

“If You Don’t Name the Dragon, You Can’t Begin to Slay It:” Participatory Action Research to Increase Awareness Around Military-Related Traumatic Brain Injury

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Abstract

Hundreds of thousands of U.S. veterans and their families are significantly affected by traumatic brain injury (TBI), yet policy-makers and the general public often lack knowledge about TBI and other “invisible injuries” related to military service. Veterans may face delayed TBI diagnoses and trouble accessing needed health care, and they and their families may face stigma and misperceptions about TBI that impede successful community reintegration. Researchers in the Department of Veterans Affairs (VA) partnered with 45 veterans with TBI and 26 of their family caregivers on a participatory action research (PAR) study that used photovoice methods to explore and convey experiences of community reintegration after TBI. Interview data and images taken by participants were used to communicate stories, reflections, and insights. This paper reports participants’ reflections about (a) how they became aware of TBI-related symptoms and the impact of TBI on their lives and relationships, (b) challenges they have encountered—including misconceptions and stigma—when disclosing TBI and other “invisible injuries” to others, and (c) strategies and resources they draw upon to counter these challenges. The authors conclude by sharing participant-identified recommendations for supporting community reintegration after military service-related TBI. This work demonstrates the power of PAR to engage veterans and family caregivers in generating knowledge to inform the programs, policies, and public discourse that affect their lives. A priority for the dissemination of the study’s findings has been to raise awareness about TBI among veterans and military caregivers.

On January 8, 2020, Iran launched ballistic missile attacks on two bases housing U.S. troops in Iraq. Despite early reports of no casualties, it was later revealed that at least 12 American servicemembers had sustained concussions and had been medically evacuated for evaluation and treatment of possible traumatic brain injury, or TBI (Lubold, 2020). At a press conference two weeks after the missile attacks, the U.S. president described the injuries as “not very serious,” saying, “I heard they had headaches and a couple of other things.” He went on to characterize the servicemembers’ injuries as less severe than those of troops who lost limbs in roadside bomb attacks, noting, “I don’t consider them very serious injuries relative to other injuries that I’ve seen...I’ve seen people with no legs and with no arms. I’ve seen people that were horribly, horribly injured in that area, that war” (Donnelly, 2020).

The Brain Injury Association of America, an advocacy and research organization focused on increasing the public’s awareness and understanding of brain injury, expressed concern that the president’s remarks minimized the

severity of TBI as “a major cause of death and disability in the United States” (Brain Injury Association of America, 2020). At the same time, the cochairs of the Congressional Brain Injury Task Force released a bipartisan statement reiterating the nation’s commitment to providing “unqualified support and respect” to persons impacted by TBI, noting, “Brain injury should never be minimized. Unfortunately, too many people, including elected leaders, are not familiar with the terrible realities of traumatic brain injury” (Office of Congressman Bill Pascrell, 2020). The commander in chief’s remarks and the responses from brain injury advocates reveal a central tension around “invisible injuries” such as TBI. While these injuries may have serious, long-term negative impacts on an individual’s health and functioning, the fact that they often lack visible and physical manifestations can impede awareness of an injury and its effects in the eyes of the injured person, those closest to them, and outside observers (Tanielian & Jaycox, 2008).

In this paper we examine these tensions around awareness of TBI through a new lens by

bringing in the voices of veterans and their family caregivers. Drawing on data from a participatory action research (PAR) study, we seek to address the following questions: 1. How do veterans develop self-awareness around the lasting effects of TBI? 2. What are the consequences for veterans and their families when self-awareness of TBI is delayed? 3. How does awareness (or lack of awareness) about military service-related TBI among family members and outside observers affect veterans as they navigate community reintegration (e.g., personal relationships, education, and work)? 4. How do veterans (and their family caregivers) pursue valued life activities despite the challenges of living with TBI?

Our work is informed by Paolo Freire's critical pedagogy, the theoretical framework that underpins PAR (Freire, 2018). A goal of critical pedagogy is to help individuals develop critical consciousness around an issue affecting their lives, thereby facilitating their ability to create and share knowledge of their own history and experiences (Ada, 1990). We were guided by critical pedagogy and PAR's recognition of researchers and participants as bringing different types of expertise to the research enterprise. Through the process of engaging participants as co-researchers—what Markham has called “respectful dialogue” (2019)—our goal was to connect their deeply personal experiences of living with TBI to the broader conversations around TBI that are happening in research and the public sphere.

The work described in this paper is built on several years of collaboration between researchers and veterans of the wars in Iraq and Afghanistan and was funded by the Department of Veterans Affairs (VA; True et al., 2015, 2021). We engaged veterans and caregivers in this study using photovoice methods, which involves giving people cameras and asking them to document, reflect on, and communicate their experiences and concerns to stimulate discussion and social change (Wang, 1999). Our goal was to illuminate and convey veteran and caregiver experiences of community reintegration after TBI and to ascertain participant-identified advocacy goals to promote recovery and improve TBI care processes, programs, and policies. In keeping with the principles of our theoretical framework, a goal of this work was to engage individuals with lived experience of military service and service-related injuries in generating scholarship and knowledge to inform programs and policies that directly affect their lives and, ultimately, to bring their perspectives

to local and national policy discussions and public discourse regarding TBI and community reintegration (Minkler & Wallerstein, 2011).

