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# ALLOWING THE UNTELLABLE TO VISIT: INVESTIGATING DIGITAL

# FOLKLORE, PTSD, AND STIGMA

by

# Geneva Harline

A thesis submitted in partial fulfillment of the requirements for the degree

of

# MASTER OF ARTS

in

American Studies (Folklore)

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2017

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# ABSTRACT

#### Allowing the Untellable to Visit: Investigating Digital Folklore, PTSD and Stigma

by

Geneva Harline, Master of Arts

Utah State University, 2017

Major Professor: Dr. Lynne S McNeill Department: English

In the introduction of 2012 issue of *The Journal of Folklore Research*, Diane Goldstein and Amy Shuman issue a "call to arms for folklorists ... to concentrate on the vernacular experience of the stigmatized." In this call to arms, they recommend that folklorists study not only the vernacular experience of the stigmatized, but also the "analysis of the performance of stigma, the process of stigmatization, and the political representation of stigma" (Goldstein and Shuman, 2012:116). Drawing on this call to arms, this thesis investigates whether memes and captioned images in the digital sphere mitigate the stigma of Post-Traumatic Stress Disorder (PTSD), and if so, how.

The emerging realm of digital folklore has fascinating implications with regard to the stigmatized vernacular. One benefit to using digital folklore to explain PTSD from an esoteric perspective is that members of the PTSD community can use an image to convey what life with PTSD is like rather than a narrative. Part of the stigma of PTSD comes from the chaotic nature of narratives due to "ineffability or inarticulateness due to traumatic experience" (Goldstein, 2012:183-4). Because these images can be quickly processed by the brain, the viewer of digital folklore might investigate stigmatized conditions and develop a more thorough understanding of them.

In order to examine how PTSD is portrayed in digital environments, I followed the guidelines of a "folkloric approach to stigma" recommended by Amy Shuman in her 2012 article. In summary, these guidelines as they relate to my research are: 1) to determine what is considered normal, 2) observe of the facets of stigma, 3) analyze both digital folklore and comments to identify how stigma is enacted by people esoteric and exoteric to the PTSD community, 4) explore cultural expectations of tellability/untellability, and 5) determine how stigmatized groups position themselves with regard to normal (Shuman, 2012:202).

After collecting multiple examples of memes and captioned images from public social media sites and applying a close analysis of both the images and the words chosen to portray PTSD, I determined how the relationship between digital folklore and the stigma of PTSD affects the tellability/untellability of PTSD.

(138 pages)

# PUBLIC ABSTRACT

Allowing the Untellable to Visit: Investigating Digital Folklore, PTSD and Stigma

# Geneva Harline

In the introduction of 2012 issue of *The Journal of Folklore Research*, Diane Goldstein and Amy Shuman issue a "call to arms for folklorists ... to concentrate on the vernacular experience of the stigmatized." (Goldstein and Shuman, 2012:116). Drawing on this call to arms, this thesis investigates how Post-Traumatic Stress Disorder (PTSD) is portrayed in social media through memes and captioned images. I argue that the genres of memes and captioned images in digital folklore work to help mitigate the stigma of PTSD because the veneer of anonymity in the digital world allows people with PTSD to be willing to share their experiences and struggles.

With my findings on the use of memes and captioned images, my research demonstrates how digital folklore can be used to determine what education efforts are needed to mitigate stigma in the offline world. Through the focus on memes and captioned images relating to PTSD, I show that through the normalization of one mental health condition, digital folklore can help to alleviate stigma because the pervasive nature of digital culture allows for an influx of minimally moderated information, creating an avenue for understanding stigmatized groups.

#### ACKNOWLEDGMENTS

Thanks to my friends and family who have been there as I wrote this—for being there when I needed someone to talk to, to help regain my footing when the research felt too intense, and for your understanding in not seeing me much during the rest of the time.

To Fish: thank you for being the first person to believe in me, and for giving me a reason to believe in myself.

To Dixie: thank you for your help in getting to a place where I could do this research, and for being patient with me while I was working on this.

To Christine Cooper-Rompato and Keith Grant-Davie: thank you for being willing to advise me on this, and for helping me discover what the focus should be.

And finally, to Lynne McNeill: this project would never have happened without you. From the time you led a non-techie person to study digital folklore through to the final edits, you have been the ideal mentor for me. If it weren't for your unfailing interest in and enthusiasm for this project, combined with your ability to read anything that was handed to you, I would have given up on it long ago. Thank you for your patience, help, and temporary tattoos while I learned how to tell the untellable.

Geneva Harline

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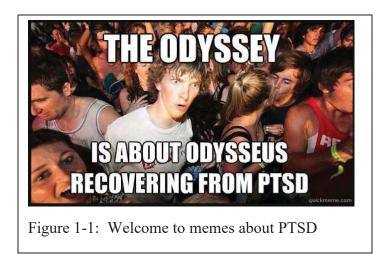
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# CHAPTER 1:

# INTRODUCTION

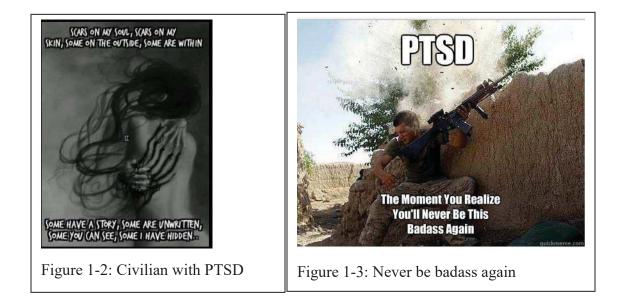
# Introduction

As long as people have been telling stories, they have included characters with symptoms of Post-Traumatic Stress Disorder (PTSD)<sup>1</sup>; however, the disorder was first labeled Post-Traumatic Stress Disorder by the American Psychiatric Association in 1980. Prior to this time, the medical field recognized the symptoms of stress related to war by names such as "soldier's heart," "shell shock," and "battle fatigue." When PTSD was first added to the *Diagnostic and Statistical Manual of Mental Health Disorders* (The DSM— in this case DSM-III), it was linked to "the trauma of war and post-military civilian life" (Friedman 2017). Since that time, there have been extensive efforts to understand PTSD and to treat it so that veterans, people who have done the unthinkable so civilians don't have to, can better reintegrate into society. Through the research which has been done on

<sup>&</sup>lt;sup>1</sup> As demonstrated in the meme above, many people have drawn a connection between the actions of Odysseus and PTSD, as well as between the way that Gilgamesh reacts to his friend Enkidu's death and PTSD in "The Epic of Gilgamesh." These correlations are shown in articles on websites about PTSD or military life (such as the *Guardian.*)

PTSD, the psychiatric community has discovered that it is not only a risk of war, but something that civilians can develop as well.<sup>2</sup> While there has been a large effort to normalize the idea of veterans with PTSD, awareness of civilian PTSD is just beginning to be largely promoted. This underrepresented side of the disorder will be the primary focus of my research.

One area of expressive culture where PTSD is being addressed on the vernacular level is digital folklore. Consider these two internet memes, which I discovered on Facebook in the summer of 2016:



Images like these are abundant online, and are clearly playing a role in the public understanding of PTSD, as this thesis will show. This kind of digital folklore plays an important role in the vernacular mediation of stigma by allowing people with PTSD to

<sup>&</sup>lt;sup>2</sup> Types of trauma that can lead to PTSD in a civilian include, but are not limited to: rape, violence, domestic abuse, traffic accidents and natural disasters.

have a voice. Though not all of the folklore featuring PTSD has a positive effect on the stigma related to PTSD, my initial research into the memes shows that the use of memes to help mitigate the stigma greatly outweighs the memes that intensify stigma. As my research has shown that people with PTSD are making such an effort to share their experiences, this presentation of that research will focus on these efforts.

# Outline

The rest of Chapter One explains the terminology relating to the integral aspects of this project: PTSD, stigma, and digital folklore. In this chapter, I rely primarily on formal, academic descriptions of these concepts for the basic structure; however, in order to paint a clearer picture of life with PTSD, I include some vernacular descriptions of what it is like to live with the disorder. As I describe each concept academically, I include a narrative from my informants as an example of how each symptom discussed actually affects someone with PTSD. Due to the stigma that still exists regarding PTSD, I am not using any identifying information—no names will be included. Some of these narratives of life with PTSD are quite graphic in order to portray the most accurate description possible.

Chapter Two explains the theories that are used as lenses through which the artifacts are analyzed. In this chapter, I begin by using disability studies to lay out the background regarding how people with disabilities of all types are banding together and speaking up for self-representation. I then consider the idea of speaking for other people through the lens of "ventriloquist folklore" before continuing on to explore the benefits of "methodological symmetry" in relation to this work. The final theory that I consider is William Benoit's ideas of "image repair" and how his ideas can be modified to understand how digital folklore is being used to repair self-image as well as the public image of people with PTSD. Once the theoretical framework is in place, I then explain the classification structure that grew out of my research.

Chapter Three offers a breakdown of the digital artifacts and how they are being used by people with PTSD to help mitigate the untellability of PTSD on three main fronts: explaining the untellability, circumventing untellability, and communicating with each other through memes.<sup>3</sup> In Chapter Four, I lay out my conclusions and explore ways in which this research can be applied to other aspects of stigma.

# PTSD

The primary description of PTSD that I use for this research is based on the diagnostic criteria in the *Diagnostic and Statistical Manual of Mental Disorders* commonly referred to as the *DSM-5.*<sup>4</sup> This is a manual that is produced by the American Psychiatric Association and is updated regularly in order to keep up with current research. After the DSM came out with its fifth edition, Matthew Friedman, a member of the committee who worked on it, wrote an article explaining the process and reasons for the updates related to PTSD. As part of the five-year process, a subgroup of five people worked to address "trauma/stressor-related and dissociative disorders." This subgroup worked closely with experts in the trauma community, including conducting a "two-hour

<sup>&</sup>lt;sup>3</sup> Goldstein explains that "the term *untellability* [refers] to limited comfort or ability of the narrator because of perceived restrictions of *context*—such as narrator interpretations of discursive safety or risk—as well as issues of *content* arising from faulty memory, confusion, fragmentation, and an inability to articulate."

<sup>&</sup>lt;sup>4</sup> The World Health Organization has its own manual, the *International Classification of Diseases* (ICD-11), which has slightly different criteria. The main difference between these manuals that pertains to my research is the inclusion of Complex PTSD in the ICD-11, which is not included in the DSM-5 (Friedman offers an excellent reason for this in his article which boils down to needing more research.) While the DSM-5 does not acknowledge CPTSD as an official diagnosis, the folklore still refers to it, showing a vernacular need for differentiating the types. In the vernacular, the groups that are dedicated to CPTSD also reflect differences in needs of people with PTSD and CPTSD.

conference call every other Friday afternoon for four years" (Friedman 2013, 549). The

research that this subgroup conducted led to a restructuring of where PTSD is located in

the DSM-they created a new chapter specifically for trauma related disorders, taking

PTSD out of the anxiety-based disorder category. The diagnostic criteria, in order to

apply the diagnosis of PTSD, includes twenty symptoms in five groupings, and requires a

minimum of six symptoms (all of which must have begun or worsened after exposure to

trauma) (Friedman 2013, 548-551).

#### Definition

This is what the flashback felt/looked like—what I was doing (as best as I remember) and what I was experiencing. I was somewhat aware of where I really was, but my mind was 11 years ago, and I could not bring it back. Once I was able to get back, I slept fitfully with only a typical level of nightmares and fear (for that time of year). Fortunately, I did not end up injured when I crawled out of bed.<sup>5</sup>

I have no clear recollection of how long the flashback lasted—I would guess that it was somewhere between a half hour to an hour or so. I had gone to bed, and the apartment was dark, since I was unable to sleep with any sort of nightlight (well, there was the glow from the coffee pot clock, but that was it). As I was curled up into my fuzzy sheets and pile of blankets, my mind started slipping back and I started remembering the time I was sitting in the dining room of the house my husband and I had shared. I was sitting with my knees glued to my chest on the beige carpet, in a room with white walls. I was leaning to my left against my lab's kennel, it was kind of old since we had been given it as a hand-me-down by my in-laws. To my right and just behind me was the door to our spare room, turned into a tv room. I could feel the pain in my abdomen where

<sup>&</sup>lt;sup>5</sup> One of my informants wanted me to include an example of a flashback that she had recently written for her therapist about a day and a half after the flashback happened. In this example, we can see that the person with PTSD is not violent, even though she had experienced violence. Her main goal was to escape the experience. While being aware of Diane Goldstein's cautions regarding ventriloquism, I have left the narrative in the informant's own words, even though it is fractured due to the high stress level she experienced while writing it down (Goldstein 2012, 181-182). I have chosen to allow her to use her own words, not only because they are descriptive and *hers*, but to help demonstrate the narrative breakdown that can hinder the telling of narratives such as these, which I will further explain later. While this account is in some ways disjointed and difficult to read, I would like to point out that when she is not talking about emotionally charged experiences such as this one, her writing is much more coherent. In some of the areas that need clarification, I have included endnotes with explanations that she provided in the interview.

my legs were pressed against the surgery site that was still healing a month later. My 15-month-old dark chocolate lab puppy was curled up on my right side. The room was cluttered since I had not had enough energy to clean after working as a dog groomer in the weeks following surgery. Across from me, under the windows, was our table. [My husband]<sup>6</sup> was sitting under the table, screaming at me, and had been for about twenty minutes at this point. Once again, he is not happy about having to put off sex because I was still healing, still bleeding from the surgery (some-what normal for that type of surgery). As his anger is ramping up, he slams his fist upwards into the bottom of the table and screamed "I WANT TO HAVE SEX WITH MY WIFE!" Flinching and shaking, I capitulate, "once my body is finished healing, I will let you use it every night after you get home from work." At that, he calms down and goes about his business as I went into the tv room and collapsed on the bean bag chair, sobbing, with the echoes of that promise running through my head. The small part of my brain that was still here/now<sup>7</sup> knew that I had to get out of the bedroom, so I slid/fell/crawled out of my waist tall bed in the dark (I can never sleep with a nightlight), miraculously missing both the nightstand and the edge of the bed that extended a few inches farther than the mattress, and also not injuring my hands or arms when I landed on them. I slid/crawled as far as I could (about six inches), sobbing, screaming without sound, hair was in my face and kept getting under my hands as I pulled myself along, then I collapsed into a fetal position, muscles were solid masses rather than flesh. So tight, and trembling as if I was gonna fall apart. Tears and drool were soaking my hair and the floor. When I had to stop moving, the muscles in my neck pulled my head back, and my body went prone (spread out lengthwise), my hands were pulling at my hair, then digging at the carpet, trying to pull me closer to the door, without any luck. I was still screaming silently and sobbing. My kitten came alongside me, and bit me—not hard, but put his jaw around my forearm (big reach for his little mouth). He did not break the skin, or even leave a welt, but there was just enough pain that I could focus on it and begin to mentally move back to the present. At that point, I realized that I had moved far enough that I could feel the edge of the door at my back. I was still in a panic state, and barely able to think-in no way clearly. I managed to finish crawling out of the bedroom, into the living room, then into the kitchen, using the green light from the coffee maker clock to avoid running into obstacles. I made it to the counter where I had tissues so I could dry my face, still crawling since my muscles didn't have the strength or coordination to allow me to stand or walk. After scrubbing my face with the tissue, still in terror, I crawled back into the living room,

<sup>&</sup>lt;sup>6</sup> Name of her husband has been removed for anonymity.

<sup>&</sup>lt;sup>7</sup> When she talks about her brain being here/now, she is referring to the time she is actually in, not the time that she was re-experiencing.

managing to turn on the light. Needing to pull out of the panic attacks I was still having, I knew that I needed to talk to someone, but my phone was in the bedroom, and I physically couldn't even look at the door at that point. I also realized that I needed my glasses from the bedroom if I was going to be able to see the phone to dial it. I looked at the door to my room, braced myself, held my breath and crawled as quickly as I could to my nightstand, grabbed my phone and glasses and got out, closing the door behind me. I managed to get ahold of a friend, who after around 45 minutes of chatting, was able to help me transition from panic attacks into being able to settle and watch a movie to get my brain onto something else. After the movie, I slept on the sofa for an hour or two, until my dog was having a hard time cuddling, and the only place he could find to lay was on my head. I managed to be able to move to the bed without terror at that point.

The next day, I was exhausted due to a lack of sleep. I was walking around in a fog, dizzy all day, my anxiety was still extremely high—causing me to have a difficult time reading tone of voice and expressions, as well as causing my chest to be very tight and painful. I had sore muscles everywhere, with cramps in my legs, and a severe migraine with nausea. By the second day afterwards, I was only tired, not exhausted. It was still difficult to get up and get going in the morning, and I was still moving slowly. My legs were sore, not crampy and my migraine was lighter. My stomach was still queasy and I was still nauseated. Anxiety was still a bit high, my chest still hurt and it was still a bit difficult to breathe. Overall, though, these symptoms lightened over the course of the day other than the anxiety. (Personal Interview).

PTSD is a condition that disrupts a person's life to an extent that most others do not

observe. The above narrative is how one person who lives with PTSD has described part

of her experience. In contrast, here is how the National Institute of Mental Health

(NIMH) defines PTSD:

It is natural to feel afraid during and after a traumatic situation. Fear triggers many split-second changes in the body to help defend against danger or to avoid it. This "fight-or-flight" response is a typical reaction meant to protect a person from harm. Nearly everyone will experience a range of reactions after trauma, yet most people recover from initial symptoms naturally. Those who continue to experience problems may be diagnosed with PTSD. People who have PTSD may feel stressed or frightened even when they are not in danger. While this is a clear and explanatory definition, it definitely does not capture the feeling of the preceding narrative. We can begin to see why people living with PTSD would feel the need to have other people better understand their situations.

# Signs and Symptoms

Most people will experience some type of trauma during their lives. This can range from a serious car accident to combat conditions or situations of abuse. Not everyone who experiences trauma will develop PTSD though, and if they do, it is not always chronic (lasting longer than a few months.) Another variable element to PTSD is symptom onset. Some people begin to experience symptoms within three months, but others do not experience any symptoms until years after the trauma occurs. A very important factor is that "[s]ymptoms must last more than a month and be severe enough to interfere with relationships or work to be considered PTSD." While PTSD is not a sign of mental illness or weakness, research has not yet determined why some people develop it and others do not, nor why it can be chronic in some people but not all cases ("NIMH » Post-Traumatic Stress Disorder" 2017).

