some screening efforts. Technology can also assist in helping PTSD researchers collect completed surveys of different types to aid in research on validating and improving the different scales through a crowdsourcing model. Finally, we believe that technology, especially reliable internet-based resources, can be very beneficial in educating patients about their diagnosis and helping them select among treatment options or different therapists/specialists,

similarly to how this work has been done with cancer [9] and other disorders.

3.4 Treatment

A variety of therapies exist for treating PTSD. Some include Cognitive Behavioral Therapy (CBT), Eye Movement Desensitization and Reprocessing (EMDR), and Mindfulness-Based Cognitive Therapy (MBCT) [15,42]. Typically therapists will use some combination of therapies to treat patients. Each therapy has advantages, but also drawbacks. CBT-based therapies are challenging for patients to endure and can also be difficult to use in cases where patients cannot remember specifics about an event. In general, treating people with PTSD can also have the effect of traumatizing the therapist. Many opportunities exist for computing technology to mitigate some of the challenges posed by the various treatment methods available for PTSD

3.4.1 Challenges

Most therapies that have been proven effective involve some amount of revisiting the traumatic experience whether by imagining the experience or repeatedly telling a story about the experience. Revisiting the trauma presents a challenge to people affected by PTSD because one symptom of the disorder is avoidance. The very nature of PTSD causes those who suffer with it to avoid thinking about or even coming into contact with places or people that remind them of the experience. In therapy, the patient is asked to confront those fears directly. This can be overwhelming and in some cases lead to the patient discontinuing treatment. Avoidance can also make it difficult to establish the types of support networks needed during and after treatment. Furthermore, many therapists have concerns about using therapies that rely heavily on repeatedly exposing patients to the traumatic event because they believe it only further traumatizes patients [11].

While therapies involving revisiting the trauma have been found effective, treatment can be complicated if the patient cannot remember the details of the event. Sometimes patients block out some aspects of an event, or they simply forget the details. In the either case, it can be difficult to make progress until the patient can access the blocked or forgotten memories [14].

Additionally, research has found that patients in some cases create false memories of their experience [21], which can further complicate treatment. Cognitive behavioral therapies rely on patients to revisit the traumatic memories. Without proper access to those memories, it is difficult for therapists to help patients make progress.

The treatment-related challenges we have outlined so far have been patient-centered. There is a particular concern associated with PTSD that directly impacts therapists. In the process of treating patients, therapists can develop secondary trauma. By helping others overcome their mental illness, therapists raise the risk of becoming traumatized themselves. Particularly for therapists who specialize in trauma, it can be difficult to process all of the experiences to which they have been exposed. Other caregivers (e.g., family and friends) are at risk of developing secondary trauma as well. The experience of caring for someone who has PTSD can be a traumatic one in itself. As a result, the challenges we describe throughout the paper are relevant to therapists and caregivers as well.

3.4.2 Opportunities

Cognitive behavioral therapies as well as exposure therapy can cause patients stress by repeatedly re-exposing them to the memories of the trauma. This stress is in addition to the stress they experience when symptoms occur outside of the therapy context. Rather than solely treat PTSD by exposure in therapy, technology might also provide mobile therapy when symptoms are actually occurring. Mobile therapy would not serve as a replacement for a therapist; rather, it could be an additional tool through which the therapist might provide treatment outside of the office context. A smartphone application, for example, could extend the reach of the therapist. The therapy would be based on the protocols the therapist already uses and would be administered by the therapist. In advance the therapist would use knowledge of the patient to organize a set of responses to the patient's symptoms and triggers. When symptoms occur, the patient could use the smartphone application to access personalized pre-scripted counseling from the therapist. As a result, it may be possible to reduce the amount of re-exposure to the event during in-office sessions. Potentially, this could increase the likelihood that the patient will complete the course of treatment. Morris et al. have explored offering therapy through mobile devices [32]; however, work is needed to determine whether this type of therapy can be effective for PTSD.