Background

It is estimated that nearly 400,000 U.S. servicemembers have suffered a TBI since the onset of the wars in Iraq and Afghanistan (National Academies of Science, Engineering, and Medicine, 2019). TBIs are typically caused by a blow or jolt to the head, or less often by a penetrating head injury, and their effects can range from short-term symptoms that resolve over time to long-lasting and debilitating changes in cognitive and motor functioning, physical symptoms such as recurrent headaches and photosensitivity, and/or significant changes in behavior and mood (Sayer et al., 2008). TBI has been associated with negative impacts on employment and relationship functioning and with increased risk of suicide (Brenner et al., 2011; Madsen et al., 2018). Around 80% of military service-related TBIs are classified as “mild,” or mTBI, and multiple studies have demonstrated strong associations between mTBI and post-traumatic stress disorder (PTSD; Bryant et al., 2010; Hoge et al., 2008).

Many U.S. servicemembers experience multiple lifetime TBI exposures, both prior to military service and throughout training and deployment, and these injuries often are not assessed or treated until servicemembers separate from military service (Brenner et al., 2010). Individuals who have sustained multiple lifetime concussions (i.e., mTBIs) are at a higher risk for emotional distress, decreased cognitive functioning, and dementia (Barnes et al., 2018; Spira et al., 2014). Barriers to diagnosis and treatment include servicemembers' reluctance to request medical treatment and a military culture that emphasizes stoicism over seeking help (MacLeish, 2013; Smith & True, 2014); veterans may be hesitant to report a history of TBI or to attribute their symptoms to TBI (Brenner et al., 2015). In addition, the overlap between TBI and PTSD in terms of etiology and symptoms often complicates TBI diagnosis and treatment; psychological trauma often co-occurs with physical injury, especially in military populations, and both conditions are characterized by attentional problems and mood changes (Tanev et al., 2014).

In 2007, the VA instituted universal screening of post-9/11 veterans for TBI exposures and developed an integrated network of specialized rehabilitative programs to provide

interdisciplinary evaluation and care for persons with TBI and comorbid conditions (National Academies of Science, Engineering, and Medicine, 2019). While these measures have been highly successful in identifying veterans with TBI and connecting them with needed services, not all post-9/11 veterans receive VA care (Tsai & Rosenheck, 2016). Furthermore, an internal audit discovered that screening and evaluation policies had been inconsistently applied across the VA during a crucial 10-year period; consequently, many post-9/11 veterans had not been evaluated by a designated TBI specialist (VA, 2018). Thus, despite growing recognition of the importance of appropriate diagnosis and treatment of TBI in U.S. servicemembers, there is still a need for increased awareness and understanding of the condition and its impacts, advocacy efforts to ensure that veterans receive appropriate treatment for their symptoms, and services to support veterans' community reintegration.

Partnered Research to Support Community Reintegration

Our work was guided by the belief that partnerships between researchers, veterans, and military caregivers will improve the relevance of research findings, lead to improvements in health care, and better inform policy downstream (Minkler & Wallerstein, 2011). Between April 2016 and March 2019, two VA researchers (GT and SO) with experience conducting veteran-engaged research and a combat veteran working in VA research (RF) collaborated with individual veterans with TBI and their military caregivers across two regions of the United States with the goal of developing community-informed solutions for improving community reintegration for persons with TBI and their families. For the purposes of our study, we defined *community reintegration* as encompassing the return of individual veterans and military families to meaningful participation in social, community, and civic life; work, education, and volunteering; domestic and family life; leisure; self-care; and spirituality and faith (Resnik et al., 2012).

In alignment with our theoretical framework, we have endeavored to disseminate our research findings through multiple channels to reach a broad audience, with veteran and caregiver participants co-presenting and coauthoring with members of the VA research team whenever possible (True et al., 2021). Partnered dissemination ensures that all types of expertise, including lived experience, can

inform policies, programs, and public awareness that directly affect veterans' and families' transition from military service to civilian life. Three authors of this paper (CU, SS, and JS) who participated in the study and one (RF) who was project manager for the study have direct experience of military service, combat deployments, living with TBI, and navigating the transition from military service to civilian life.

Methods

Community-engaged research has been conceptualized as a continuum that spans three models: an *advisory model*, in which members of a community provide overall guidance and input throughout the life of the project; an *employment model*, in which community members are salaried members of the research team; and a *participatory model*, in which people affected by the research topic are collaborative partners in the research (Roche et al., 2010). Our photovoice study employed all three. We had an advisory board that included three veterans and three military caregivers, the study's project manager was a veteran, and our veteran and caregiver participants were coresearchers throughout most phases of the project, including the identification of themes in the data and dissemination of findings. In addition, before beginning study recruitment, we developed relationships with leadership and staff at several veteran-serving nonprofits to facilitate the recruitment of participants and the dissemination of findings back to veteran communities. Institutional review boards at the Southeast Louisiana Veterans Health Care System and the VA Portland Health Care System reviewed and approved all study methods.