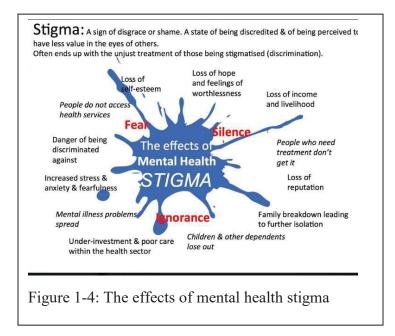
As NIMH explains, "a doctor who has experience helping people with mental illnesses, such as a psychiatrist or psychologist" may diagnose an adult with PTSD if he or she exhibits the following symptoms for at least a month:

- At least one re-experiencing symptom
- At least one avoidance symptom
- At least two arousal and reactivity symptoms
- At least two cognition and mood symptoms

("NIMH » Post-Traumatic Stress Disorder" 2017)

The differences between the medical and the vernacular explanations highlight the issues at hand—that defining this condition doesn't lead to understanding what it is like to actually experience it. Throughout the rest of this thesis, further examples will show how people who suffer from PTSD are using digital folklore to provide their own articulation of their condition.

# Stigma



At the root of the idea of *stigma* is judgement based on a preconceived image, both from the stigmatized person and the people surrounding him or her, judging who each other is, asking "how are you deficient?" In his influential work, *Stigma: Notes on the Management of Spoiled Identity*, Erving Goffman explains that stigma "refer(s) to an attribute that is deeply discrediting but it should be seen that a language of relationships, not attributes, is really needed." He goes on to explain that stigma is associated with the idea of "normal" and "normals" and that "we believe the person with a stigma is not quite human" (Goffman 1963, 3-5). This belief that the stigmatized are somehow less human than others creates a disconnect when it comes to interacting with the stigmatized, which then leads to discomfort on both sides.

The idea that there is something deficient in some people, and some way in which they are not good enough for the society in which they live, is held by the stigmatized as well as the "normals." The "normal" people are judging others, and the "stigmatized" people judging themselves against the "normal," or even judging others with the same condition, and how they believe the normals see them. It is this judgment that makes the stigmatized attribute the focus of attention on the person, to the detriment of both their public image as well as their self-image.

In the case of the flashback that was presented earlier, it is possible to see several ways in which the person might hesitate to explain what she lives with due to a fear of loss of respect from others. The first is that the level of fear engendered by this experience left the woman incapable of behaving in a manner that would be considered acceptable, as seen in this excerpt:

I slid/crawled as far as I could (about six inches), sobbing, screaming without sound, hair was in my face and kept getting under my hands as I pulled myself along, then I collapsed into a fetal position, muscles were solid masses rather than flesh. So tight, and trembling as if I was gonna fall apart. Tears and drool were soaking my hair and the floor. When I had to stop moving, the muscles in my neck pulled my head back, and my body went prone (spread out lengthwise), my hands were pulling at my hair, then digging at the carpet, trying to pull me closer to the door, without any luck. Though I included this example at her request, she did express embarrassment at this point, as well as the fear of losing the respect of others.<sup>8</sup> The importance of a first-hand account such as this one is that it is common for people with PTSD to hear normals try to say they understand by expressing that they experience bad dreams or anxiety as well, so they know what the person with PTSD is going through. This minimizes the experiences of the person with PTSD and makes it difficult for them to express the full extent of their situation because the stigma of not being in control of oneself due to fear disintegrates their self-image. As demonstrated by Renato Rosaldo in "Grief and the Headhunter's Rage" (1989), it is impossible to understand the seemingly extreme ways that people can react to deep emotions until one experiences them personally.<sup>9</sup>

Minimization by normals also leads people with PTSD to hide how long it can take for them to recover from an episode such as this one. In a society that promotes the idea that people should be able to just shake off anxiety, it is discrediting for a person to have to admit that they cannot do so. My informant explained that after experiencing the flashback she shared, it took her days to be able to function at her normal level again, and this ability to recover that quickly is due to years of treatment. At one point, she experienced episodes such as this one on a nightly basis. In order to be certain she was accurate and her memory was not playing tricks on her, she confirmed the frequency with a former roommate. Despite being constantly overwhelmed by her PTSD, she felt the

<sup>&</sup>lt;sup>8</sup> In the nature of reflexive ethnography, the woman has read and approved of the way in which her narrative has been used to illustrate a flashback and to show how it can lead to self-stigma. Her hesitations regarding fear and embarrassment are the reason that her narrative is shared completely anonymously. <sup>9</sup> In this article, Rosaldo explains how the Ilongot tribe would engage in headhunting when a family member died, and the paralysis their grief led to once they were no longer allowed the catharsis of headhunting due to Western influence. Rosaldo did not understand this level of grief until he experienced it himself with the death of his wife.

need to hide it from her friends and coworkers because the people around her often expressed disgust for people who cannot handle stress.

Another layer of stigma that is experienced by the person with PTSD is the stigma related to the traumatic experience itself. When presenting the narrative above, my informant felt that she needed to add the caveat that this was the last straw before she left her husband. In the decade between that experience and now, she has been torn between the shame of being divorced and the self-disgust that she feels from having been with him for a year. These conflicting emotions have both been reinforced at times by well-meaning people who are close to her, as well as by what she hears from the culture at large. When the traumatic experience is something that the person is told that they should have been able to prevent, stop or put up with, it makes it more difficult for them to be able to share with others. This inability to share due to damage to the person's self-image further contributes to stigma stemming from both the self and normals.

The final stigma-causing attribute that the narrative above demonstrates is the inability to follow the commonly accepted rules of narratives. In her article, "Rethinking Ventriloquism: Untellability, Chaotic Narratives, and the Choice to Speak For, About and Without" (2012), Diane Goldstein explains that, "narratives and narrators *are* governed and constrained by local norms of coherence, norms that assume competence for satisfying audience expectations regarding structure, order, form, and content" (183; emphasis in the original). Some of the concerns that Goldstein presents regarding the use of "chaotic narratives"<sup>10</sup> as we, folklorists, receive them is that instead of being

<sup>&</sup>lt;sup>10</sup> Goldstein uses "*chaotic narratives*...to refer to those narratives that lack an apparent order or organization and that are unpredictable and confusing" (Goldstein 2012, 183).

representative of the informant who shares them, they may actually intensify the stigma of that person due to the inability of the informant to follow these local norms (ibid, 191). Due to the extreme duress that the informant above experienced, both during the original trauma as well as the flashback, her narrative is told in a chaotic form. She jumps between past and present tense; the order of events is disjointed and elements of the narrative are incompletely conveyed. This is due to the inability of the brain to fully process the trauma of the experience. While the chaotic nature of the narrative is due to trauma and not lack of cognitive ability, sharing it in her original voice does run the risk of furthering the stigma of PTSD. While being aware of this risk, I believe that it is also essential to the integrity of this work to show PTSD can affect an otherwise normal person.

PTSD is considered a "concealable" stigma, at least to a degree. Unlike the loss of a limb, it is not possible to see PTSD just by looking at a person. Because it is concealable, it is sometimes possible for people to "pass" as normal despite living with PTSD. "Passing" adds to the anxiety related to the disorder because the person is adding the stress of the possibility of discovery to the stress inherent in the disorder. "Passing" also increases the stigma of PTSD because it means that normals then do not see it demonstrated that people with PTSD are not scary. In this way, stigma becomes a cycle—stigma causes people with PTSD to choose not to disclose in fear of loss of respect, which leads to greater stigma.

Some of the reasons to conceal this condition stem from a lack of information (on the part of normals) on the subject, such as the stigmatized person losing employment opportunities and experiencing pity or fear from normals. While this condition can be concealable, there are also benefits to acknowledging it as well. If an employer is understanding and willing to learn about the condition, it may open employment opportunities that would otherwise be unadvisable. Experiencing understanding from the people around them can lead to a decrease in the anxiety/hypervigilance because they have one less threat—there is no longer the threat of people finding out about their condition. The people around them might also be willing to work with them in minimizing the hypervigilance—such as letting them take a seat with the back to the wall so they don't have the threat of people coming up behind them.

One of the most detrimental effects of the stigma of PTSD is that it discourages people from admitting they have a disorder and need treatment to improve their quality of life. Many times, it requires medication. I have seen comments from both people with PTSD and normals that either disparage medication or hold it up as the only method of treatment. In reality, each person's experience with PTSD, and therefore the needs relating to it, are unique. While there are things that the majority of the community may be able to do to help, there is no one cure, there is no uniform way to deal with it. This is why it is important for each person to get the help they need, and for it to be tailored to how they should best deal with PTSD. Digital folklore is an effective, non-threatening method for raising awareness of what PTSD is, and why it should be treated because it is presented in a format that enters into a person's awareness from a minimally moderated format.

A person with PTSD already has a heightened sense of danger. This sense of danger is further intensified by having a disorder which is greatly misunderstood and stigmatized, and it makes socializing, and often, basic tasks difficult. For people with

PTSD, the main symptom that relates to this is called "hypervigilance." This is a greatly

heightened awareness of surroundings, especially related to the possible threat level. This

contributes to a higher level of anxiety whenever they are in a space that is not familiar or

"safe." The following is a description of what this can be like from an informant.

#### Hypervigilance

One of the often referred to symptoms is known vernacularly as 'hypervigilance' (in the list above, it shows up as 'always being on guard for danger'). This is actually a major part of PTSD, and falls into the hyperarousal category of PTSD diagnostic criteria. While this is referred to, it is seldom described-those who deal with it understand it, because we live with it all the time. But what is it like?

How quickly can you do this?

Walk into a room.

Consider how you dressed today. Is anything binding, preventing you from moving in any way? Is your clothing likely to cause a threat in any way? Can you easily and safely run in the shoes that you are wearing? Do your arms and legs move freely?

Now, look around and tell me \*every\* possible exit and what it would take to get there-doors, windows, what is in the way-glass, floor level (second or third story?), desks, cords, people (again, keep your clothing choices in mind). How quickly could you get out, and how badly could you be injured? Once you leave the room, how do you get out of the building or where can you hide? What are <u>all</u> the social consequences of taking that exit (including people finding out that you have a mental illness)?

Who is in the room- how many people, what gender, body types, personalities, any immediately noticeable weaknesses or weapons (or is there anything that could be used as a weapon)? What mood are they in? How likely is that to change and how quickly? How well do you know them, and can you read the signs of their mood shift? If needed, can you defend yourself against them? Again, what would that cost-physically and socially?

What is the noise level of the room? Can you hear people walking up to you from outside of your vision? Speaking of vision, is there anything that effects your vision-light level, obstructions? What are the most likely things to change in the room? How quickly can you notice a new threat (someone walking into the room, for example?)

Oh, and by the way, is there or will there be, anything that triggers your particular brand of PTSD?

Add in common stress symptoms, increased levels of sensory input, and a tendency to err on the side of a threat occurring.

Repeat this every 5-10 seconds (personal interview).

A challenge for people with PTSD and the people who want to understand them is the inability to explain symptoms such as hypervigilance succinctly. In an attempt to do so, people with PTSD are turning to digital folklore.

#### **Digital Folklore**

As the world moves toward becoming largely digitized, folklorists are becoming aware of the need to observe how this new form of communication creates and encourages folklore. This need has become apparent enough that in 2009, Trevor Blank compiled and edited a book on several various types of digital folklore that had already become tradition. In this book, *Folklore and the Internet: Vernacular Expression in a Digital World* (2009), Blank cautions our discipline, saying that "[a]s scholars, we mustn't neglect technology and mass culture" (12). While there are no discussions in Blank's book regarding memes specifically, there are several chapters which address the idea of using the internet to create variations of an item being folkloric, such as Elizabeth Tucker's chapter on "Missing Women" and Lynne McNeill's chapter on "The End of the Internet," as well as a chapter by Russell Frank which covers the idea of passing on an already created work (specifically, emailed jokes). These chapters will be influential to this study on PTSD memes because they provide a baseline for how to approach internet creations as folklore.

Robert Glenn Howard, in his article "The vernacular Web of Participatory Media" (2008), states that "individuals are able to by-pass old media institutions like publishers or network television producers and offer their vernacular creations to Internet audiences. This situation has created whole new fields of public discourse" (491). This is the case for social media, where there are few or no restrictions regarding what people can post. This allows people to create and publish artistic forms of communication that might otherwise be edited or modified by a filtering agent such as a publisher. In a question, which is very applicable to the idea of using memes to communicate about difficult subjects, Howard asks, "When an individual expresses his homosexual identity by cutting and pasting an institutional document [in this case, the FAQ of Dignity USA's website] into his personal blog, is he enacting interests alternate to that of the institution? If so, where does the institutional text end and the vernacular text begin" (Howard, 2008:491)? He later answers that "By extending human connections through network communication technologies... the vernacular web holds open the possibility of transformation through discourse" (Howard, 2008:492). This is exactly what I am hoping to observe regarding the relationship of digital folklore, stigma, and PTSD. Does social media and the folklore that arises from this form of communication allow for the "possibility of transformation" by opening up a discussion about topics that have previously been untellable?

For this project, in order to limit the vast amounts of material available, I have chosen to focus on memes and virals, and the conversation trends that they generate. In her 2013 book, Limor Shifman defines memes as:

(a) a group of digital items sharing common characteristics of content, form and/or stance, which (b) were created with awareness of each other, and (c) were circulated, imitated, and/or transformed via the internet by many users (41). She differentiates memes from "virals" in that virals have a single origin point, and only one version, as opposed to memes, which—folklorically—have several variations from multiple origin points. Shifman also asserts that

both viral and memetic content involve engaged communication, albeit associated with different engagement levels. In the case of the viral, the communication may involve personalized meta-comments..., whereas memetic content invites modifications of the text itself (59-60).

Given the differences in memes and virals they can be studied separately and in different ways; however, I will be using both in my study, because they both contribute to bringing the idea of PTSD into the realm of everyday life. For the sake of ease of reading, I refer to all images as "memes," which is common in vernacular parlance as well.

# **Methodology:**

As stated above, folklorist Amy Shuman has laid out a basic structure for a folkloric approach to stigma. In order to meet her criteria, I will use the following methods (Shuman, 2012:202):

- <u>Determine what is considered normal</u>: As I do not have expertise in the field of psychology relating to trauma, I have examined basic literature on PTSD in order to determine what is considered "normal" when compared to people with PTSD.
- 2. <u>Observe the facets of stigma:</u> In order to observe the facets of stigma in digital folklore, I searched Facebook to identify and compile artifacts (memes, virals, and the discussion surrounding these genres) over the course of six months. While similar artifacts exist on multiple social media sites, I made the decision

to focus on Facebook due to the abundance of material and the built-in context from the comments and "likes."

- Analyze both digital folklore and public comments to identify how stigma is enacted by people esoteric and exoteric to the PTSD community: After compiling the artifacts, I coded them in an organic process which is described in the next chapter.<sup>11</sup>
- 4. Explore cultural expectations of tellability/untellability

and

5. Determine how stigmatized groups position themselves with regard to normal: Once the material was coded, I then analyzed the artifacts taking into consideration whether the digital folklore creates a method for making the "untellable" into something either tellable or showable. This allowed me to determine the messages that the memes are conveying.

While my research concerns stigma relating to a protected group (people with PTSD), my project did not require me to collect identifiable information from members of the group. I focused almost entirely on the memes that are created regarding PTSD and conversation *trends*. As is explained in the American Folklore Society's *Position* 

# Statement on Research with Human Subjects, folklore

methodology is therefore based on listening, observation, and conversation in the normal environment of the activity being studied. The ethics of such research demand that the researcher learn and follow the community's rules of conduct and take the community's lead in the direction of the research. This emergent process, with its continual negotiation of consent, is very different from the top-down

<sup>&</sup>lt;sup>11</sup> Folklorist Willian Jansen uses the term "esoteric" to describe a group's folklore about itself, and uses the term "exoteric" to describe a group's folklore about other groups.

'systematic investigation, including research development, testing and evaluation' defined by the Common Rule (http://www.afsnet.org/?page=HumanSubjects).

Through "taking the community's lead in the direction of the research," I have had a few people in the PTSD community who are familiar with my research request to be allowed to share their experiences. These experiences are invaluable for granting insight into the unique lived experience of PTSD.

# CHAPTER 2:

#### THEORETICAL FRAMEWORK

This chapter will introduce a number of theoretical frameworks that apply to the vernacular expression of PTSD. In addition to the core concepts explained in Chapter One, the following theories are important to the understanding of how and why people with PTSD are choosing to use digital folklore in order to convey their experiences.

#### **Disability Studies**

Disability studies is a cross-disciplinary approach to studying disabilities, with an eye towards reducing the cultural limits put on the people who are classified as "disabled." This discipline is allowing the disabled to come together, rather than being segregated by the disability that they live with, in order to have a stronger cultural and political voice. Rather than having medical professionals and people who have never had the lived experience of dealing with a disability day in and day out speak to what the disabled are capable of, the disabled are joining together to demand that they be treated with respect.

One of the attitudes that is being challenged by disability studies is the attitude that a disability is a personal trial to be "overcome." One of the goals of this discipline is to encourage society to plan for accessibility from the beginning whenever creating something, whether it be a designing a building with ramps or creating a website with screen readers in mind. This will allow people with disabilities to participate in society as much as possible, rather than relegating them to the outside (Linton 1998, 11).

Many people with invisible disabilities, in order to participate more fully in society, choose to hide or "pass" as someone who is not disabled. While this allows them

to seem normal, it does take an emotional toll on them, reinforcing the idea that their disability makes them less than whole. For some, the decision to "pass" does not come from themselves, but from the people around them, their family and friends, people who are often well-meaning, and often just trying to help the person with a disability avoid the negative reactions from others (Linton 1998, 17-21).

In order to help reduce the stigma of disabilities, one of the areas that disability studies has focused on is the language that we use to discuss disabilities. The most common examples of this are the use of "person first" language and not using pity-encouraging terms when talking about disabilities. Person first language means that rather than referring to the disorder first "PTSD person," we should refer to them as a "person with PTSD." In so doing, we highlight the fact that this is a person who happens to have PTSD rather than highlighting the disorder. The use of pity-encouraging terms, such as "confined to a wheelchair" and "afflicted with diabetes" are discouraged, as well. These terms bring to mind the image of weakness and an inability to enjoy life rather than simply acknowledging that the person is increasing mobility with a wheelchair or monitoring their blood sugar and food intake (Linton 1993, 9-16). As will be seen in the next chapter, people with PTSD are also fighting against the idea that they are objects of pity, but would rather been seen for the strength that they have developed.