The stigma related to PTSD hinders affected persons from seeking treatment. Providing access to therapy over the Internet could allow those experiencing shame related to the disorder to receive treatment without having to expose their identity. Typically through asynchronous means of communication, the patient can interact with a therapist and receive treatment. Again, the therapist would develop an online version of the techniques that are used in the office for patients to access at their convenience. In addition, technology could support text or audio communication for synchronous conversations while still preserving anonymity. Lange et al. have had some success with providing treatment through an online system [27]. Although, treating people over the Internet might increase greater access to treatment, especially for those who would not seek treatment otherwise, it is also problematic. Therapists rely on interactions with patients, particularly visual cues such as smiling or grimacing. Without these visual cues, one of the primary means of assessing patient progress is taken away. While access to help might increase for those dealing with shame or financial concerns, the ability of the therapist to provide the best care for the patient may be decreased.

Internet therapy also raises privacy and confidentiality concerns for therapists. It is important for the therapist to be assured that the patient's confidentiality can be protected. While online security protocols (e.g., SSL) provide some measure of security, the patient's identity and health records are still prone to being compromised. This potential breach in patient privacy could lead some therapists to avoid the use of remote therapies altogether.

Teleconferencing systems are already in use in the healthcare domain [8,12]. In contrast to Internet therapy, the therapist has access to a visual of the patient, which allows the therapist to better assess the patient's state. However, for mental health and PTSD, concerns of privacy are again an issue. Further work in teleconferencing systems might include developing systems that anonymize the identity of the patient while still providing the therapist with visual access to the patient's physical responses to therapy. Another approach might leverage virtual environments

(e.g., Second Life) to create a safe and anonymous space for the patient while still providing the therapist with information about the patient's physical reactions to treatment. This would allow the patient to remain anonymous but still provide the information needed by the therapist. In both cases, the technology would need to transfer the patient's physical movements and facial expressions into a digital form (whether a Second Life avatar or other virtual character).

A support network is helpful when trying to cope with PTSD [50]. Group therapy is a part of the treatment of PTSD that allows those with PTSD to connect and support one another. Unfortunately, those affected with PTSD tend to avoid the people and activities that are helpful to them, which can lead to the worsening of their condition. Online social networks may provide a good means for patients to receive support but maintain some distance at the same time. An online therapy group that allows people to connect and engage with a group, as they feel comfortable, might provide another means for increasing access to care while also providing the support needed to deal with PTSD. In this therapy group, members could start without revealing any personal information. As members become more comfortable, they could add more information to their profiles (e.g., profile picture, interests, the traumatic event they experienced). This type of online social group could be useful for those dealing with stigma and lack of financial resources as well as those seeing a therapist. For both groups, an online social network that accounts for the concerns of mental trauma patients (e.g., stigma, avoidance) could provide access to support from others in the same situation.

Because accurately or completely remembering the traumatic event can be an issue for patients, technology might jog the memories of patients by using captured media from the actual traumatic event. The field of Ubiquitous Computing studies the deployment and use of computing technology in physical environments to create a collection of services that improve the human experience. In the case of mental trauma, services might be developed that allow people involved in traumatic incidents to access the media recorded of that incident for use in therapy (e.g., traffic camera video in the case of a car accident). Other techniques such as passive capture (e.g., SenseCam [18]) might also provide access to records of the traumatic event. In the absence of media captured through ubiquitous systems, personal or symbolic (e.g., stock photo collections) media could be used to help patients remember the details of their individual traumas.

The use of Virtual Reality (VR) therapy as a substitute for traditional exposure therapy is a current hotbed for research [25]. For those who have trouble activating the memory of the trauma, VR environments are created as a realistic representation of the environment in which the trauma was experienced [35]. Studies of these types of therapies have shown improvements over no treatment at all, as well as similar improvements in symptoms when compared to traditional exposure therapy in the military [38,34,37,39] and general populations [7,40].

Storytelling is an integral part of treatment, especially with cognitive behavioral therapies. Some therapies, such as narrative therapy [41], focus primarily on storytelling. In either case, patients are asked to orally share or write stories related to their traumas. An opportunity exists for researchers to more deeply explore supporting the process of eliciting stories and supporting their documentation. This work might focus on providing a means for a patient to document symptoms, thoughts and reactions to situations for later discussion with a therapist. This

research could also explore providing tools for therapists who are experiencing secondary trauma to debrief through storytelling. In this case, the stories may not be shared with anyone else to protect patient confidentiality, but could provide a way for therapists to externally express their experiences.