Recruitment

Veterans were eligible for study participation if they had served in the post-9/11 service era (Operations Enduring Freedom, Iraqi Freedom, or New Dawn [OEF/OIF/OND]) and had a TBI diagnosis documented in their medical record. We identified eligible veterans via the VA's electronic health record (EHR) and through referrals from VA staff in relevant clinics and community-based nonprofits, as described above. To confirm the eligibility of those veterans referred to the study, we verified the presence of a TBI diagnosis in the EHR. Veterans were mailed or handed a study flyer, and a member of the study team followed up by phone or in person with each prospective participant to describe the requirements of participation in more

detail and to answer questions. For each veteran who expressed interest in study participation, we asked, “Can you identify a family member or friend who is involved in supporting you in your health care and/or community reintegration?” We contacted these veteran-identified caregivers to see if they were interested in participating in the study with the veteran. Veterans who could not identify a caregiver were eligible to participate solo (i.e., without a study partner). Caregivers were not eligible to participate without a veteran study partner. Participants provided written informed consent and were compensated \$40 for each in-person study visit they completed.

Sample

A total of 45 veterans enrolled in the study, of which 26 had a caregiver study partner. Most veterans identified as male (89%) and ranged in age from 24 to 56 years (mean = 37). Nearly three quarters (73%) were White and non-Hispanic. By design, all veteran participants had a TBI diagnosis; the majority also had a diagnosis of PTSD (91%) and/or depression (67%). About three quarters of the veteran participants had served as

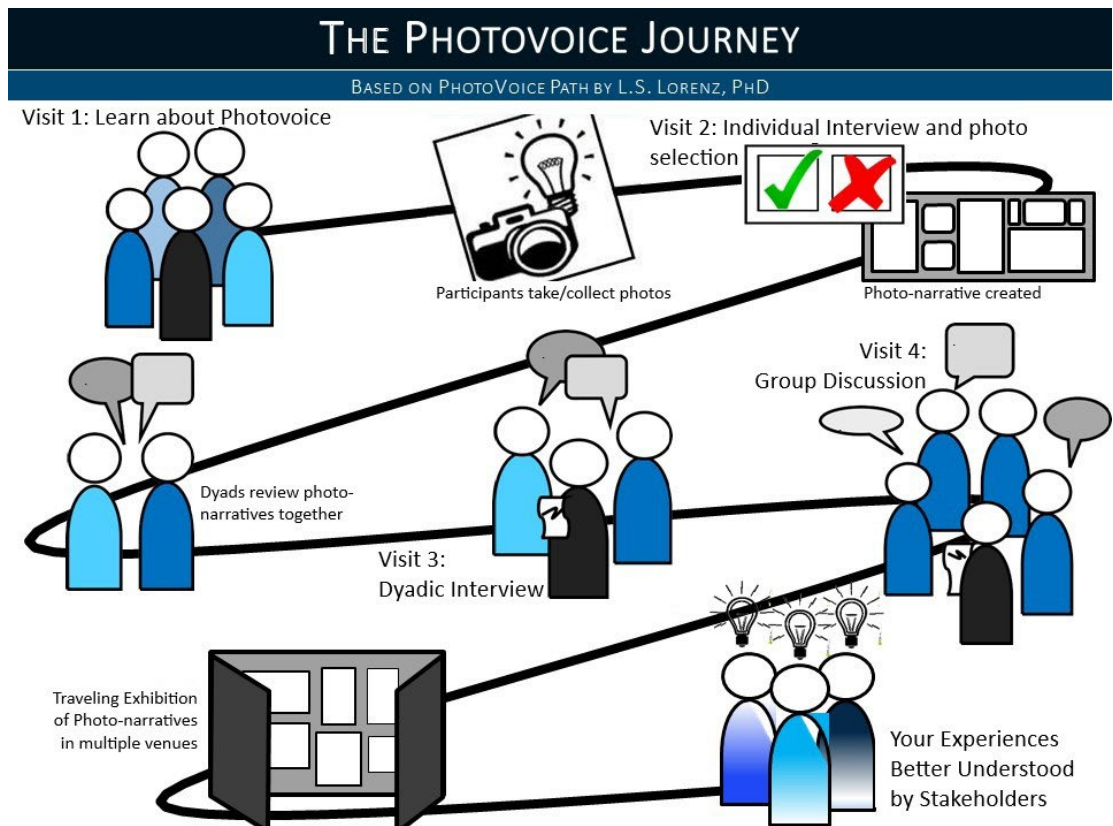
active duty military, and 22% had served in the National Guard or military reserves. Participants represented four branches of military service, with a majority having served in the U.S. Army or U.S. Marine Corps.

Of the 26 caregivers who enrolled in the study, most were women (88%) and non-Hispanic White (85%). Most were the spouse or partner of a participating veteran (81%); the remaining caregivers were parents, adult children, or siblings of the veteran participants.