The final applicable term that disability studies fights against is Goffman's "normal." To use the word "normal" indicates that anyone who does not fit into that category is lacking. Lennard Davis, in an early work on disabilities, explains that "the word 'normal' as 'constituting, conforming to, not deviating from, the common type or standard, regular, usual' only enters the English language around 1840" (1995, 24). He

explains that "the application of the idea of a norm to the human body creates the idea of deviance or a 'deviant' body." This leads to the idea that any traits which are deviant are undesirable, and therefore, society reacts negatively when they encounter them (35). Rather than referring to people as "normal," Davis chose the term "temporarily abled," which highlights the idea that at any time, these people may develop a disability. While in some ways, the research in this thesis aligns with the goals of Disability Studies, when it comes to rejecting the use of the word "normal" to indicate people without PTSD, it does not. I chose to use the word "normal" based on the way that the people with PTSD use it in the memes and their comments.

This is because the entire discussion of "normal" and how it is constructed socially is slightly different for people with PTSD, as is shown by the digital folklore. One of these ways is that people with PTSD are fighting to be recognized as having a real disability, and they are expressing a desire to return to normal. Because the people with PTSD differentiate themselves from normal, despite the goals of Disability Studies as a whole, I have chosen to use the term "normals" to indicate people without PTSD.

#### Ventriloquist Folklore:

This is not a section about folklore relating to Jeff Dunham, but rather dedicated to the discussion among folklorists regarding who has the right to speak for other people, and the issues that we need to be cognizant of when so doing.<sup>12</sup> Whenever folklorists write an ethnography, they are choosing how to present their informants, and therefore influencing how the world will perceive them. Whether or not the informants should be

<sup>&</sup>lt;sup>12</sup> Jeff Dunham is a ventriloquist and comedian whose work was popular around the time that this thesis was written.

consulted is a debate which has raged for decades. There are strong feelings on both sides of it, from Alan Dundes's tendency to write what he wanted with no concern for how his informants reacted to Henry Glassie, who respected an informant's desire to have her words edited to remove expletives. When it comes to representing our informants legally or socially, we need to be even more careful to achieve an accurate representation.

It is tempting to believe that, as ethnographers, folklorists have the inside scoop on what our informants want and need, and therefore, we have the right to speak for them. Even as an ethnographer who has personal experience living with PTSD, throughout my research I maintained an awareness that every one of us has a unique experience with the disorder. While my experiences allow me to better understand those of the community for whom I am speaking, the focus is on them and their attempts to reach out (which is why I chose to avoid the use of the plural first person in my analysis).

Speaking for other people should never be done without consideration, even if there is a very good reason that they are unable to fight effectively for themselves. The term "ventriloquist folklore" was coined in Susan Ritchie's 1993 article, "Ventriloquist Folklore: Who speaks for representation?" In this article, Ritchie cautions

one of the major effects of folklore research is the re-presentation of persons, or 'informants,' in a new context... Fieldwork manuals often recommend a common-sense morality backed up with a dose of legal caution as a solution to problems that might arise from the representation of others in our work (367).

Ritchie cautions that we, as folklorists, need to consider more than just the legal and moral aspects of our research and fieldwork. We also need to consider the results of our informants being seen in a new context. Once our works brings them into the minds and eyes of the public, there is no way for the informants to have a say in how they are regarded, nor how their words are used (Ritchie 993, 367-368).

When dealing with people who have mental challenges, folklorists need to be especially careful in their consideration regarding presentation. Our concern should not only be to consider how our informants will feel about how they are presented, but we also need to carefully consider the impact of our presentation choices on others. This was demonstrated in Diane Goldstein's 2012 article, "Rethinking Ventriloquism: Untellability, Chaotic Narratives, Social Justice, and the Choice to Speak For, About, and Without." In this article, Goldstein describes a situation in which she had to choose whether to use the "chaotic narrative" of her informant or to interpret his words in a way that followed the narrative norms. As she explains the choice that she made about how to represent him, along with the consequences and the hindsight-induced analysis which followed, Goldstein makes it clear that even the best intentions can have undesired results, and that there may be unintended, and serious, consequences to what we present (Goldstein 2012, 181).

When choosing what to include in this research, I had to balance the realities of the stigma related to PTSD, the "chaotic narratives"<sup>13</sup> which Goldstein describes, and the desire to give my audience a glimpse of what PTSD can do to a person. Overall, I have chosen to allow the memes and the comments people made on them to provide substance to the voice of people with PTSD, with two extended additions from the informant

<sup>&</sup>lt;sup>13</sup> Goldstein uses the terms "chaotic" and "untellable" for narratives relating to trauma. She explains that "[c]haotic and untellable narratives are chaotic and untellable precisely because the nature of trauma makes the narrator unable to put the experience to words. Trauma affects the self in such a way as to make coherence impossible, at least temporarily" (2012, 186).

included in Chapter One. While I acknowledge Goldstein's concerns that, even with extensive contextualization, chaotic narrative can misrepresent the narrator, I chose to include my informant's story in her own words in an attempt to help people understand some of the difficulties that are faced by people with PTSD.

When including narratives from the comments, I have chosen *not* to quote them directly, but to generalize trends, or paraphrase if a narrative was particularly relevant. This seemed to be the most effective way for me to include the voice of people with PTSD without compromising the safe place that they have discovered online. While the internet is generally considered to be public rather than private, my work deals with a population that rarely feels safe anywhere, and I chose to minimize the risk of reducing what safety they may have found.

# **Methodological Symmetry**

In "The Terror that Comes in the Night," David Hufford's ethnography on the phenomenon of the "old hag" in Newfoundland, he uses medical research to show that there is a medical foundation for the phenomenon. This approach, asking the same questions of science and the folk, is called "methodological symmetry," and it is useful when considering what the folk are saying about a condition for which there is a medical explanation. Further work that has used this or similar approaches has shown the value in being cognizant of what is being said by the medical community and the folk. In Sheila Bock's article on the stigma related to diabetes, she demonstrates how even members of the medical community can have folk attitudes towards their patients (Bock 2012, 156).

# Similarly, in Diane Goldstein's 2004 book "Once Upon a Virus," she

demonstrates the value of looking to folklore to determine where to best direct education efforts. In this work, she explains

it behooves public health officials to be aware of these narratives—not just as an indication of the rumors they need to combat, but also as a resource for understanding risk, local perspectives on public health efforts, and areas for improvement. But being able to interpret what the narratives are saying requires a degree of respect for the narratives and their tellers, a willingness to relinquish sole expert status, and a recognition of lay authority. It requires moving on from thinking about communities as target groups and narratives as ephemeral quaint stories (Goldstein 2004, 176).

The idea of the medical community showing respect for personal narratives ties in directly with my research. People with PTSD face many challenges when it comes to telling their stories. The traumas they have faced have repercussions on their mental and emotional state that are difficult to describe, and often hits them out of the blue. Trauma also plays a role in the idea of "chaotic narratives," as it affects people's abilities to narrate their stories coherently. Digital folklore is allowing the people with PTSD to present their experiences in a way that circumvents many of the difficulties they face.

### **Image Repair**

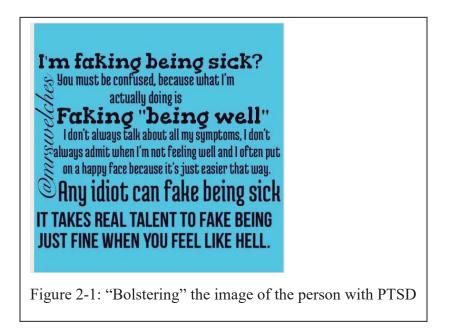
Image repair tactics, as explained by Communication Studies scholar William Benoit, are typically defensive tactics that are used after a person (or corporation) commits or is accused of an offense. Benoit has identified five categories broken down into fourteen sub-categories of tactics that are used to repair the image of someone who has been accused of an offense from an outside source. The tactics offer a problemsolving strategy for real, potential (pre-emptive image repair), or perceived problems, and they are generally directed from a defendant to an accuser regarding an action that effects their image.

A major issue for people with PTSD, and in fact one of the symptoms listed in the diagnostic criteria, is a misplaced sense of responsibility (Friedman 2013, 552). Sometimes, this is directed at an outside person who was not the actual person responsible, but often, this is directed within—to the person with PTSD. This brings in a new element of image repair—the need to repair *self-image*. Repairing the self-image of the person with PTSD is important to the person's ability to reach the highest level of functioning possible (it is not always possible to completely eliminate the disorder). Many times, the image repair tactics are being applied from an outside source—someone else is reassuring the person with PTSD that their experiences are normal and that PTSD does not make them bad or less of a person.

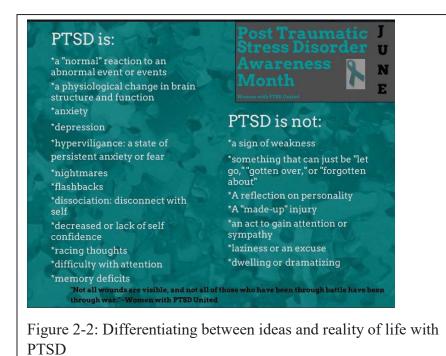
The digital folklore is being used to help accomplish this image repair by shifting responsibility to the correct person or to the disorder, as need dictates. The message in the case of much digital folklore is about the reality of the disorder and comes directly from a person with PTSD. Rather than an accuser, the memes are directed at attitudes about the PTSD. In this form, many times, these tactics are used in an attempted preemptive image repair of PTSD. In doing this, the person with PTSD can control how the information is disclosed, and can create the image that they want—the information that they want people to have, in the way that they want it presented. If the person with PTSD is using the digital folklore as a tool for telling their friends and families that they live with PTSD (as I saw in a few instances), the digital folklore allows them to direct the audience's

attention to a particular aspect of PTSD, allowing them to have greater influence on how the message is received.

While my use of Benoit's theory is different than he intended, in that I am looking at both internal and external perceptions rather than just external, I offer the following examples to demonstrate that self-image repair, as well as preemptive repair of the image of PTSD, is one of the major functions that the digital folklore plays.



**Figure 2-1:** Combating the idea that people with PTSD are faking the disorder, or that they are looking for sympathy, some of the memes are using a modification of "reducing the offensiveness" through "bolstering" the image of the person with PTSD. This meme is classified as using a bolster technique because it is "attempt(ing) to increase the audience's positive affect for the rhetor in order to outweigh or counterbalance the offense" of talking about or admitting to the PTSD (Benoit 2011, 85).



**Figure 2-2:** "Differentiation argues that the act performed by the accused was a less offensive than a similar action" (ibid, 85). The underlying argument is that "it is not X, it is Y." In this example, the folklore is being used to differentiate between common ideas of PTSD and the reality of it. In doing this, the person with PTSD is asserting that their actions are less offensive because the actions are due to PTSD. Another example of "differentiation" can be seen in Figure 2-1, when the meme says that the speaker is not "faking illness," they are "faking being well." Figure 2-1, in demonstrating both "bolstering" and "differentiation" also demonstrates how image repair tactics can be blended in the same meme.

**Figure 2-3**: In this example, the folklore is being used to show the "defeasibility" related to PTSD by explaining how the symptoms of PTSD are making being around other people not feasible (ibid, 85). This is a way for people with PTSD to overcome the negative self-image that is a part of the disorder. Once they can acknowledge that it is the PTSD that is making it difficult to be around people, people with PTSD can learn to be more aware of what it is that is triggering them. Figure 2-2 further demonstrates "defeasibility" in memes (along with differentiation) when it explains the aspects of PTSD that are beyond the control of the person with PTSD.

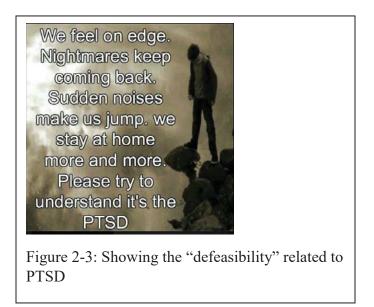


Image repair is not a central theory in my research, but as I worked with the material, it became clear that people with PTSD are working overall to repair the image of the disorder and the people who live with it. Each of the tactics described in the next chapter is combating some form of incorrect self-image or stigma inducing misconception regarding PTSD. While Benoit's theory of image repair is not generally applied to attempts at *self-image* repair, I argue that in this case this is precisely what people are doing. They are claiming that they do not deserve to be judged because of the PTSD, and also reminding themselves and each other that *they do not need to judge themselves harshly either*.

#### **Categorization of Case Studies**

The frameworks described above manifest in vernacular expression throughout the body of memes that this work examines. The memes, as individual pieces, beg for a deeper analysis. Any one of them can give insight into what people with PTSD are experiencing and desiring. One of the difficulties I faced in conducting this project was to avoid looking too deeply at any one meme, but rather to take them as a whole. While there is inherent value in a deep examination of the individual memes, the purpose of this work is to broadly examine the larger patterns of how the memes are being used to express and circumvent the untellability of PTSD in order to mitigate the stigma of the disorder. Prior to the analysis that occurs in the following chapter, I needed to categorize them in order to better determine what they were saying.

Categorization of the memes that comprised my research was an organic process that underwent three major shifts as I narrowed my focus. I began by separating the memes by whether they were from an esoteric or an exoteric perspective. Once they were grouped in this way, I determined how they were being used to mitigate or intensify the stigma related to PTSD. As I was working with the memes, I noticed that there were far more esoteric memes than the exoteric, so I focused on the esoteric which led to the second level of categorization. The second round of categorization that I used was to determine which ideas and/or misconceptions about PTSD the memes were being used to correct. This brought to light some very real concerns that the people with PTSD experience, from expressing a need to prove that PTSD is real to focusing in on symptoms and how difficult it is to communicate their experiences.

This final round of categorizations, and the one that I settled on for Chapter 3, comes from the fact that all of the memes shared a common main theme—they are trying to communicate. This is being done in three main groups: 1. that PTSD is untellable, 2. that people want to help others understand, and 3. that people with PTSD are using memes to encourage each other to keep fighting. Within each of these three groups are several categories, which will be explained in more detail in the following chapter.

# CHAPTER 3:

### ANALYSIS

On March 12<sup>th</sup> of 1990, disability rights activists staged a demonstration to protest that the Americans with Disabilities Act was continually being stalled on its way to approval. As reported by the *LA Times*,

At the close of the rally, when dozens left their wheelchairs to crawl to the Capitol entrance, spectators' attention focused on 8-year-old Jennifer Keelan of Denver, who propelled herself to the top of the steep stone steps using only her knees and elbows (Disabled Persons Rally).

Disabled Americans fought for the ADA because it included guarantees to rights that would allow them to become full citizens. However, as is the case with any equal rights legislation, the legal rights are only the first step. Changing the attitudes and preconceptions that are held by others is a much longer road, and it requires helping others to understand the lived experience of the people who are seeking equality (Disabled Persons Rally).

In disability studies, there is a slogan that says, "Nothing about us without us." This statement encapsulates the idea that people with disabilities demand not to acted upon or decided for—but rather to have agency for themselves because they are the ones that understand the trials and capabilities of the disabled. In order to understand the lived experience of people with PTSD, and therefore help them to create a support system that they need in order to survive, there needs to be a way for them to overcome the difficulties in communication that are inherent in the disorder. In many cases, helping people understand PTSD also means convincing them that it is real and that it has a real effect on the people who live with it. In order for all of this to happen, PTSD needs to become a part of normal conversation, not something that we shy away from in discomfort.

But how do we do this? How do we take a disorder that people do not always believe and do not like to discuss and make it a part of daily conversation? How can people with PTSD find a safe space in which to find each other, and engage in discussions about the realities that they face?

People with PTSD have turned to the digital sphere, and are sharing their experiences on social media in the form of memes. One of the sites where this is happening in force is on Facebook. On Facebook, people are allowed to create groups that can limit the audience for who sees what is posted, and therefore allows for rules and moderation of those rules. While what is posted in these groups is less public, people from the groups often take the memes and share them on their own Facebook walls.<sup>14</sup> I have observed people using memes to share their experiences with PTSD, as a bonding tool between people with similar experiences, to reach out to a family member or friend with PTSD, and even as a tool which allowed them to admit to having PTSD.

In order to assess the communicative contexts in which the memes were shared, I have relied on the comments that were included in the post. In order to gauge the reception of the memes, I also observed the comments that were posted in response to the memes. The overwhelming majority of the responses were people acknowledging that the meme spoke to their experience with comments such as "true," "this is me," or "thank

<sup>&</sup>lt;sup>14</sup> A Facebook "wall" is an individual's personal Facebook site which is customizable to an extent. People often post news about their lives, opinions on political and social movements and cat memes. Sometimes, the memes are more serious in nature, as well. To "share" something simply means to click a link which will copy the digital element (in this case, memes) and then choose whether they would like to share it publicly on their wall, or privately in a message. I was able to see public shares, but not any of the private ones.

you for posting this." While I chose to not directly quote the comments, especially those that shared identifiable experiences, they played an important role in assessing how meaningful the memes were to people with PTSD.

The memes that I collected were those that had the quickest and greatest numbers of shares, likes and comments relative to other memes shared in the same group at the same time. These memes broken down into three major groups: "Explaining Untellability," "Circumventing Untellability", and "Talking to Each Other." "Explaining Untellability" is further broken down into "Hiding," "Non-understandable," "Difficult to Explain" and "Responses." "Circumventing Untellability" is broken down into "Trauma Based," "Awareness," "Lists," and "Single Symptoms." The final group, "Talking to Each Other," falls into two categories, "Validation" and "Strength." Within each of these categories are several themes.

#### **Explaining Untellability**

One of the major concerns of people with PTSD is that, if they fail to pass as normal, they will incur pity or see the condition of PTSD minimized by others. Pity is when people look on those with PTSD as if they are pathetic, and minimization refers to people without PTSD making light of the lived experience of those with PTSD. Both of these issues, pity and minimization, are related to the "untellability" of PTSD, which some of the digital folklore works to circumvent.