We have outlined many of the challenges involved in the PTSD experience starting prior to a traumatic event through treatment. We examined these challenges from the perspective of patients, therapists, and caregivers (i.e., family and friends) when relevant. We discussed opportunities that exist for designers of computing technologies to address some of these challenges. The ideas that we have presented here are meant as inspiration for the research community and in no way represent well-reasoned design ideas. There are certainly issues related to each idea beyond those we have highlighted. Our hope is that the community begins to explore more deeply the way in which employing computing technology to treat mental trauma differs from treating physical ailments. It is also our hope that our ideas for developing computing technology provide a springboard for in-depth discussion of how current and future technologies should be integrated into the therapy context. In the following section, we discuss some of overarching issues that should be considered when engaging in work with PTSD in particular.

4. DESIGN CONSIDERATIONS

Based upon the research we conducted in this space, we have organized a number of concrete design considerations for technology designers who are interested in working with patients and therapists from the PTSD community. The considerations include both advice and precautions for conducting user-centered design with therapists and patients as well as suggestions for how technologies might fit into the PTSD experience.

- *Confidentiality should be of great importance:* As with any mental disorder or otherwise “invisible” disability, confidentiality is extremely important, as the accidental disclosure of the disorder to others may result in extreme hardship for the patient. Thus, any technology design or data gathered from the patients will require high security and removal of any identifying information at a minimum. Further action may be necessary to prevent data mining techniques from identifying patients even in anonymized data [46]. We recommend that researchers work closely with therapists and human subjects ethics boards to ensure patient privacy and confidentiality are maintained.
- *Technology could make the condition worse:* People with PTSD might be very sensitive to their disorder and try to actively block memories or triggers. Often with treatment, the situation may get worse before it gets better. Thus, it should be expected that technologies designed for therapy may also have this effect. We recommend that designs give trained therapists complete control over the amount of exposure and rate at which therapy is administered, rather than producing an entirely automated solution.
- *Access to patients may be difficult:* In our own studies, we found it very difficult to access to patients directly, as therapists were concerned that by interviewing them, we could make the situation worse or possibly trigger flashbacks or some of the fear for which we were not trained to handle. In addition, observation of therapy sessions was also difficult to do because of patient confidentiality rules and a fear on the part of

therapists that the therapy may somehow be compromised. Thus, it may be difficult for researchers hoping to do participatory design or directly interfacing with the patients themselves. Matthews and Doherty outline a number of strategies for working with individuals with mental disorders, such as working directly with therapists and testing technologies initially with peers with no disorders [29]. We expect that these strategies would work similarly with patients with PTSD. In addition, we have been seeking creative ways to become a part of the PTSD community, such as attending public support groups for family members or social events posted on Meetup.com.

- *Technology designs should work with the therapist:* Many of the therapists we interviewed were very hesitant to have technology “replace” face-to-face therapy, as they felt that the personal experience, particularly the relationship developed over time helped them assess how much a patient could handle and when it was time to stop. However, they were in favor of technologies that could support face-to-face interaction or help patients work on exercises between those therapy sessions. Therapists also mentioned they would be willing to sacrifice face-to-face therapy for video or chat-based therapy if there were no other alternatives (e.g., for patients who desire to remain anonymous and would not seek treatment otherwise).
- *Therapists are often very paper-oriented:* As many others have pointed out, the benefits to paper-based systems are still many [43] and for therapists treating PTSD, they are no exception. We found that many therapists kept 100% of their records on paper, took notes on paper, and communicated almost entirely using paper or the telephone. The reasons for this were primarily for confidentiality purposes. If they had control over the paper and could physically see it locked, then they would trust that it was secure. With computing systems, security was less visible and thus there was a certain level of distrust over them. Other reasons were that most of their training was done using paper-based approaches and note-taking strategies, as well as just the ease and quickness of access. In addition, therapists felt that taking notes on paper enabled them to pay better attention to the patient, sit with them face-to-face, and communicate more effectively. Any technology designs should accommodate these concerns perhaps by using digital pen and paper to preserve the usability and communication aspects, and also by using strategies to secure digital documents that are understandable by therapists, such as using a physical hard drive which can be disconnected and locked in a safe.
- *There is large variability in both patients and therapists:* From our interactions with therapists, we found that they all had their own unique styles and strategies for conducting therapies. In addition, they would apply different techniques in different ways depending on the needs of the patients. Technologies need to be extremely flexible and perhaps even programmable by the therapists themselves to account for the wide variety of differences. In addition, because the cause of trauma may be very different from patient to patient, and the cause is often integral to treatment, customizability based on the traumatic event (e.g., for exposure therapy, allowing the therapist to import her own pictures or videos) would increase the likelihood of success.
- *Evaluations may need to be done on a case study basis:* Although it is rarely easy or straightforward to evaluate a new