Photovoice Procedures

The study sought (a) to encourage veterans and caregivers to reflect on their experiences with health, illness, and community reintegration after military service and (b) to engage them in advocacy for supportive services and environments designed to help them and other veterans and their families pursue valued life goals. We framed photovoice as a PAR method that has the potential to bring the lived experiences of veterans and caregivers to policy-makers and to raise awareness about the challenges facing individual patients and communities (Wang, 1999). We used a graphical

Figure 1. Photovoice Methods



representation adapted from Lorenz (Figure 1) to outline study methods for participants (Lorenz & Chilingerian, 2011).

Study participation involved four distinct visits. During Visit 1, members of the research team met with veteran participants or with veteran-caregiver participant pairs (dyads) to discuss the principles of PAR and the goals of the study. Participants were given cameras and asked to take photographs to illustrate their daily lives and experiences with TBI and community reintegration. Between Visits 1 and 2, a period of approximately two weeks, participants took photographs or selected relevant photos from their personal collections.

At Visit 2, a member of the research team trained in qualitative methods met with each participant one-on-one to collect photographs and conduct a photo-elicitation interview, where photographs taken by the participant were used as prompts to generate reflections and evoke stories. For this interview, we used a semistructured interview guide adapted from Wang's SHOWED method (1999). At the end of Visit 2, each participant reviewed their photographs and shared with the researcher any special instructions regarding how a specific photograph could be used and how they wanted to be identified in the dissemination of findings (e.g., by their full name, by their first name only, or by a pseudonym). These interviews were digitally recorded and transcribed.

Once transcripts were available, a member of the research team developed a photo narrative for each participant by matching text (i.e., what the person said about their photographs) with each photograph. Photo narratives were laid out in Microsoft Publisher to resemble picture books, and these "books" were mailed to participants to make edits as needed until they were satisfied that the books captured their perspectives. This process provided an opportunity for member checking, whereby data are shared with participants to check for accuracy and resonance with their intentions and experiences (Birt et al., 2016). Veterans and caregivers who were participating together were also asked to share their photo narratives with each other sometime between Visits 2 and 3.

During Visit 3, researchers met with veteran-caregiver dyads and conducted semi-structured interviews to elicit joint reflections on how reading each other's photo narratives affected their knowledge and understanding of one another's perspectives and experiences. These interviews were audio-recorded and transcribed.

For Visit 4, we invited participants to attend one of six small-group meetings. The goal of these discussions was to support community building and co-construction of knowledge (Minkler & Wallerstein, 2011; Tang Yan et al., 2019). The researchers presented preliminary themes identified in the data and displayed illustrative excerpts from participants' photo narratives on the walls to facilitate sharing and discussion. Researchers asked participants to reflect on what themes felt most relevant to their experiences and to consider whether there were themes they felt were missing or underdeveloped. Researchers and participants discussed priorities for the dissemination of the study's findings, including preferred formats for dissemination (e.g., public exhibits and presentations) and target audiences (e.g., VA administrators and policy-makers, other veteran and caregiver groups). At these meetings, many participants spontaneously connected with each other, sharing knowledge of resources and exchanging contact information so they could stay in touch outside of the research project. These meetings often laid the groundwork for papers such as this one.

Data Analysis

We used a grounded theory approach (Chun Tie et al., 2019; Strauss & Corbin, 1998) to analyze data, which we modified to suit health services research conducted in a grant-based system. A modified grounded theory approach allows for analysis that involves initial open coding, the combination of a priori codes with any data-driven inductive codes that emerge, and iteration throughout the analysis process. Drawing upon two sources—(a) the preliminary coding of individual photographs and transcripts that we used to develop photo narratives and (b) an iterative review of eight randomly selected transcripts of photo-elicitation interviews—members of the research team (including three of the coauthors [GT, RF, and SO]) developed a codebook consisting of codes (i.e., brief labels assigned to a selection of text), code definitions, and examples from transcripts. Each transcript was coded in Atlas.ti by a primary coder who applied codes to the transcript and a secondary coder who "audited" the coded transcript and noted any areas of disagreement in the application of codes. Coding disagreements were tracked through written memos and discussed and resolved by consensus at biweekly coding meetings (Cascio et al., 2019).

Through the iterative process of (a) creating photo narratives by linking photographs to quotations from transcripts, (b) member checking with participants to refine the photo narratives, (c) gaining input from participants through small-group discussions, and (d) team coding of transcripts, we identified recurrent themes around veterans' and caregivers' experiences of living with TBI and other "invisible injuries" related to military service. These themes included barriers and facilitators to community reintegration as well as recommendations for policy and programmatic change to support veterans and their families in postmilitary life. To develop the current paper, we supplemented our previous analysis with two 60-minute phone calls during which researchers and coauthor veterans identified the themes and associated data (both illustrative images and quotations) that we wished to highlight and include in this manuscript.