The condition of PTSD is untellable due, in part, to lack of a frame of reference.<sup>15</sup> The "normal" for someone with the condition is not the same as the "normal" for

<sup>&</sup>lt;sup>15</sup> Trying to explain what it is like to live with PTSD to someone who has never experienced it is like trying someone who has always lived shelter-less and self-reliant in an untamed forest trying to explain their life

someone without it, and even the "normal" for people with PTSD varies from person to person. Inherent in PTSD is a very high level of ambient stress, a lack of sleep, hypervigilance (always being on guard and aware of threats), and nightmares. The causes of PTSD are untellable for this reason, but also because they are often considered horrific to normals (which is part of how the experiences cause or aggravate PTSD). Being constantly reminded that it is horrific that you saw your buddy die or that you experienced years of abuse makes it really hard to want to share that experience.

In making traumatic experiences taboo not only to perform (which is good) but also to discuss (not so good), society has removed any possibility of a frame of reference or a culturally accepted form of response. On top of these social reasons that PTSD is often untellable, there are also neurological changes in the brains of people with PTSD that can actually make coherent narration impossible.<sup>16</sup> The memes allow people with PTSD to use an image to convey their message when words fail, relying on flexibility of metaphors inherent in showability rather than the more stable requirements of narration in tellability.

The memes are being used to explain four different aspects of the untellability of PTSD— "Hiding" aspects of PTSD, the idea that PTSD is "Non-Understandable" for people without PTSD, that it is "Difficult to explain" what it is like to live with PTSD and people "responding" to common replies when they do reveal their PTSD.

to one who has never been outside of an intercity mansion. The person with PTSD has a very different perspective on what dangers exist in the world and is constantly on high alert due to the effects of the disorder.

<sup>&</sup>lt;sup>16</sup> People with PTSD struggle with coherency in narratives because PTSD changes the neurology of the brain causing a deficit in memories and linking PTSD symptoms to reminders of the trauma (Tapia et. al. 2007, Cisler et al 2015, Scott et al 2017, Thomaes et al 2013, Rabellino et al.).

## Hiding

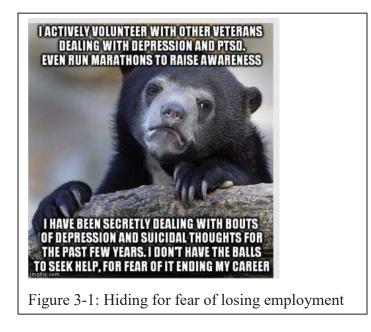
The first issue that shows up in the memes is the idea that people with PTSD are hiding or masking most of what it is like to live with PTSD. <sup>17</sup> While not the highest percentage, it is still a respectable six percent (fifteen out of 252), and remarkable because the memes in this category were shared hundreds of times within hours. These memes are often accompanied by comments that reflect that they are often told to not complain, or to stop being dramatic. To "just get over it."

The primary form of image repair that these memes use is differentiation. The memes express that the person with PTSD may seem like they are fine, but they really are not. Some of them are defiant in saying that despite others accusing them of faking being sick, they are actually faking being well, or wearing a mask so that others do not have to deal with how injured the person with PTSD really is.

One of the main themes of comments that accompany these types of memes is the lack of belief that the people with PTSD experience from people who don't understand. Many of them said that they had tried to talk to their families, their doctors, and even at times their therapists, and they were instructed to move on, or to stop complaining. The comments included a lot of frustration because the people had worked hard to reach beyond the walls of learned distrust to try to show a little of what they were living with, only to find the responses were negative. They felt like the people they tried to talk to did not *want* to understand or to believe them. In some ways, this may be the case. One statement that I saw several times was that people do not want to believe that one single

<sup>&</sup>lt;sup>17</sup> For examples, see Appendix One, Section One

incident, something that anyone can experience at any time, can so dramatically change a person's life.



There are some cases, where if the person shows the full extent of what they are dealing with, the full extent of the damage that has been done, it will cause damage to the support system they do have. This is especially true in cases of abuse. Some of the comments indicate that the abuse was caused by a friend or lover of someone they are close to (such as being abused by a mother's boyfriend) and that the person they love who was unable to protect them did as much as they could. This demonstrates that the person is minimizing their experiences with PTSD to protect their loved one. Other comments along this line explain that the family knows about the abuse, but that they do not want to believe that the abuser could perform such actions, or that to acknowledge the full extent of the damage would force the family or friends have to react to what was

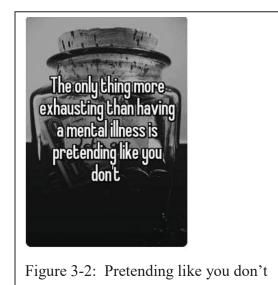
done. It is much easier for the families to ignore it rather than restructure their entire world-view.

The third reason that I saw most often was that the people living with PTSD were tired of the reactions of others: the unsolicited instructions of how to deal with PTSD, the fear that the person with PTSD would react in violence or have a flashback. They expressed being tired of the questions that others ask, and the pity that normals expressed. The commenters expressed that they were tired of trying to educate people about PTSD, especially when it was ineffective. The commenters also said that they did not feel like it was their job, and that people just didn't really care to learn. One meme (Figure 3-1) explains that the person deals with depression and suicidal thoughts, but doesn't say anything "for fear of it ending my career."

In addition to the reactions of normals, people with PTSD have to fight the influence of self-disgust when explaining PTSD. Self-disgust is often a part of PTSD, and they so commonly associated with each other that the authors of one study suggest that it may even be "possible that a person particularly apt to perceive the self as disgusting may be more likely to develop PTSD" (Brake, et al. 2017, 2). This is especially concerning if a person takes into consideration that when people do not talk about what they went through, it allows self-disgust to grow, and that self-disgust may drive the people to "eliminate oneself" (commit suicide) (ibid, 2-7). Memes allow people with PTSD to gauge the attitudes of their friends and family without necessarily revealing that they live with PTSD. It was common during the time I conducted my research for people to share memes on individual walls with minimal comments. In almost every instance that I observed, the responses were positive and supportive.

Far too often, it is so much easier for the people with PTSD to pretend like everything is "normal" rather than to admit that they are once again having a bad day. Rather than being accused of "faking it" or acknowledge the pity that they see whenever they mention their problems, they put on a mask and do what they can to get on with their day. Or they find themselves unable to face the world at all—the thought of one again being among people who do not understand what they are experiencing is paralyzing and they stay home where the dangers are more familiar.

Several of the memes in the category of "hiding" begged for people to understand, and to accept that at times, even though the person says that they are OK, they want people to know that they really are not. That they are on the edge of drowning or collapsing emotionally. Unfortunately for people on the outside, it is sometimes impossible to tell the difference between when the person is really OK or just faking it. The degree to which the people with PTSD learn to perfect pretending like they are OK contribute to the very reasons that the people feel the need to hide what they experience. All of this combines to contribute to how difficult it is for people who do not live with the disorder to understand or believe what it is like. Having memes that a person with PTSD can easily share reinforces that there are others that live with similar experiences. Knowing that they are not the only person who feels the need to fake being well can help people with PTSD find the courage to show others what they experience. Being able to share memes that demonstrate the tendency of people with PTSD to hide their experiences can help the other people in their lives to be open to believing when they do share. In this way, the memes are functioning as a form of vernacular group therapy.



# Non-understandable

The next category of memes in this grouping consist of expressions about how difficult or impossible it is for the *audience* to understand what it is like to live with PTSD, even if the person with PTSD isn't hiding his or her experience. <sup>18</sup> Out of the 252 memes that I analyzed, there were thirty-six in this category. The audience is admonished to *listen* when people try to explain what it is like; the memes ask "how do you run away from things that are in your head?" and recommend that people try spending a "day thinking in my head" (see figure 3-3).

In the form of image repair, many of these memes use the "counterattack" to say that the person with PTSD is trying to explain themselves, but that the audience is not understanding or not listening. The other method that is often used in this category is "defeasibility" when they explain that it is not feasible to understand PTSD. In one

<sup>&</sup>lt;sup>18</sup> For examples, see Appendix One, Section Two

poignant example, the person with PTSD is expressing relief that the audience does not understand what it is like to live with mental illness.<sup>19</sup> In these examples, a common theme is that PTSD is impossible to understand if you have never experienced it.

Some express how difficult it can be to deal with in inescapability of PTSD. When a person encounters something that "triggers" their PTSD, it can cause nightmares, flashbacks or even just the physiological reactions to extreme stress or anxiety.<sup>20</sup> A couple of these examples express the difficulty that comes when the person with PTSD does not know or understand what it is that is causing the reaction. This reaction is not something that the person chooses, but is caused by a restructuring of the brain (Rabellino et al 2015; Wrocklage et al 2017; Thomaes et al 2013).



<sup>&</sup>lt;sup>19</sup> See Figure 1-2-31 in Appendix One.

<sup>&</sup>lt;sup>20</sup> This can include: difficulty breathing, tunnel vision, excessive sweating, inability to think coherently, losing connection with surroundings ("blacking out"), and inability to speak among other symptoms.

Some of the memes contain explanations of how a person with PTSD can have a reaction to everyday experiences, such as practical jokes, television shows, or sudden loud noises. Because PTSD rewires the brain to be hypervigilant, everyday experiences can have unintended consequences. In the comments on some of these memes, people shared incidents where a friend did something they thought was funny that ended badly: putting their hand in the face of the person with PTSD which caused a flashback to an abusive situation and resulted in the friend trying to call the person back to the present by reassuring her that he was not the abuser. Another common type of narrative from the comments was when someone cornered the person with PTSD—at a party, or a meeting, or a family gathering—and the person lost track of what they were doing and reacted violently in an attempt to escape, only to realize later what they had done. These types of incidents were unfailingly recounted with a sense of fear and self-disgust that they would have reacted violently, even though they were unaware of what they were doing at the time.

The inability to appropriately handle "normal" situations and interactions with others often makes it so the person with PTSD feels incapable of being around people. This intensifies their tendency to avoid being around others, which intensifies the way that they react. In some of the comments that accompany these types of memes, people share their experiences with therapies such as CBT,<sup>21</sup> EMDR,<sup>22</sup> or Prolonged Exposure,<sup>23</sup>

<sup>&</sup>lt;sup>21</sup> Cognitive Behavior therapy, EMDR and Prolonged Exposure therapies involve the person with PTSD working closely with a therapist in order to remember the trauma and reprocess the memories in a way that they are easier to live with. Cognitive Behavior therapy (CBT) focuses on helping the person become aware of the way that they respond to the trigger and change the response.

<sup>&</sup>lt;sup>22</sup> Eye Movement Desensitization and Reprocessing (EMDR) uses some form of engaging alternating sides of the brain in quick succession while reprocessing the memory. The most common form is through visual cues, but auditory and tactile are also used.

which helped them be able to overcome or intensified the negative way that they handled such situations. In creating an environment that allows people with PTSD to share their experiences with therapies, the Facebook groups where the memes are shared allow the people to better decide which therapies to pursue, as well as giving them a support group which will help them deal with the trials of therapy.<sup>24</sup>

	or you. You shouldn't have to understand.
	don't understand why some people can't get out of bed in the
	ng. Good. I hope you jump out of bed every single day ready to e world by storm.
100000000000000000000000000000000000000	don't understand how someone could drag a blade across their ood. I hope your never that desperate to feel something.
If you	don't understand what would drive someone to keep starving
	elves or purging despite everything they've lost in the process. I hope you stay healthy and happy in your own body.
If you	don't understand how someone can be so overwhelmed with
and the second second	to the point where they can barely function. Good. I hope you feel confident.
Contract of the second	don't understand how someone can go night after night with no Good. I hope you rest peacefully every night.
If you	don't understand why someone won't just go to church or
	or find someone who can help them. Good. I hope you always onewhere to turn.
If you	don't understand how someone can keep swallowing bottles of
pills, t	ring knots in ropes or standing at the tops of bridges. Good. I
hope y	our never that desperate for relief.
If you	don't understand. Good. Your not supposed to. But under no
circum and cr	stances does it mean you can judge. Because that's just unfair uel.

<sup>&</sup>lt;sup>23</sup> Prolonged Exposure therapy (PE) is when the person with PTSD is put into safe situations that are similar to the one which caused the original trauma, such as a person whose trauma causes them to have anxiety while in a car going on repeated long car rides. All of these therapies require that the person with PTSD work closely with a trusted therapist in order to successfully be able to reprocess the trauma and learn to live with it.

<sup>&</sup>lt;sup>24</sup> Making decisions with PTSD is often a challenge for people with PTSD. Due to hypervigilance, they can be easily overwhelmed by multiple choices, as well as by trying to assess possible negative consequences to a choice. This can be true of something as simple as type of coffee or salad or what restaurant to visit, let alone what type of therapy will work with them. Another very common factor in choice of therapy is the person's inability to trust when finding a therapist, and the problems with trying multiple therapists (every time they see someone new and they have to explain what brings them in again, it causes them to deal with symptoms.) An ill-fitting therapist can cause the PTSD to get worse rather than better, making this one of the scariest decisions that the person has to make. Having a place where they can go to share experiences helps make the decision less scary and increases the chances that the person will pursue the help they need.

### Difficult to explain

Part of the reason that it is so difficult for outsiders to understand what it is like to live with PTSD is because it is difficult for the people to explain their experiences. Twenty-one of the memes express how difficult it is for the people to *explain* what it is like to live with PTSD. These memes illustrate the difficulties in finding the words to explain what the person is feeling, or the fact that despite wanting to talk about it, all they could do is to "whisper, 'I'm fine'" (meme found on Facebook).<sup>25</sup>

Some of the memes in this category relate the difficulty in explaining what it is like to live with PTSD to the fact that the person them self does not understand what is going on. Many times, the person with PTSD is unaware of what has triggered their symptoms, or what is causing the reaction that they experience. When they try to explain what they are going through, and the audience is demanding answers or clarity, it makes the effort of trying to explain insurmountable. Some of the symptoms of PTSD are so strange that they seem unreal, even to the person who lives with them, let alone to an outsider.<sup>26</sup>

Other memes, such as Figure 3-5, express the difficulty that the person has in finding the words to explain what they are dealing with. Studies of brain scans of people with PTSD have shown damage to the frontal lobe as a common factor in PTSD. Damage to this area can affect a person's ability to think of the best words to use. Another area that is commonly damaged is the hippocampus, which is responsible for short term

<sup>&</sup>lt;sup>25</sup> For examples, see Appendix One, Section Three

<sup>&</sup>lt;sup>26</sup> One example of this is dissociation-when a trigger causes the person to lose connection with what they are doing. Sometimes this involves a person who is mobile and can end up miles away, with no recollection of where they are or how they got there. In other cases, it can involve the person having what appears to be an absence seizure or passing out.

memory (Demers et al 2015; Sullivan et al 2013; Cisler et al 2015; Scott et al 2017). One of the beautiful things about the memes is that they often combine short snippets of the experience of life with PTSD in a form that people can share with others, without having to try to find the words themselves, making the sharing of memes one way to tell the untellable. Another is that the memes and comments are written and people are sometimes capable of writing even if they are unable to speak something (Rapp, et al. 2015, 899-900).

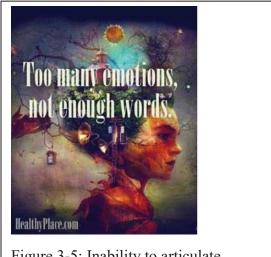


Figure 3-5: Inability to articulate

Another commonly expressed theme in this category is the lack of language relating to PTSD. While people have long acknowledged that war changes a person, PTSD as a diagnosis is fairly young—it was first included in the DSM III<sup>27</sup> in 1980, and studies are still being done to figure out what factors into the cause and reality of PTSD. Because the disorder has come onto the scene so recently, and has been so stigmatized,

<sup>&</sup>lt;sup>27</sup> The DSM is the diagnostic manual for the American Psychological Association.

our language has not developed words which are capable of clearly conveying the experiences.<sup>28</sup>

Not only are there issues with finding the words and having words to describe the experience of life with PTSD, there is also the problem with acceptability of the narrative and the narration. Many of the traumas that cause PTSD, whether in civilians or veterans, are not considered culturally acceptable for discussion or stories in the first person. While it is "normal" to encounter abuse and violence on television or in stories about "someone else," people maintain their sense of personal safety by creating the worldview that trauma is something that they can prevent. In hearing a first-hand account, often by someone they know well, they are forced to acknowledge that trauma can happen to anyone, and the preventative measures that we are taught are not always effective.<sup>29</sup> In working with veterans with PTSD, folklorist Kristiana Willsey discovered that her informant, Brad, "realize[d] quickly that in his earnest attempts to use storytelling as a means to close social gaps, he is in fact widening them—his audience is ill-equipped to interpret his experiences, and he is giving them too much information, or at least the wrong sort of information" (Blank and Kitta 2015, 220). The more that people with PTSD experiences these sorts of negative reactions from their audience, the less they feel able to explain what they are going through.

<sup>&</sup>lt;sup>28</sup> An example of this can be seen in the word "dissociate". To dissociate can mean that the person sees their brain/mind as separate from their body or self, they may become completely unaware of what they are doing (sometimes to the point where they wake up in a different area with no idea how they got there,) experiencing something similar to a petit mal or absence seizure, or even having multiple personalities. Unfortunately, language that is this indistinct not only makes it difficult to explain to friends and family, but also to therapists. A person can go for years thinking that their therapist knows what they are referring to, only to find out that they had very different ideas of what is happening.

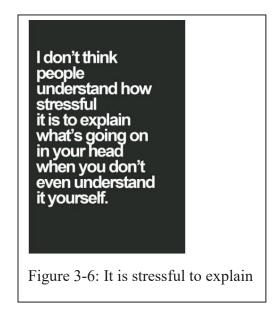
<sup>&</sup>lt;sup>29</sup> Since it is so difficult for people with PTSD to tell their stories, they generally only tell the people they know well enough to trust.

The other aspect of the narrative that makes it difficult to explain is that when a narrative relates to trauma, it is impossible for the first-person narrator to follow the acceptable patterns of narration. Diane Goldstein has written on this effect, and how detrimental it is to the credibility of the narrator. In her article *Rethinking Ventriloquism*, she refers to these types of stories as "chaotic narratives" and explains that

chaotic narratives are not uncommon, and even in situations that evoke great sympathy—those that are deeply violent and traumatic, those in which the narrator is more clearly a victim/survivor and not a perpetrator—the chaos threatens to misrepresent narrators, further silencing their perspectives and the articulation of experience (Goldstein 2012, 183).