technology design, technologies for Post-Traumatic Stress Disorder may require some special considerations. Because the length and treatment of the disorder can be really variable and the symptoms very diverse, it may be hard to design a well-controlled evaluation study that compares treatment between groups of subjects. Thus, designers may need to focus on more of a single-subject [36] or case study [55] evaluation of new systems that are evaluated. In addition, the length of an evaluation study may need to be variable, as some participants may respond to treatment very quickly while others may take many years to make progress. Evaluation metrics should focus on making positive changes or moving toward success, rather than expecting an actual improvement in the condition itself.

- *Work with both a domain expert and a therapist:* Access to patients and resources for design and evaluation are very important in this domain. The best person to serve in that role is someone who can provide domain expertise, such as a PTSD researcher. Because accessing study participants may be difficult, someone who has a good understanding of the range of the disorder and what works and does not can be a good proxy for access to a large pool of subjects. In addition, therapists who work directly with patients can provide a more in-depth view of individual experiences and provide a depth of understanding of participants.
- *Therapists are open to exploring technology use:* Lastly, we underscore that while the therapists we talked to were mostly happy with their entirely paper-based current practices, the ones we interviewed were open to the idea of exploring how technology could be used to improve the process. Our intent is not to replace the therapist, but instead to augment their practices and make their work more efficient and able to reach more people. We believe that the introduction of technologies into the process should be made slowly, so as to allow for gradual change.

5. CONCLUSION

Our goal in this paper was to present the challenges that exist in PTSD treatment and highlight opportunities for technologists to contribute solutions. We have presented a number of challenges related to the PTSD experience from pre-trauma to treatment. Some of these included vulnerability to mental trauma, avoidance as a barrier for people seeking treatment, re-traumatization effects of some therapies, and lack of education about PTSD. The challenges presented represent opportunities for exploring how computing technology might help. We have presented work in the literature that has initiated efforts to address some of these challenges. Yet, much more work is needed where supporting care of PTSD patients, the family and friends of patients, and the therapists themselves is concerned.

By presenting potential directions and ideas for advancing work in this area, we aimed to inspire thought about how, where and when computing technology should be integrated into the process of caring for those with PTSD. From self-care to therapist-administered mobile therapy, computing technology can be integrated into the treatment process to support all stakeholders involved in the PTSD experience.

However as research is conducted in this area, it is important to carefully assess the impact of technology and the role it plays. Through engaging in this work, interactions with therapists and domain experts, we have encountered a number of issues it is important for others in the research community to consider.

While these design considerations might seem limiting, we believe they expose the uniqueness of employing technology in this domain and calls on the research community to use it's collective energy to innovate solutions to such a significant (in numbers and impact) problem.

We are continuing to interview therapists to more deeply explore their work processes and attitudes about technology. More work is needed in documenting the experiences of patients and exploring how technology might fit into their lives. This paper has presented the challenges and opportunities largely from the perspective of clinical studies of PTSD treatments and our interactions with therapist and domain experts. It is important to more richly capture the experience of patients to determine whether and how computing technology might support their journey toward a reduction in PTSD symptoms.

Post-Traumatic Stress Disorder represents a significant problem not only in the U.S. Military but also in the general population. Using computation to address this problem could yield significant benefits in the lives of those impacted by trauma, and also society at large.

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