Results

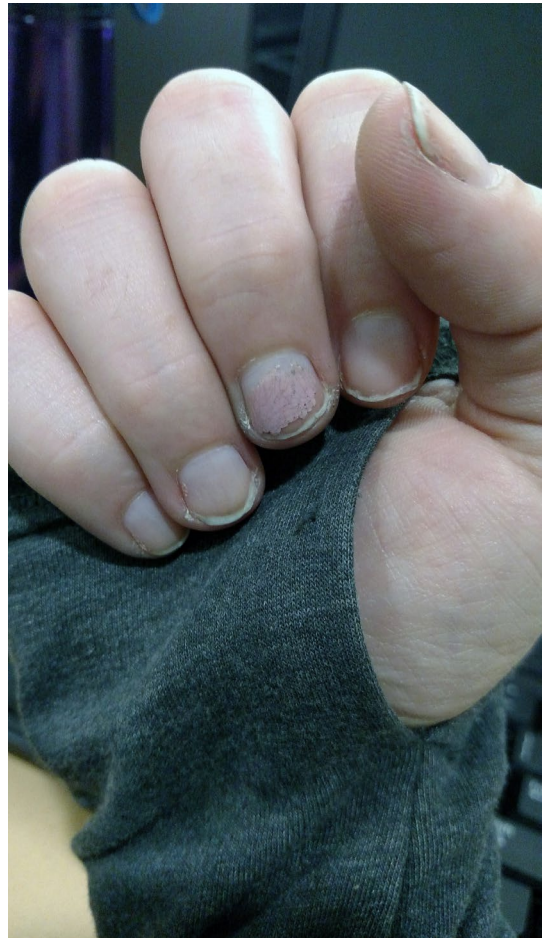
Many themes emerged from the larger photovoice study. Elsewhere, we have published the insights we gained into the experiences of family caregivers of veterans with TBI (Abraham et al., 2021; Wyse et al., 2020). In this paper, we chose to focus on themes relevant to different dimensions of TBI awareness, including (a) veterans' reflections on how they became self-aware of TBI-related symptoms and the impact of TBI on their lives and relationships; (b) the challenges veterans and family caregivers encountered—including misconceptions and stigma—when disclosing "invisible injuries" to others, and how these challenges may be compounded by civilian-held stereotypes of veterans as homogeneous; and (c) strategies and resources that veterans and caregivers draw upon to counter these challenges. We included photographs and quotations to illustrate each theme; all identifiers used here were selected by participants.

Developing Self-Awareness of TBI

Many veterans described their recognition of TBI's lasting impacts on their lives and relationships as a process that unfolded over multiple years post-military service. A veteran who identified herself by the name "Feral" provided a photograph of her bitten-down fingernails to convey the anxiety and frustration she experienced as she grew more self-aware of cognitive impairments related to her TBI:

I feel anxious in social situations. I feel anxious about meeting obligations. I feel anxious about not being able to focus on things. It feels like I'm always doing something wrong, and everything I do wrong feels like the end of the fucking world. Half of my problems are from my TBI. You feel stupid when you used to be a writer, an English major, and now you can't find your vocabulary. You're looking somebody in the eye and don't remember their name.

Image 1. I feel anxious about everything. You feel stupid when you can't find your vocabulary.



Veterans and their caregivers recounted how TBI diagnoses helped the caregivers better understand their veterans' initially frustrating behavior. One example came from John, who shared a photo of groceries to illustrate how his memory issues strained his relationship with his wife:

My wife asked me to get butter. I came back with everything besides butter. At first, she was annoyed. She didn't understand why I wasn't paying attention, [that] I'm not doing it to spite her. Then she found out about the TBI because she came for the MRI with me...She was like, "Wow, that makes so much more sense!"

Image 2. My wife asked me to get butter. I came back with everything besides butter.



In contrast to John's experience, in which his TBI diagnosis helped his wife accept changes in his memory and cognition, other veterans described the challenges they faced in getting their TBI recognized in a health care setting, even as their TBI symptoms created problems in their personal lives. As Josh relayed:

I feel there are a lot of guys that are missing out on their TBI diagnosis. When I went to talk with [the VA doctor], he was like, "Nah, you've got PTSD." And I was like, "Okay, is it possible I have both?" He looked at the scan of my brain and said there was no permanent physical damage, so I didn't have TBI. I can't argue with him, because if he don't think I got it, he ain't interested in treating it. But it's the inability to stay on track that drives me nuts now. I forget where I put my keys, I forget that I'm supposed to be somewhere. I had a relationship with a girl that was living with me, and she said, "I feel like I'm living with an old man who has dementia."

Josh eventually received a TBI diagnosis from a different VA doctor, but by that time his relationship had ended.

Veterans like Josh described how seeing themselves through the eyes of their loved ones helped them become self-aware of their TBI symptoms. Through photovoice, these veterans illustrated the negative consequences that accompanied their delayed self-awareness of their own TBI symptoms and their inability to access adequate care and support. Eddie, for example, provided two photographs to illustrate the painful loss of his family:

This is what happens when you don't deal with what you need to deal with. You think everything is okay, and you put everything that's bothering you on the back burner...I was so used to the isolation that I didn't give [my wife] enough attention. This picture was taken when I was still with my son and his mom. This is us starting something new, trying to become a family, making plans. [But] there were so many unresolved issues, as far as my PTSD and TBI, I had so much going on in my brain and in my life, that it resulted in this photo of me standing alone.