Often the person with PTSD is aware that their attempts at narrating their experience break with the "norms of coherence," but are incapable of maintaining these norms. Some of the symptoms of PTSD, notably avoidance and inability to remember often make it very difficult for people to narrate their experiences without fighting the personal emotional impact of their narrative (Scott et al 2017; Tapia et al 2007; Thomaes et al 2013). Memes in this category often refer to how chaotic the brain feels when the person has PTSD (such as Figure 3-5), or they have images which attempt to depict what it feels like. Some of these images include a veteran with a grenade in place of his head, or a woman looking at her legs and explaining that she "only sees a wound" (memes in appendix one, section three).

Following the advice of Ann Ferrell and "valuing casual responses as data," I noted that when I discussed my research topic, I experienced encounters similar to these responses (Ferrell 2012, 131). I had people express surprise or reflection when I mentioned that *civilians* can have PTSD. I was told that people with PTSD are just looking for attention, that they should just accept that they are different, that they need to quit taking advantage of the government. When I tried to discuss my research, the spectrum of responses ranged from people expressing that the experiences related in the research gave them anxiety, to people requiring extensive explanations as to what PTSD is and why it would be difficult for people with the disorder to talk about it. While I had several people with PTSD express an interest in discussing it, they later expressed that were unable to actually handle the discussion, or they only wanted to see the finished product (because dwelling on the everyday aspects of the disorder in a way that research requires can intensify symptoms).



# Responding

In many of the comments, people with PTSD share common replies that they hear when they mention that they have PTSD. Twenty-one of the memes that I collected were direct responses to replies that are similar to the ones described, and it is clear what types of replies they are in response to. For example, in Figure 1-4-13 in Appendix One, the meme is in response to the common idea that "time heals all wounds." <sup>30</sup>

One of the biggest themes in this category is the assertion that PTSD is real, and not something that people can just "get over." The attitudes expressed in this category ranges from didactic to defiant, with one that expresses that people who do not believe that PTSD is real suffer from low intelligence and large egos. Another simply asks the audience to listen without judging. Most of the memes in this category are using "differentiation" between commonly heard attitudes towards people with PTSD and the responses that the people with PTSD would like to share in order to repair the image of PTSD.



<sup>&</sup>lt;sup>30</sup> For examples, see Appendix One, Section Four

Another theme of these memes is a call to avoid comparing traumas or experiences.<sup>31</sup> Many times, when a person with PTSD tries to explain what they are experiencing, they hear how the audience has dealt with the same thing. Sometimes this may be true, or it may sound true, but for the person with PTSD to say that they have anxiety when grocery shopping is not the same as someone who just dislikes taking the time to go to the store. Another common response in this theme is the idea that "drowning in 30 feet of water instead of 60 is still drowning," showing the use of differentiation to counteract the other person's attempt at minimization. Just because one person's experiences sound less intense does not make them less valid or difficult.

These memes in the category of "Untellability" allow people with PTSD to open the door to being able to explain how difficult it is to talk about PTSD, as well as to show a desire to be able to share their experiences.

These four sub-categories, which focus on the difficulties of communicating what it is like to live with PTSD, in total comprise thirty seven percent of the memes. The overall sense of these memes is the degree of *loneliness* that people with PTSD feel—that there is no one around them who understands what they deal with every single day, and that there is no real way for them to explain it.

### **Circumventing Untellability**

Despite the difficulties that the memes in the previous group express regarding talking about what it is like to live with PTSD, there are others which try for an explanation. These attempts at explaining fall into four categories: "Trauma-based," in which memes focus on PTSD stemming from a traumatic event, a simple call for

<sup>&</sup>lt;sup>31</sup> For examples, see Appendix One, Section Four

"Awareness" about PTSD, "Lists" related to PTSD, and memes which explain "Single symptoms."

## Trauma-Based

I collected seventeen memes that focus on the fact that PTSD is based on a traumatic event.<sup>32</sup> Some of the memes in this category claim that PTSD it is an injury, not an illness, differentiating the person with PTSD from people with a genetically based mental illness.<sup>33</sup> These memes reinforce the idea that PTSD is not a failing of the person; rather, it comes from outside of them. This is reflected in Matthew J. Friedman's explanation of how the finalization of PTSD came about in the DSM 5:

At the end of the day, however, it was decided that exposure to a traumatic event is a crucial part of the PTSD construct. For affected individuals, this event is a watershed in their lives. Things are never the same afterwards. There is a major discontinuity between their pre- and posttraumatic sense of themselves, their world and their future (Friedman 2013, 550).

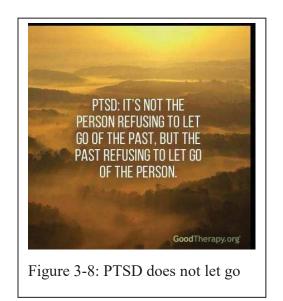
Often accompanying these memes are brief stories or statements of the trauma, or expressions of desire for things to be "normal" again, or a lament that the person feels as if they will never be able to return to normal.

Along with the memes that specifically state that PTSD is trauma-based are the memes that use the trauma-based diagnosis to differentiate between the disorder and the person. When these memes are posted in PTSD Facebook groups, they are often accompanied by a post reminding the people that PTSD is a normal reaction to a traumatic event, or that the people matter. The memes themselves are calling for a re-

<sup>&</sup>lt;sup>32</sup> For examples, see Appendix Two, Section One

<sup>&</sup>lt;sup>33</sup> This is a form of differentiation that attempts to remove from PTSD some of the stigma that accompanies the mentally ill, but at the same time, it may be stigmatizing to people who do have mental illnesses that are genetic based rather than trauma based.

imaging of PTSD as not being a reflection of the person who lives with it, but rather a normal reaction to an abnormal trauma.



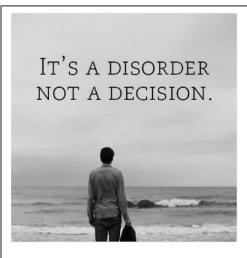


Figure 3-9: PTSD is not a decision

These memes call for people to understand that people with PTSD would let go of it in a moment if they could, but that the disorder will not let them go. For people with PTSD, the past is in a part of their daily life in the form of intrusive memories, flashbacks, and nightmares. This is not a choice for the person with PTSD; it is due to their brains being re-circuited (Thomaes et al 2013; Rabellino et al 2016).

#### Awareness

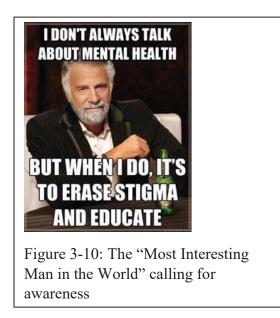
Twenty-nine of the memes are simply calling for more awareness of PTSD. Many of these are from June 2016 (PTSD awareness month) and are in teal and white (teal is the awareness color associated with PTSD). <sup>34</sup> Some of the memes detail the risks that are associated with PTSD, such as the twenty-two veterans a day (approximate number of vets who commit suicide daily) or the risks of unemployment and drug abuse that can accompany life with PTSD.

Four of the memes in this category are calling awareness to the fact that veterans are not the only people who can have PTSD, but that civilians can, as well. Much work has been done to call awareness to veterans with PTSD, and to create a support system for them. With the level of work that has been done to create awareness and destigmatize veteran PTSD, often people assume that PTSD is a disorder that is *only* experienced by veterans. These memes seek to counter that assumption. They call for people to acknowledge that PTSD is just as difficult for a civilian to live with as it is for a veteran, and that they face many of the same challenges. These memes comprise a call to accept the validity of civilian PTSD.

<sup>&</sup>lt;sup>34</sup> For examples, see Appendix Two, Section Two

Another theme in this category is memes that call awareness to the risks associated with PTSD, such as common causes, statistics related to how prevalent it is, as well as statistics related to problems that people with PTSD experience. These memes demonstrate that developing PTSD is not abnormal, and they are intended to make audiences aware of the causes of trauma and the socially unacceptable behaviors into the awareness of people. While these are typically things that are not socially acceptable narratives, the more that people encounter these narratives, the easier it is for people to discuss.

The third major theme in this category is the idea that our society has a strong need to talk openly about mental health and mental illness. Some of these memes are simple black and white paragraphs, while others feature celebrities such as Prince William or the "Most Interesting Man in the World," as in Figure 3-10.<sup>35</sup>



<sup>&</sup>lt;sup>35</sup> At the time of this research, Prince William of England was campaigning to normalize metal health as a topic of discussion.

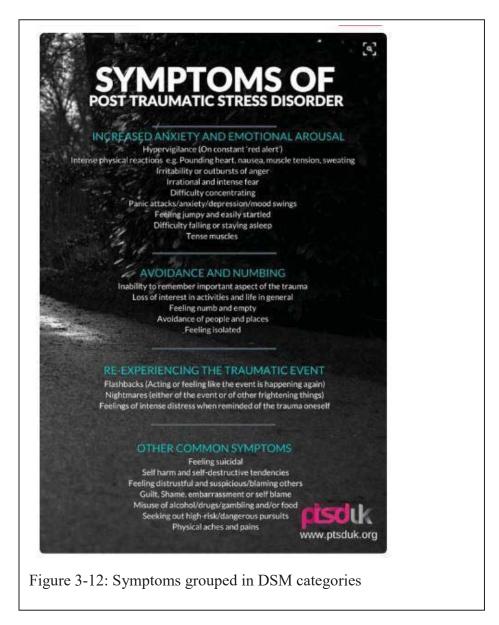
Lists

Thirteen of the memes I collected comprised various lists associated with PTSD. <sup>36</sup> Most of these are lists of symptoms, as in Figure 3-11, but there are a few that are lists of things that the audience should and should not do when relating to people with PTSD. These are all laid out in an easy-to-read format, with one or two background colors, and highly contrasting lettering in a standard font. The memes vary between the symptoms being grouped the way that the DSM does and being laid out in a simple list form.



<sup>&</sup>lt;sup>36</sup> For examples, see Appendix Two, Section Three

PTSD, like many other psychological disorders, is diagnosed primarily through the symptoms that are presented. As stated in Chapter One, diagnosis requires that a person exhibits six different symptoms in four categories. The memes in this category list many, if not all, of the symptoms, often in terminology that is more friendly to laypeople than the list in the DSM.

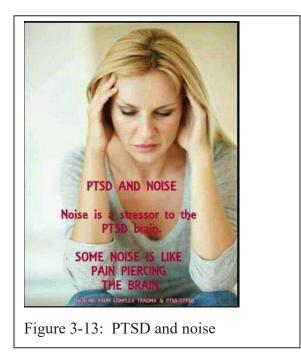


These memes are shared with people pointing out the symptoms that they experience ("all of these/them" was encountered at least half the time.) Some of the symptoms that are listed on the memes are not the same as the list in the DSM, but are side-effects of PTSD, such as "mistrust" or "communication problems." Given how extensive these lists are, they all fail to mention one symptom/side effect that is often mentioned in the next category, even as they can be used as an explanation, and that is "exhaustion."

### Single Symptom

Thirty-two of the memes<sup>37</sup> explain just one symptom, or one common experience. Many of these memes focus on the symptoms that are unique to PTSD—hypervigilance and being "triggered". Still others express the frustration that PTSD does not care about what you are trying to do, it will hit at any time. A few offer tips on how to deal with panic attacks and the like. My favorite of these, due to its unfortunate accuracy, is the one that offers tips to beat insomnia, and ends with "NOTE: If your insomnia is severe enough to require any of these techniques, they won't work." This category and the previous category "Lists" both try to explain aspects of what it is like to live with PTSD. The difficult part is that showing someone a list of twenty possible symptoms, or explaining in detail what *one* symptom is like, cannot possibly convey what it is like to live with multiple symptoms at once. As one meme I collected states, "it is difficult to take my problems one at a time when they refuse to stand in line."

<sup>&</sup>lt;sup>37</sup> For examples, see Appendix Two, Section Four



Many of the memes in this category are short statements about one aspect of PTSD, with images to enhance the message, such as figure 3-13 seen above.

Another common theme in this category, as mentioned previously, is the idea that people with PTSD experience a very deep exhaustion. The memes that are included in this theme discuss what it is like to be on constant alert—and for someone with PTSD, constant means day and night; sleep—if it happens at all—is often interrupted by flashbacks and nightmares. The person's brain never stops scanning the environment with all senses for any and all possible threats. This level of alertness, combined with no sleep and the emotional roller coaster that is inherent to PTSD, create a level of exhaustion that is difficult to accurately describe to someone who has never felt it.

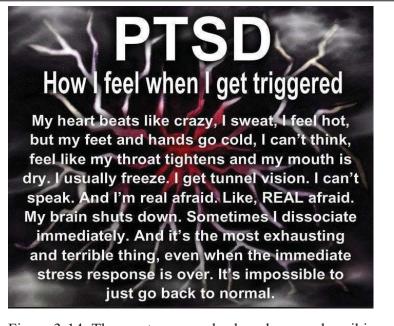


Figure 3-14: The most commonly shared meme describing "triggered"

The final major theme in this category is a reclamation of the word "triggered." In popular media and memes which mock millennials, "triggered" has come to mean the same as "offended" or "annoyed." When it comes to people with PTSD, a "trigger" is a very, very real thing. The word itself is indicative of what it really is—a very small thing that sets off an explosive chain reaction that can have a very large, real effect on the person. A trigger can be anything related to the original trauma(s)—a sight, a smell, a sound, etc. Because of how the brain is rewired by the trauma, this trigger throws the person into a fear or panic state. Often times, the triggers are set off by common elements of society, and there is nothing to escape except for a memory. So the person is left with this intense fear state that is often caused by something that they do not consciously recognize. The following category of memes are ones that have maintained a very strong presence not only throughout the six months that I was collecting artefacts, but they have remained strong while I have been in the writing process. They are some of the most liked and most shared memes that I have encountered.

When they are shared on a person's personal Facebook timeline, the person often leaves either a short comment acknowledging the truth of the meme, or they will leave nothing at all. The responses are, for the most part, overwhelmingly supportive. In only one case that I observed, the person who shared the meme was told to not talk about their experiences, and they pushed back—essentially telling the respondent that staying silent about it is what causes people to commit suicide.

These categories which convey a desire to try to call awareness to PTSD and what it is like to live with it comprise thirty-six percent of the memes that were collected.

#### Talking to each other

The final group of memes that I found were the ones that were from a person or people with PTSD and directed at others with PTSD. These memes can be used, with discretion and understanding, to demonstrate how to convey support to the person with PTSD.

All of these memes could fall under the category of validation, but within that category, one theme stood out sharply. While thirty-seven of the memes were "me too" or "it's ok to take care of yourself" messages of various types, thirty-one expressed the idea of the strength and the warrior-like mentality that it takes to live with PTSD. Since nearly half of the memes in this group have the same theme, I coded them into their own category. Memes in this group are usually posted with a statement that admits to the poster's need to hear the message of the meme. In so doing, the person posting the meme is allowing the reader to also acknowledge that they need the message. The responses on memes such as these range from being happy that the meme was posted to an extreme disbelief in the message. There were a few instances in which someone responded to these memes that they were ready to give up. On the responses that showed suicidal ideation, others were quick to respond with support and encouragement.

"Some of the most comforting words in the universe are "me too." That moment when you find out that your struggle is also someone else's struggle that you're not alone, and that others have been down the same road." ~Unknown Figure 3-15: Me too

## Validation

The thirty-seven memes that show support between people with PTSD often include bits of advice, encouraging viewers ask for help, and to not cling to unhealthy relationships. <sup>38</sup> They offer a virtual hug to the person with PTSD, or a ribbon for getting out of bed (often a struggle when they wake up from not sleeping.) There are reminders that it is not bad to have a relapse (it is often terrifying and disheartening, to be doing really well for a while, then have all of the demons return.) There are reminders that the person matters, that they are "badass" and that their difficulties are valid. In short, these memes allow one person with PTSD to reach out to others. To say that they understand the struggle the others are going through, or to acknowledge that they needed to have the reassurance as well. These memes are allowing people with PTSD to build a community of others who understand their struggle without having to come up with the words themselves. The words and images are a reminder that they are not alone, and a reminder too that others might need to have someone to connect with, as well.

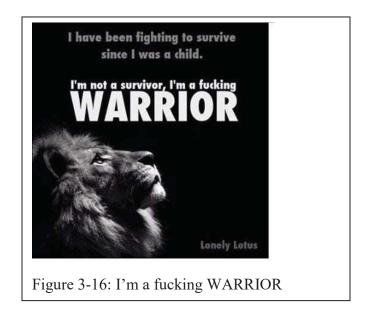
## <u>Strength</u>

There are thirty-one memes that express the idea that the person with PTSD is a warrior. <sup>39</sup> This theme connects with the already established warrior ethos of veterans. It is also due to the fact that people with PTSD fight the disorder almost every day of their lives. Memes in this theme often use words like "fighting" to survive and "forcing" themselves to continue. Many of the causes of PTSD in civilians, such as rape, domestic abuse, and child abuse, are situations in which the person was forced into the role of a victim. When the person removes themselves from the abusive situation and then learns

<sup>&</sup>lt;sup>38</sup> For examples, see Appendix Three, Section One

<sup>&</sup>lt;sup>39</sup> For examples, see Appendix Three, Section Two

to live with an injured brain, they re-image themselves as "fucking warriors."<sup>40</sup> The memes talk about the strength that it takes to force themselves to wake up and continue the fight.



In this category, the memes send out the overt message that the person who fights is strong, and the unstated message that the person should continue the fight, even if they don't see the end to the struggle. I did not see any that referred to the person returning to a life without PTSD. It was surprising to note that when memes about being strong were shared in Facebook groups for people with PTSD, these memes opened the conversation for people to admit how tired, and sometimes suicidal, they were, and how misunderstood

<sup>&</sup>lt;sup>40</sup> Often, when a person has something invisible which "others" them, they find ways to make that "othering" noticeable immediately. Not only do some of the memes use expletives, many of the people with PTSD who commented on the memes used the same type of language.

that they felt by the people around them.<sup>41</sup> It was very reassuring to see that others in the groups responded almost immediately to comments such as these, offering support and encouragement, and a reminder that the strength that comes from PTSD is the ability to continue on despite the exhaustion, and that there are times which are easier.

This group comprised twenty-seven percent of the memes. While memes in this group can demonstrate how to be supportive, discretion is advised because each person with PTSD has a different experience. The one thing that is not recommended is to tell the person with PTSD that "I know how you feel." The supportive person may be able to get a glimpse of what it is like to live with aspects of PTSD, but to live with the full spectrum of a PTSD diagnoses, day after day, brings a level of exhaustion that is inexpressible.

## Wrapping up

Overall, there are a few common elements that run through memes about PTSD. The first is the color scheme. While there is some variation, the majority of the memes are monochromatic or in blue tones. This is an interesting phenomenon because it invokes common descriptors for lack of joy such as feeling "blue" or "bleak." Many of the memes, in addition to being visually bland, are very text-heavy.<sup>42</sup> This demonstrates

<sup>&</sup>lt;sup>41</sup> While suicidal ideation is common for people with PTSD, it is unusual to talk about in face to face interactions. Even when mourning the loss of a fellow person with PTSD to suicide, it is common to refer to suicide as "losing the battle" with PTSD rather than saying that the person killed themselves. One of the benefits of reaching out in a Facebook group for people with PTSD is that the person is directing their plea for help to others who understand and therefore less likely to judge them for the way that they feel. <sup>42</sup> See Figure 1-1-2, Figure 1-2-8, Figure 2-1-6, and Figure 2-4-11 in the appendices for examples.

further demonstrates two purpose of the memes—to convey as much information as possible in a short time, and to articulate something that is typically untellable.<sup>43</sup>

Visually, people in the memes are almost never shown making eye contact with the audience. They are looking in every other direction, highlighting the shame and exhaustion that many of them feel.<sup>44</sup>

The final theme that is seen throughout the memes, in all of the categories that I set out, is the idea of PTSD being separate from the person. This is conveyed both visually and verbally. In the visual representations, the image will include a monster with an indistinct form. In the verbal descriptions, the memes refer to the "monsters" or the "demons" that people with PTSD fight. This also accentuates the fact that the person *can* fight PTSD.<sup>45</sup>

<sup>&</sup>lt;sup>43</sup> Once one person finds a way to explain an untellable aspect of PTSD, the memes allow for others who identify with that aspect to borrow the explanation.

<sup>&</sup>lt;sup>44</sup> See Figure 1-3-9, Figure 2-2-1, Figure 2-4-15, and Figure 3-2-15 for examples.

<sup>&</sup>lt;sup>45</sup> See Figure 1-2-3, Figure 1-2-6, Figure 2-2-8, Figure 2-4-23, and Figure 3-2-18 in the Appendices for examples.

## CHAPTER 4:

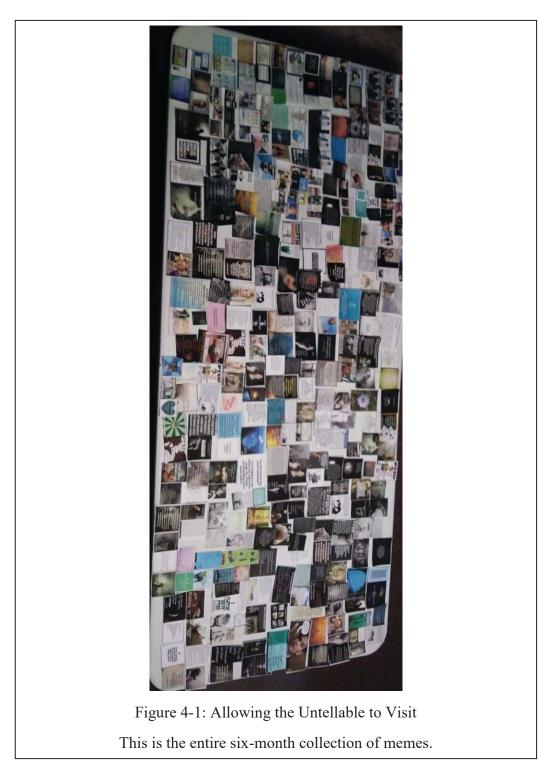
#### CONCLUSION

PTSD is a common disorder that can affect anyone who experiences trauma, and it has lasting effects which greatly impact the lives of the people who live with it. While there is a great deal of variation inherent in the disorder—from short term to chronic; the severity and combination of symptoms—it is something that people with PTSD would like normals to understand. Research has shown that a strong social support system is essential to the health and well-being of people with PTSD, as well as to their chances of recovery. The lack of a social support can contribute to the negative self-image that people with PTSD face, and therefore contribute to the high risk of suicide. PTSD is not an easy disorder to live with-either for the person who has it or for those that love them, and it often has a detrimental effect on relationships (Zang et al 2016; Woodward et al 2015; LeBlanc et al 2016; Maercker and Hecker 2016; Maheux and Price 2015). These are not trials that are faced by only people with PTSD, however, but by everyone who lives with a mental illness.

People with mental illness face numerous problems when it comes to explaining their lived experience to others. When they try to explain their lives, they are incapable of adhering to the rules which govern narrative expectations due to gaps in their memories, inability to articulate the words needed, and a lack of language structure to adequately convey their experiences. In addition to the linguistic limitations that they face are the social limitations. They face very real fears such as loss of employment, social status or even loss of family and social support. Many of the symptoms of mental illness contribute to a sense of self-disgust that also leads to silence. This stigma-induced silence is detrimental as it also prohibits people from admitting that they need professional help and treatment. The barriers to conveyance of the experience of living with mental illness cannot be overcome all at once, but must be removed a stone at a time. In order to do this, mental health needs to become a part of normal conversation. One way that people with PTSD, and other mental illnesses, are encouraging this is through digital folklore.

In using digital folklore, people with PTSD are able to convey snapshots of their experience in a way that does not overwhelm either themselves or the audience. Social media allows the audience to choose whether they wish to engage with the speaker or not, as well as the extent to which they do—whether it be through a simple "like" to acknowledge that they read the meme to a full conversation. This method also allows the speaker a degree of control over how much they engage, as well as allowing them the time they may need to process the words and emotions that sharing their experience can cause.

Through the use of digital folklore, people with PTSD are asking people to listen to and understand their lived experience. They are saying that they want to be a part of society, but that there are limits to what they can handle. These limits are not simply them being dramatic nor are they something that the people with PTSD are faking, but are very real limits which are difficult, if not impossible, to overcome. It is not the fear of what is possible that causes them anxiety, but the memory of the trauma they experienced. People with PTSD are using digital folklore to learn to tell the untellable in hopes that their audience can learn to hear it.



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# APPENDIX A: EXPLAINING UNTELLABILITY

#### Section 1: Hiding

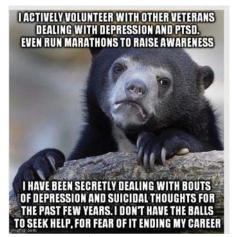
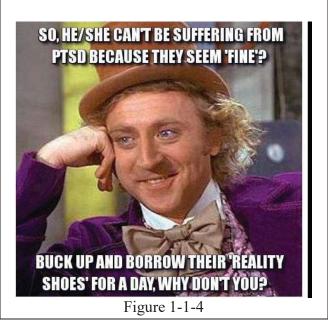


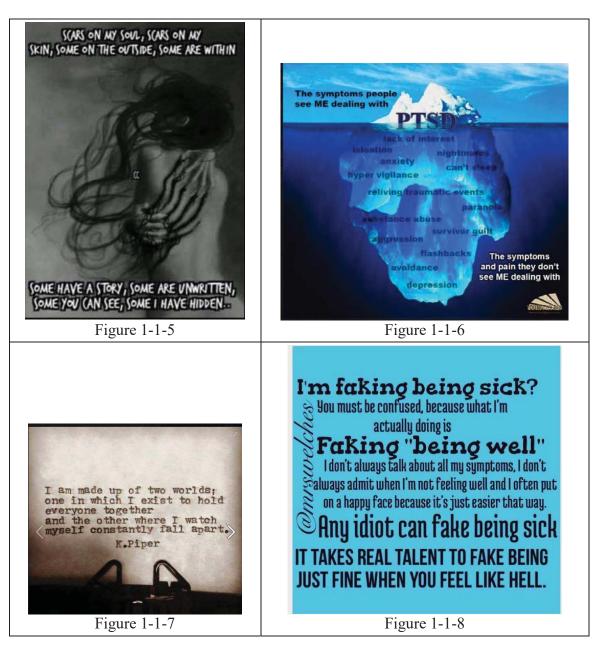
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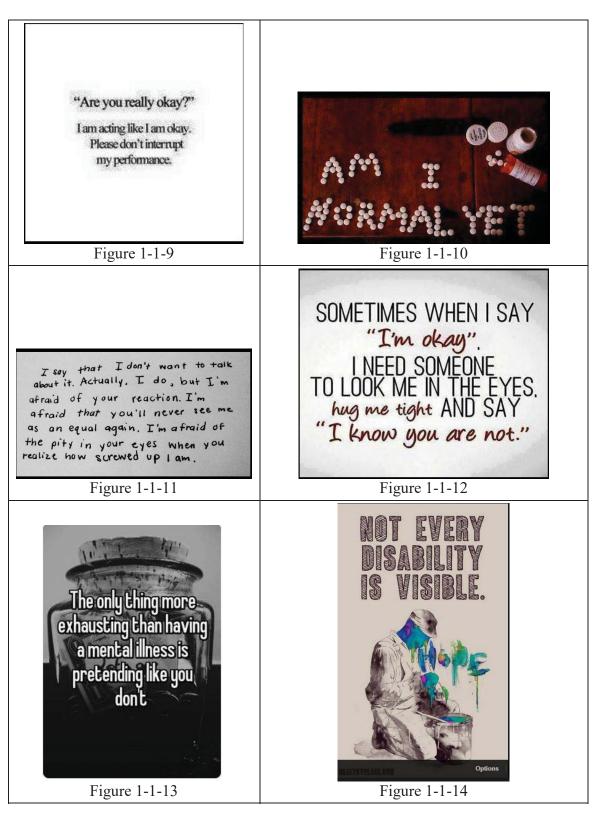
I notice everything. And by everything, I literally mean everything. I notice when someone stops hitting me up like they used to. I notice when the way someone talks to me starts changing. I notice the little things that people do, and the little things they used to do. I notice when things change, and when it's no longer the same. I notice every single little detail. I just don't say anything.