Image 3. This is what happens when you don't deal with what you need to deal with.



Other veterans who developed self-awareness through observing the impact of their illness on their loved ones were able to access health care and begin the recovery process before those relationships were irretrievably lost. As Carlos relates:

My rock bottom was when my wife was crying almost every day. She was telling me all the things I needed to notice about myself, and it went in one ear and out the other. I finally took a step back and listened...and really dug deep and said, "Why is my wife crying? She's crying because of me." It opened my eyes to, "I'm not who I want to be. If I want to work towards my goal, that person I am supposed to be, then I need to start now...The doctors are there, telling me something, so why don't I start taking notes?" After that, every time I went to an appointment, I would say, "Well, can I come next week? Can I come twice a week? Can I come three times a week?" They would recommend or suggest things, and I would jump to them.

Finally, some veterans shared how the process of engaging in the study itself—of reflecting on their daily lives or hearing about the experiences of other veterans and families through study participation—led to increased self-awareness and a desire to educate others about symptoms and impacts of TBI. Ray, a combat veteran with multiple TBI exposures who was also the study's project manager, observed:

It was astonishing how much I didn't realize about TBI and the symptoms and the signs that I was feeling and going through during my transition. Hearing others' stories made me reflect on the experiences I had in school, my relationships, my social life, and my professional life. It really took me aback. I struggled a lot more than I should have. It would have been less of a struggle if people understood more about what TBI is.

A common goal emerged from our study participants: to educate veterans, their families, health care providers, and other civilians about symptoms and impacts of TBI and to ensure that other veterans and families are able to access the resources they need to support their health and quality of life.

Coping With Misconceptions and Stigma Around Disclosure of TBI

Veterans and caregivers shared their frustrations and negative experiences with public

misconceptions about "invisible injuries" such as TBI. Many veterans took photographs to illustrate the challenges they faced in social situations at work and school when others did not perceive them as injured, trust that they were experiencing TBI-related symptoms (e.g., photosensitivity or chronic migraines), or believe that they needed special accommodations (e.g., closed window shades, dim lighting, or wearing sunglasses indoors). JD shared his experience with an employer who, despite being a veteran, lacked a basic understanding of TBI:

I was trying to explain my own TBI to my employer, who was a military guy who didn't see combat. And he said, basically, he doesn't understand why I can't get over it. Because people can get over alcoholism, and he related it to alcoholism. I mean, it's just frustrating.

Caregivers also shared how ignorance about "invisible" military-related injuries caused stress in the course of their daily lives. As Sharon, caregiver to her Marine veteran husband, described:

The first time we went to the airport, I was terrified. There were no resources for me to reach out [for help], because he looks normal on the outside. He stands by himself. He can smile. When I went to the desk to ask if we could board first, I said, "I will sit in the back of the plane even though it's more uncomfortable, so there is nobody behind him. He doesn't feel comfortable [with someone behind him]." But [the gate agent] pushed back, saying, "He's not disabled. He doesn't look disabled."

Another caregiver, Jennifer, contributed a photograph of a ripped coffee filter to represent how her husband's TBI and decreased tolerance for alcohol resulted in his having a "torn filter," which led to challenges in social situations even with close family:

My friends and family are understanding, but there are times when [my husband] says stuff. On New Year's Eve, we were all drinking and he started going off about something. I could tell my family was getting kind of angry with him and I said, "You have to remember [he] has

a brain injury, he does not mean it this way.” This is one of the things I deal with on a daily basis because it is not going to change...The brain injury is not going to repair itself and he is not going back to a hundred percent again. I would like for people to be more understanding and take a step back and not get so easily offended.

Image 4. You have to remember he has a brain injury; he does not mean it this way.



In addition to expressing their frustrations with others' misconceptions and lack of knowledge about TBI, veterans spoke of how stigma and bias negatively affected their ability to engage in work and school. JD, who worked as a child welfare advocate after separation from military service, faced professional challenges related to public knowledge of his service-related injuries:

Unfortunately, the situation I was in [when injured], it was highly publicized so I'm in three or four different books and all these articles about what I did. If you Google my name, PTSD or TBI comes up...People will use that against me in court when I testify, [saying], "This guy shouldn't have been around my children because he has PTSD and TBI, and he's going to swipe my kids." I get that all the time, so I fight on many different levels. You're not just in a personal fight with having TBI, but the populace itself is so prejudiced they can't see people like me.

Many veteran participants were using their Post-9/11 GI Bill benefits to attend school after separation from military service. Some reported a reluctance to disclose their TBI or to seek disability accommodations in school settings

due to concerns about stigma. Veterans shared experiences of hearing civilian student colleagues repeat stereotypes about veterans with TBI and PTSD as "damaged." As Sawyer recounted:

In grad school, a classmate of mine kept talking about veterans dealing with TBI that she was working with, she kept talking about veterans like we were puppies. Like, "They don't know how to get help and they are so confused and they don't know how to advocate for themselves." And I finally snapped in class one day...There's a section of the population that thinks we're stupid because we had our brains scrambled.