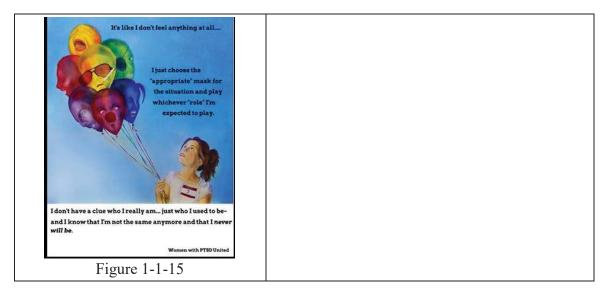
Figure 1-1-2



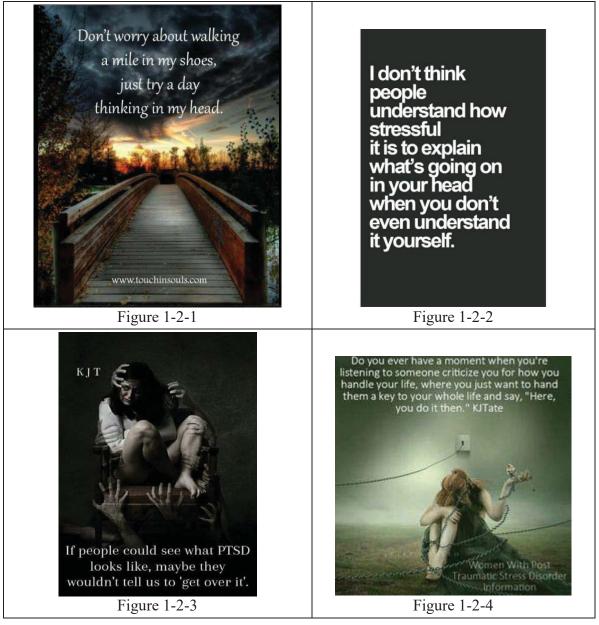


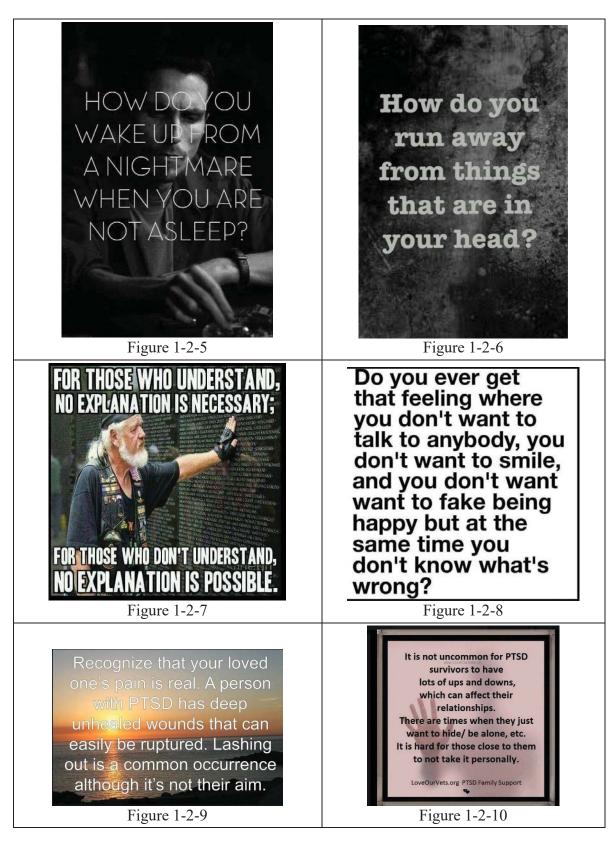


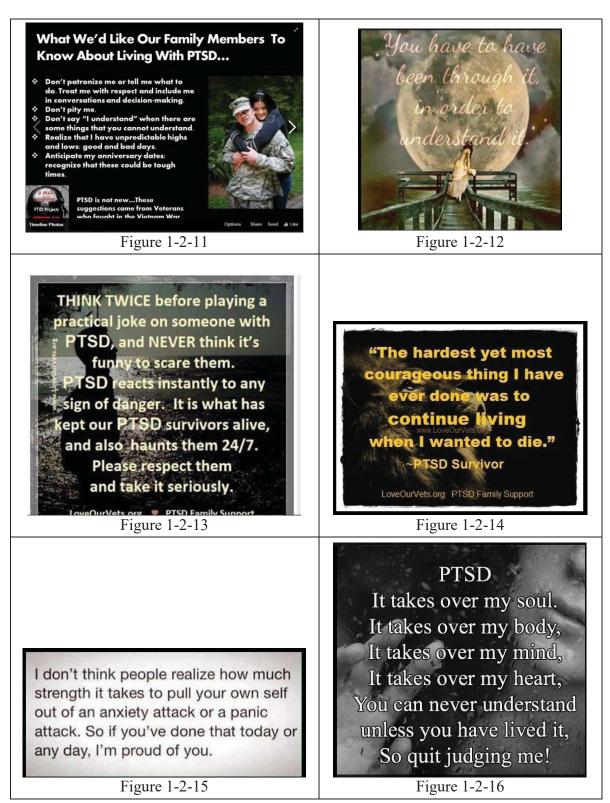


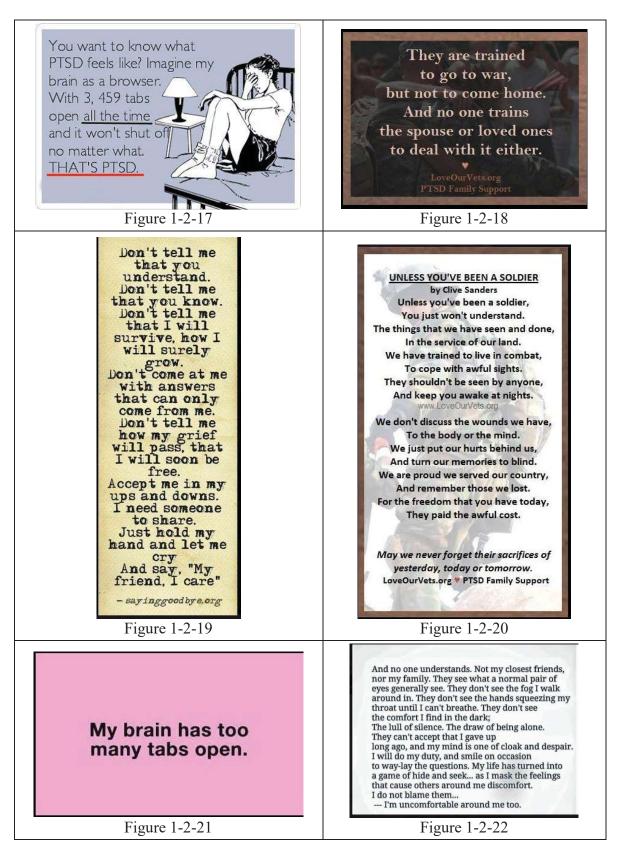


## Section 2: Non-Understandable

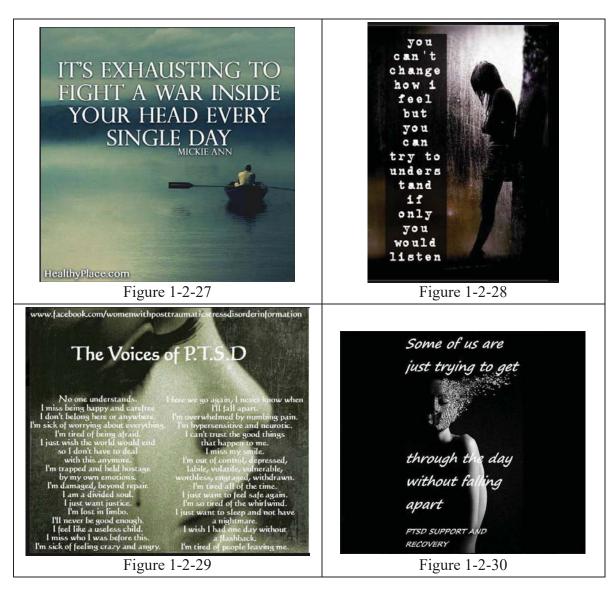


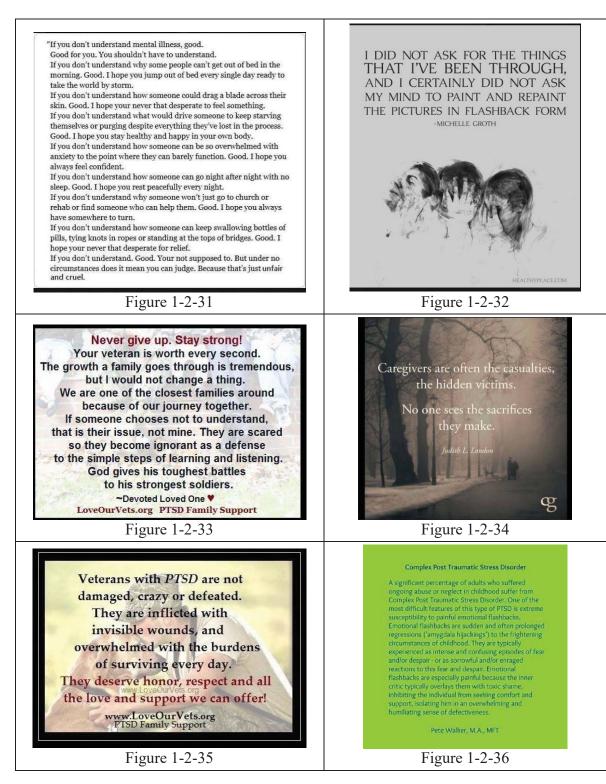




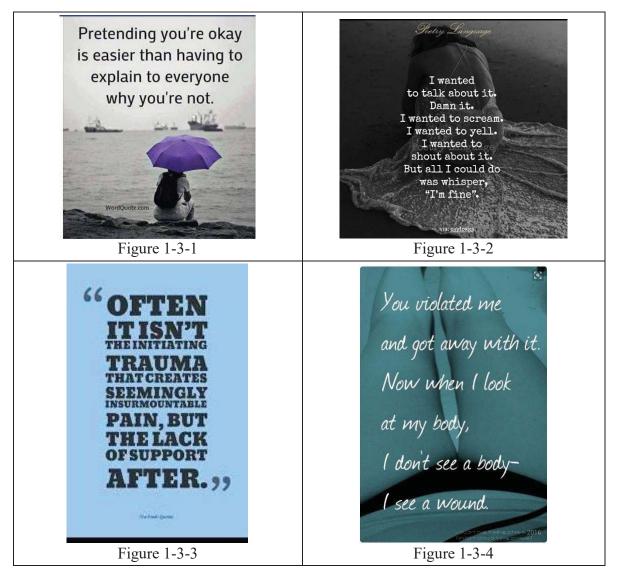


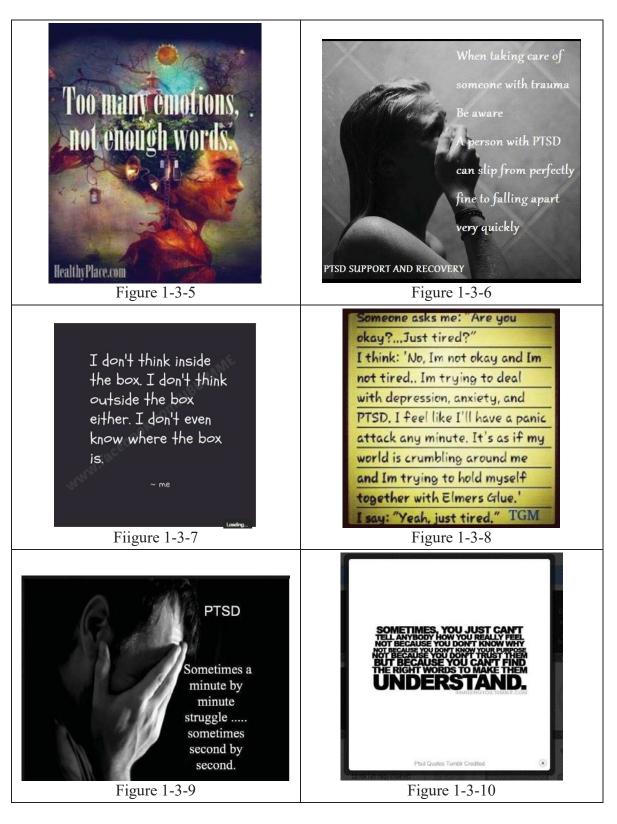


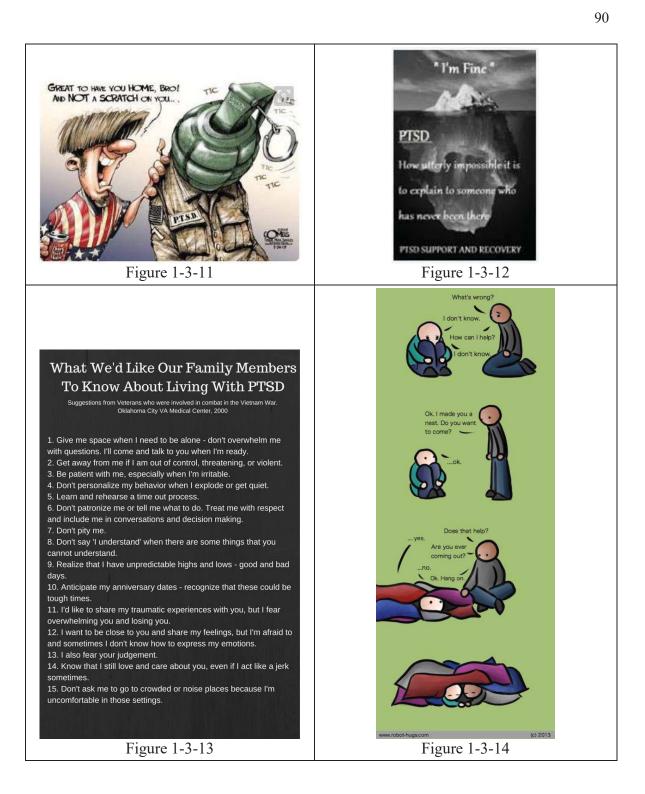




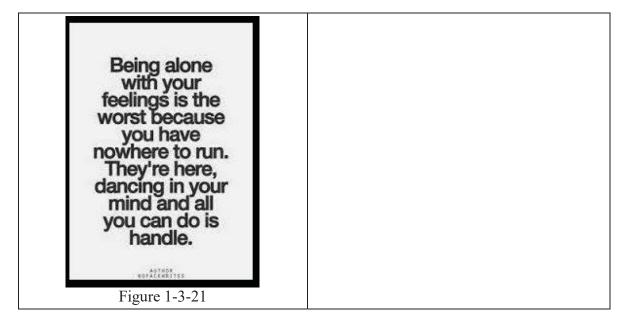
## Section 3: Difficult to Explain



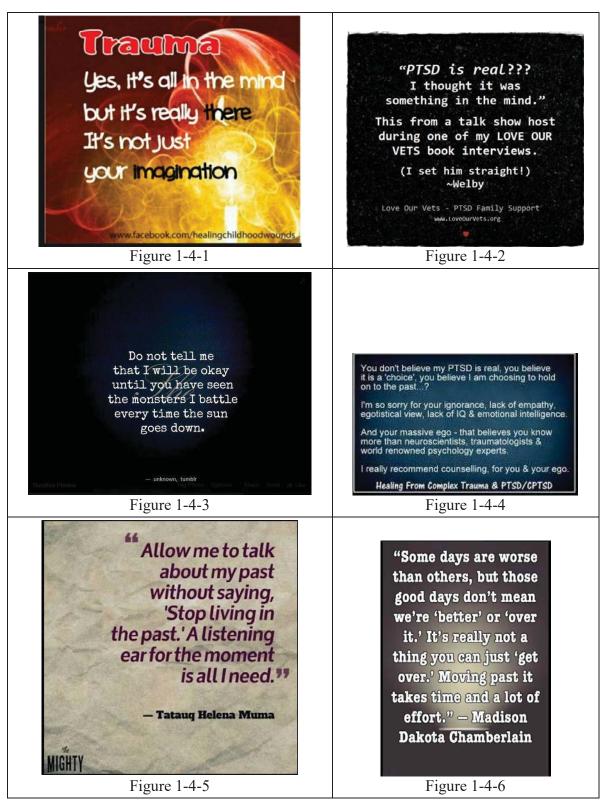


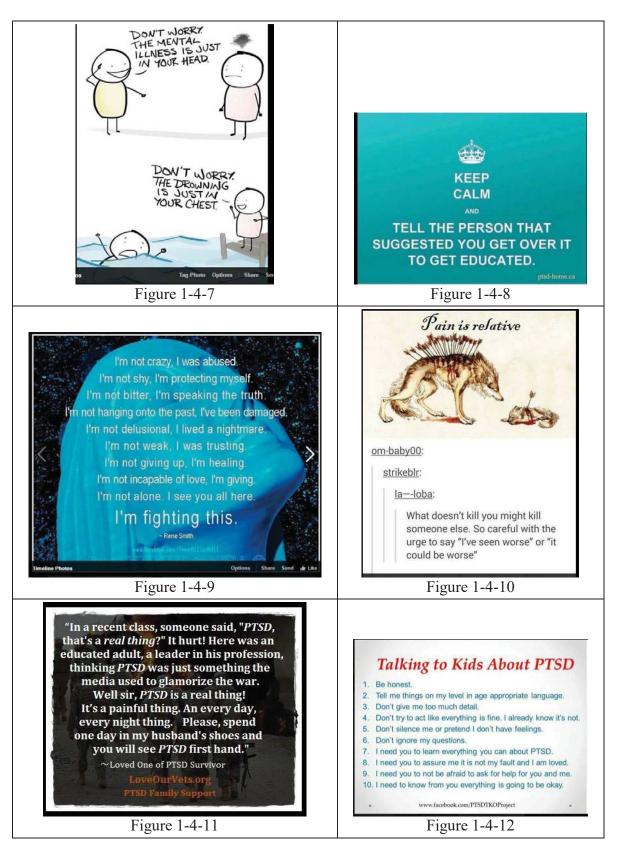


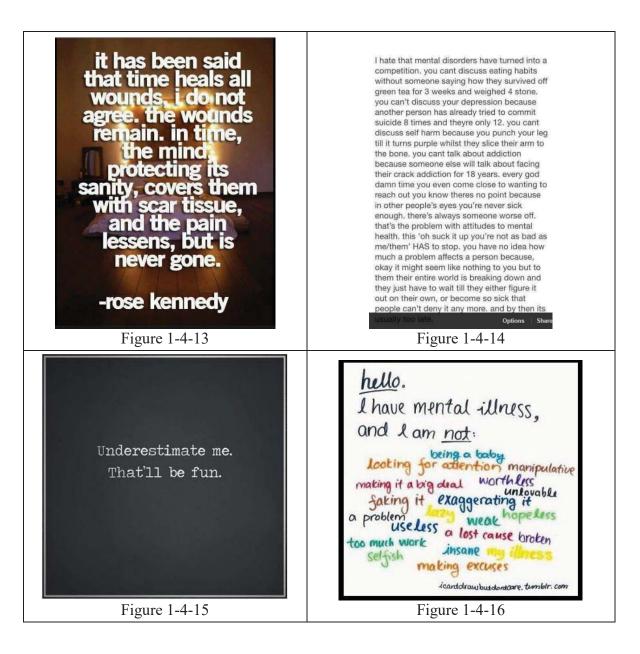


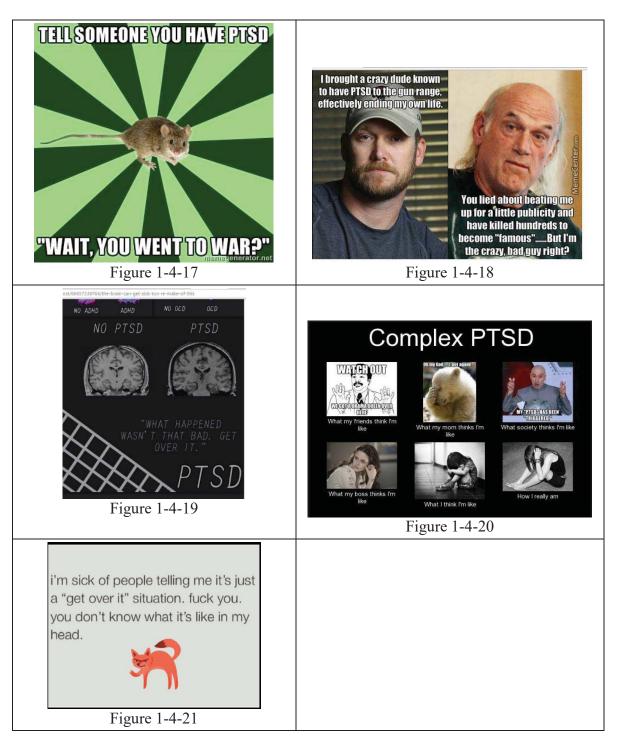


### Section 4: Responses





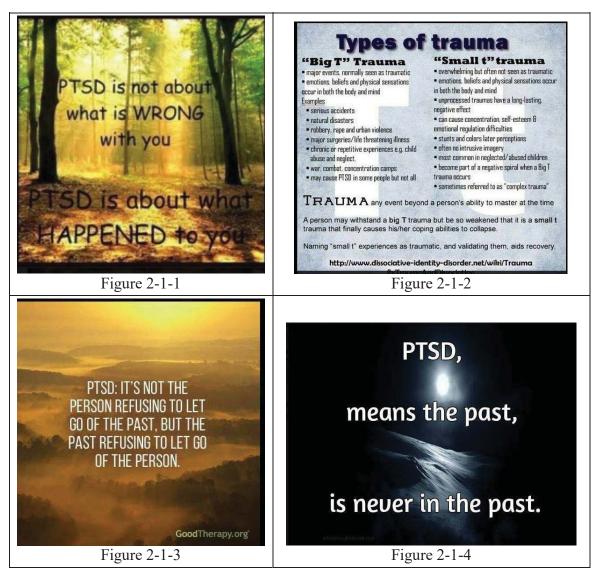




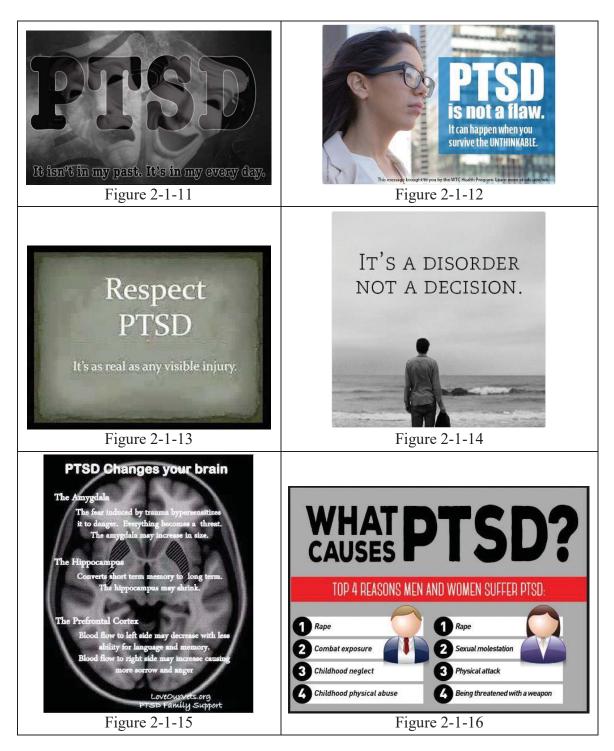
#### APPENDIX B: -

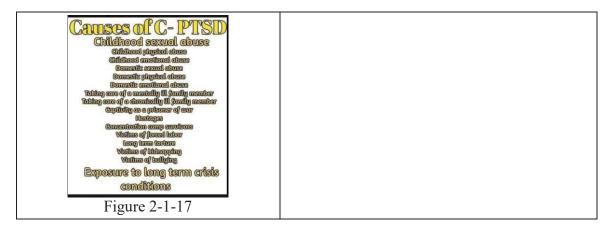
#### CIRCUMVENTING UNTELLABILITY

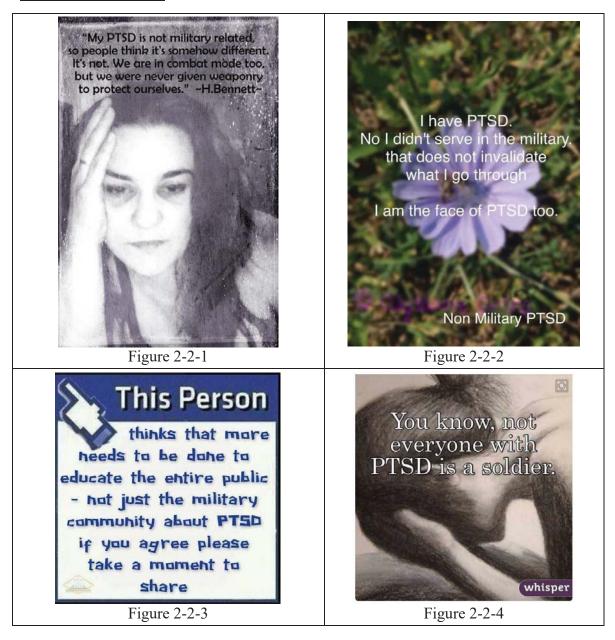
### Section 1: Trauma Based

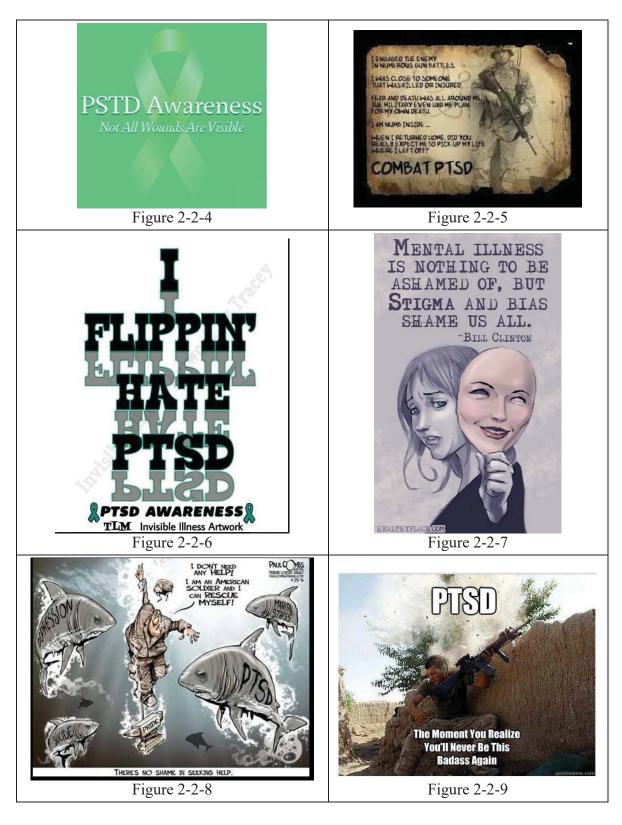






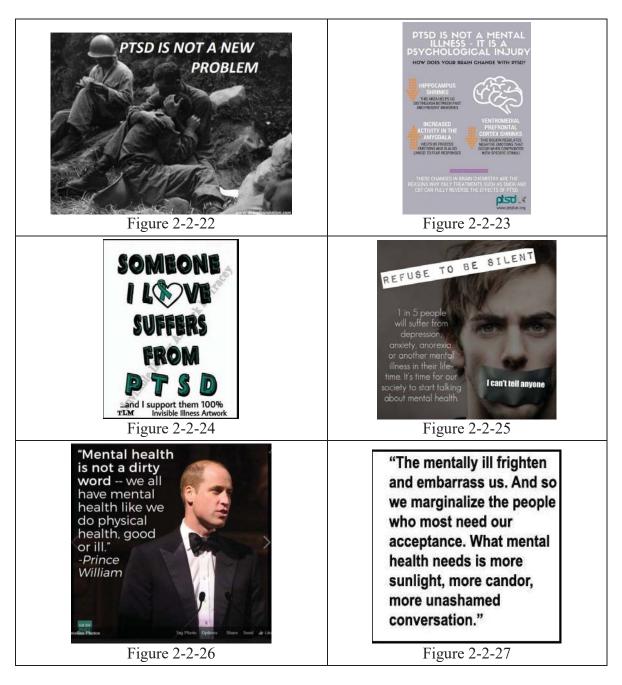


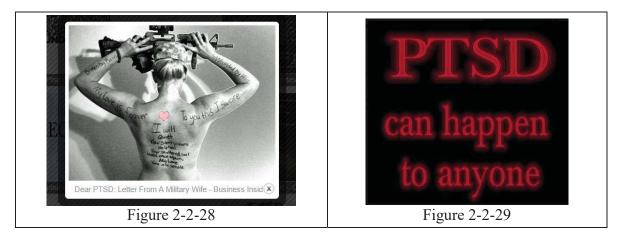








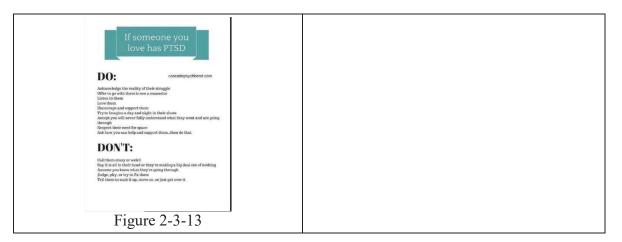




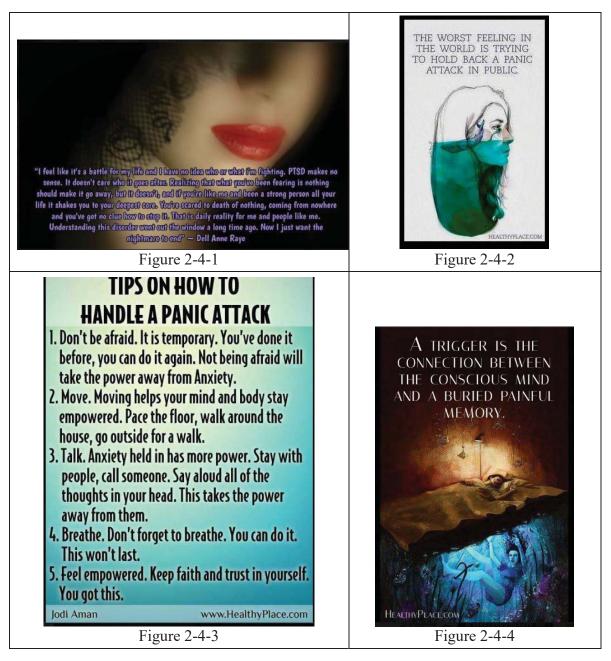
## Section 3: Lists of Symptoms





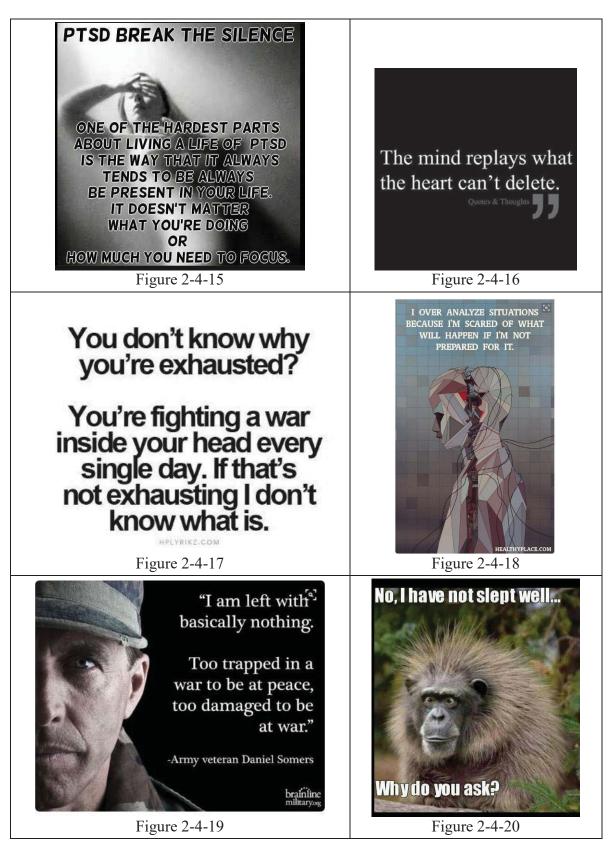


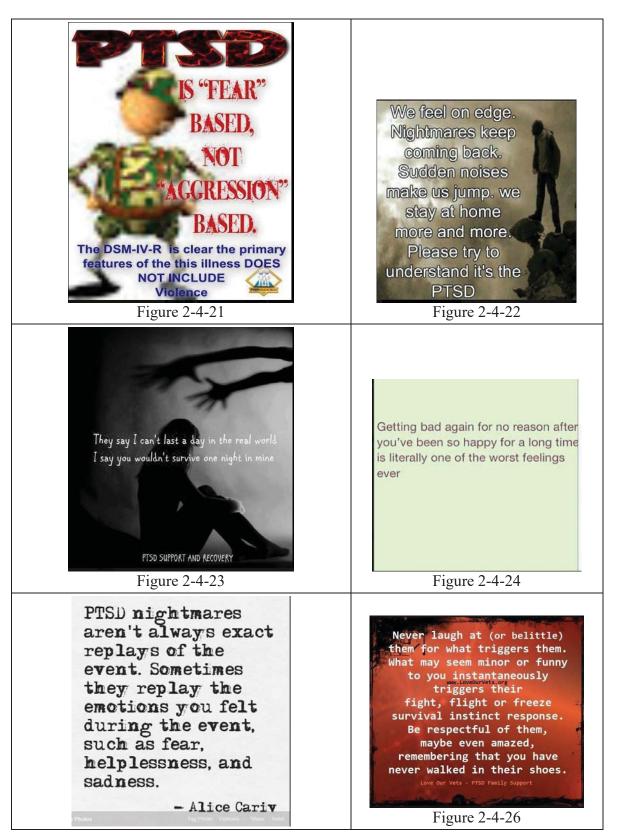
#### Section 4: Single Symptom

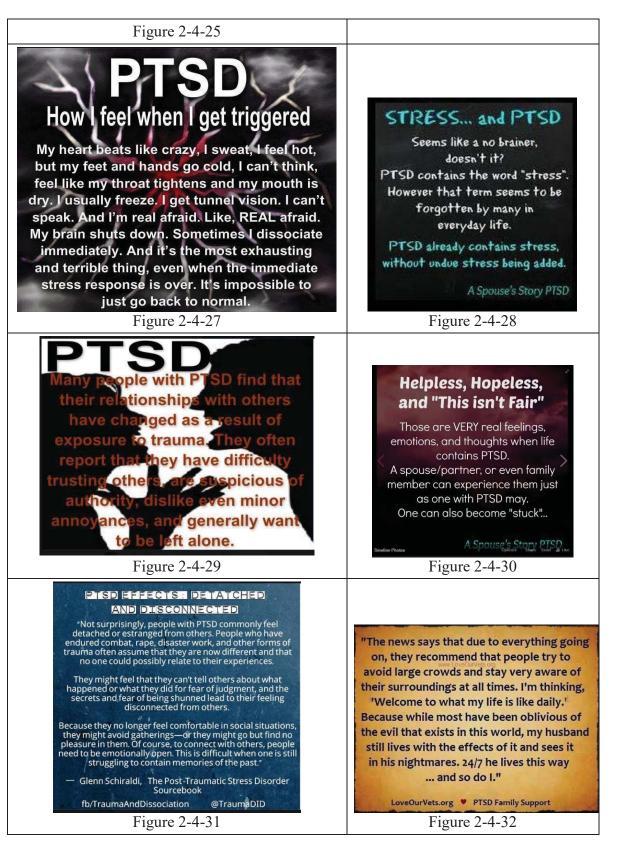


"A trigger is the connection between T HAD the conscious mind ThE and a buried DREAM painful memory." AGAIN. Dr Bill Figure 2-4-6 Figure 2-4-5 n P SD find that relationships with others their have changed as a result of exposure to trauma. They often PTSD AND NOISE they have difficulty repor Noise is a stressor to the trusting othe spicious dislike even minor autho SOME NOISE IS LIKE annoyances, and generally want PAIN PIERC be left alone. FROM COMPLEX TRAGMA & PISO Figure 2-4-7 Figure 2-4-8





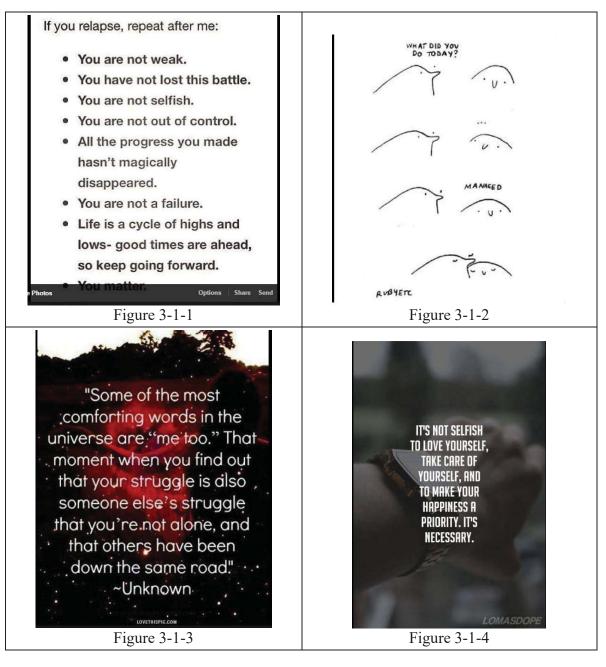




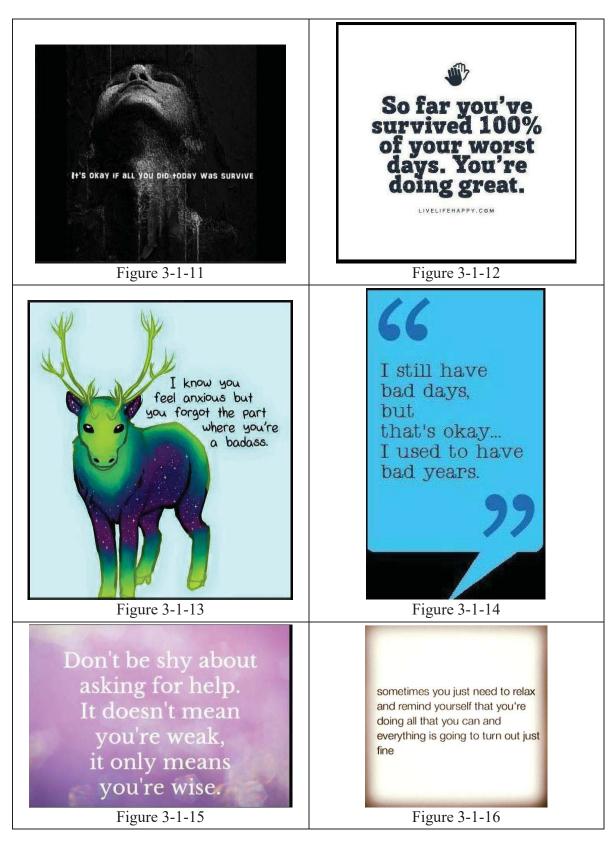
#### APPENDIX C: -

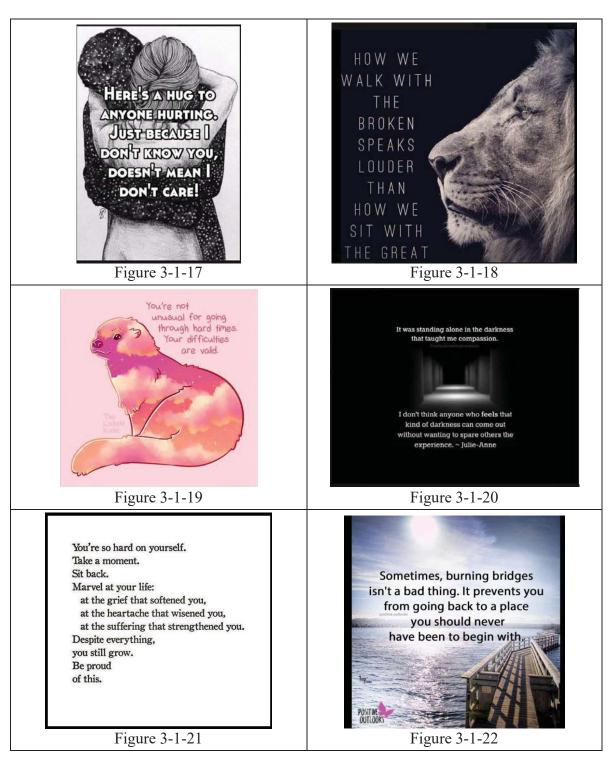
### TALKING TO EACH OTHER

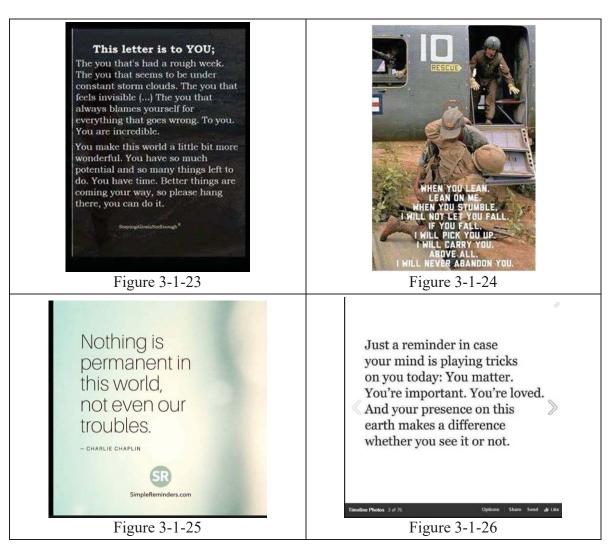
#### Section 1: Validation

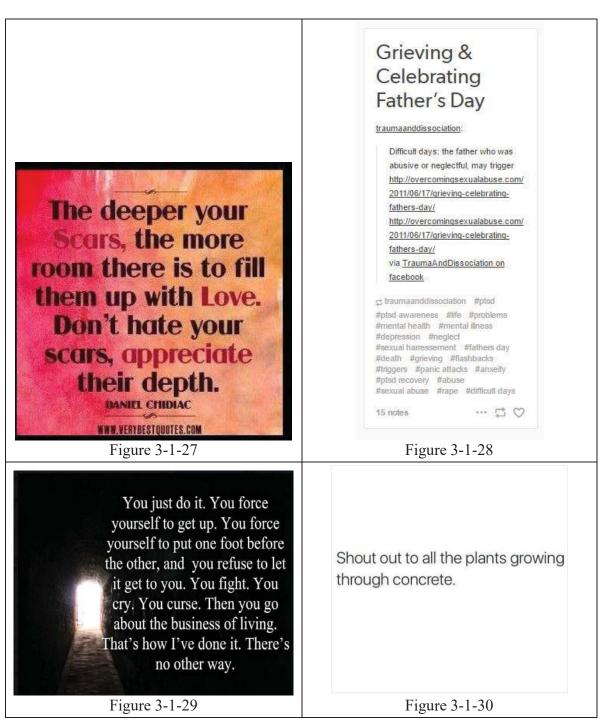




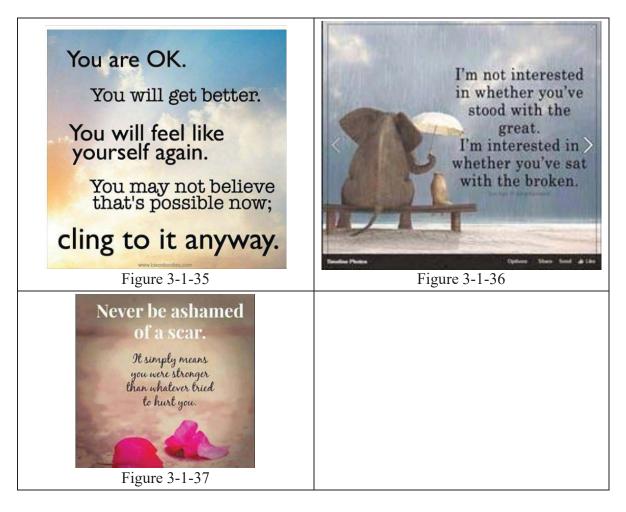












# Section 2: Strength