Participants also observed how civilians tend to characterize veterans as a homogeneous community rather than as individuals with diverse backgrounds and perspectives. This general lack of awareness about individuals' intersecting identities compounded the negative effects of stigma and misconceptions about TBI and thwarted participants' efforts to connect with potentially helpful resources. Feral, a transgender woman, described her struggle to be recognized and accepted for her intersecting identities as both a combat veteran with a TBI and a transgender activist. JD, who served in the Marine Corps and later in the Army, shared two photographs—one of his Quran alongside his service medals and dog tags and another of his Marine Corps portrait and medals—to illustrate his multiple identities as a Muslim and a self-identified "queer, Marine-looking, bald male." He shared the challenges he faced when navigating educational and professional settings where he does not always feel recognized or welcomed by other veterans:

You go to school or to an employment resource center, and there's a bunch of veterans. But when you mention that you're queer, you know then that you're no longer part of that sect or whatever. You lose that camaraderie... I understand there's prejudice in the world, but that's another aspect of this; that we're out in the professional world and we're being judged not just for TBI but for being veterans. And then we have a lot of stigmas to overcome.

Image 5. We have a lot of stigmas to overcome.



Sawyer echoed and expanded on these sentiments; as a woman who returned to school after separation from military service, she pointed out that not all veterans experience the idealized notion of “camaraderie” emphasized in popular culture, and this can leave many veterans feeling unsupported even in spaces intended to serve student veterans:

Some veterans are going to be completely different [in terms of] their needs and wants and desires. What [women veterans] want from the veterans resource center may be different than a lot of the male soldiers, Marines, airmen. When I was in the Army, there is no band of brothers when you're the only woman and 156 dudes. I never got that camaraderie. That doesn't exist when you're the only one of your gender. There's institutional trauma that continues on in a lot of ways for women after we leave the service. So, when you walk into a resource center and you get told “one place fits all,” it's definitely frustrating.

Sawyer's observations also touch upon a common thread present in participants' photo narratives: Many veterans, especially women or members of racial or sexual minority groups, experienced institutional betrayals and traumas during military service that may complicate community reintegration.

Living With TBI and Navigating Community Reintegration

Veteran-caregiver pairs described the important role that caregivers played in recognizing and helping their veterans manage challenging situations. For example, Sean, caregiver to his Army veteran wife, Sawyer, shared a photograph from when he and his wife encountered crowds and other stressors while sightseeing and he recognized the need to cut their trip short:

Sawyer can't enjoy herself, because she's in that headspace where crowds are bad and not something she is comfortable being in. It's like, “Alright, we're gonna have to vacate the premises, go home, and feed our puppies.”

Image 6. Alright, we're gonna have to vacate the premises, go home, and feed our puppies.



Reflecting on the experience of participating in the study with her husband, Sawyer was surprised to realize how much her husband had absorbed the impact of her symptoms and helped her to manage them by anticipating potential triggers and adapting with her:

My husband participated [in the photovoice study] and seeing and hearing things he said that I had never heard him say before, that was really eye-opening for me. He has become hyperaware of things that will upset me. I had never considered that he would become considerate of that. It's like a secondary learned trait that my trauma has brought; he had to learn, just from adapting to me.

In the face of these challenges, veterans and caregivers described strategies and resources they used to manage symptoms and pursue valued life activities. Participants often used humor to relate their frustrations and coping mechanisms. Ben, a veteran with a collection of T-shirts poking fun at stereotypes of combat veterans (e.g., as “dangerous” or “medicated”), provided a photograph of himself “giving the finger” to the camera to illustrate his difficulties with understanding people and his advice to people who want to communicate with him:

Speak slowly. It takes me a while to understand what you're talking about, and it helps so you can communicate to me and I can relay it back to you. When you're talking to me, I'm more focused on the words than on what's being said, and I have to break it down for myself. It frustrates me that my mind works like that. A lot of times, I just sit there quiet and try to catch what I can.

Image 7. It takes me a while to understand... I just sit there quiet and try to catch what I can.



Veterans explained how they came to terms with their own and others' views of changes in their cognitive functioning and adjusted their expectations for professional pursuits post-TBI. JD shared photographs of two cars he was in the process of rebuilding and said:

I was on my way to be an academic... I am changing my path because of the cognitive delays I face. People that meet me now, they don't see any problems with me. But people that knew me before say, “Oh, wow, you're not as witty, you're not as fast.” I know I can't go back and get my PhD and do what I wanted to do before the war. But I've always enjoyed working on cars, and this is something with my deficits I can still do.

It is important to note that the veteran participants also described strategies that helped them pursue career and educational goals despite cognitive challenges. JD went on to a career in child welfare, and at the time of this writing Carlos and Sawyer were both pursuing higher education.

Discussion

We value photovoice for its rootedness in critical consciousness, which fosters in-depth understanding of social and political worlds through the eyes of people who have experienced

stigma, oppression, or suffering in order to expose contradictions and help reframe public and policy conversations (Bowleg, 2017; Freire, 2018).

As evidenced by recent public discourse and the personal experiences of our veteran and caregiver collaborators, TBI is still a misunderstood condition. Participants' narratives illuminated how delays in getting a diagnosis and developing self-awareness of TBI symptoms negatively affected their relationships, health, and quality of life. In this way, our findings build on previous studies of the impacts of TBI and other invisible injuries on family caregivers (Griffin et al., 2012; Moriarty et al., 2015, 2018; Voris & Steinkopf, 2019).

Even after veterans and caregivers gained insight into TBI, they still had to contend with the invisibility of the injury, the public's general lack of knowledge about TBI, and stigma when navigating valued activities and life goals in community, work, and educational settings. Previous research has associated TBI with negative changes in self-concept, depression, and decreases in self-esteem (Carroll & Coetzer, 2011). Although participants in our study used photovoice to share journeys that included periods of grief and loss as they became aware of TBI-related changes in themselves, their stories also included acceptance, growth, and finding new purpose. After their injuries, veterans found support in their caregivers, coped through humor and self-awareness, advocacy for themselves and other veterans, and adopted new life goal. Many veterans noted the limitations of resources and services that treated veterans as a homogenous community and failed to account for veterans' intersecting identities and diverse experiences of military service.

Veteran and caregiver participants had specific advice and recommendations with respect to policies and practices that could best support community reintegration. First, they emphasized how important it is for veterans to recognize their potential exposure to repeated concussions as an occupational hazard of military service and to disclose any relevant history fully to their health care providers. Our participants acknowledged exposure to a wide range of concussive events, from "getting your bell rung" during basic training, to whiplash incurred by jumping out of airplanes, head trauma from falling equipment such as dislodged metal from makeshift up-armored vehicles, blast exposures from improvised explosive devices and rocket attacks, and overpressure from firing large weapons. Many veterans in our project faced years-long delays in getting their

TBI diagnoses, and they shared their stories in hopes that other veterans would recognize shared experiences and seek out a TBI evaluation if they had not yet had one or pursue a second opinion if they felt an initial medical evaluation had been incomplete. Likewise, caregivers shared insights about their growing awareness that "something was going on" with their loved one. They explained how their own research or education from health care providers helped them understand how their veteran's symptoms were related to TBI, and they wanted other military caregivers to have access to knowledge and resources before their relationships deteriorated beyond repair. A priority area for the dissemination of findings from our study has thus been raising awareness about TBI among veterans and military caregivers.

Second, participants had recommendations for improving veterans' experiences in employment and educational settings. They observed that many veterans were reluctant to disclose their TBI and other invisible injuries to employers, instructors, and school administrators out of embarrassment or concerns about being stigmatized. As one consequence, veterans often missed out on services and accommodations that could help them succeed. Other researchers have reported similar findings among veterans seeking higher education (Rattray et al., 2019). An important goal for future education and advocacy work includes destigmatizing the disclosure of invisible injuries and ensuring that veterans are aware that their disclosures are confidential by law.

Participants also noted the need for well-resourced veteran student centers with staff trained to help facilitate difficult conversations between veterans and faculty or veteran and civilian students. They emphasized the importance of maintaining these centers as welcoming spaces for veterans with diverse experiences and identities, and they noted that campus resources for women and sexual and gender minorities (i.e., LGBTQ students) could be important potential collaborators in program development for veteran student centers. Many participants in our study had gone into service professions or were pursuing education with the intention of helping other veterans; they emphasized their commitment to creating safe spaces for veterans to share their experiences, disclose their needs, and receive support.

Limitations

We analyzed photovoice data using a PAR framework, with a focus on identifying participant-informed goals for advocacy and education. Data analysis through a different lens may have yielded different interpretations. We drew our study participants from two regions of the United States, and most (although not all) were receiving care from a VA medical center. Veterans and caregivers drawn from a larger national sample, including more veterans who do not receive VA care, would likely provide additional experiences and perspectives on TBI and community reintegration. We focused on themes that we identified as important and relevant to most study participants based on data collected through photo narratives and small-group discussions (Visit 4). We also consciously incorporated the personal examples of our veteran-participant coauthors (CU, SS, and JS) to illustrate the selected study findings. The investigators leading this research share a background in feminist theory and an appreciation for standpoint theory, reflexivity, and positionality, as these affect the perspectives that each contributor brings to a collaboration such as writing with study participants (Closser & Finley, 2016). Although the themes presented are grounded in the study data, a different combination of authors would likely foreground different examples while including additional participants as coauthors could have broadened the diversity of views represented. We have developed a traveling exhibit that includes photo narratives from every veteran and caregiver who contributed to the study, and we continue to find opportunities to co-present study findings with a variety of collaborators to make sure that as many voices and perspectives as possible are represented.

Conclusion

Veterans' and caregivers' contributions and insights demonstrate the power of using photovoice to engage persons with direct experience of living with invisible injuries related to military service in generating knowledge to inform the programs, policies, and public discourse that affect their lives. Photovoice is a PAR approach that facilitates co-ownership of data and research findings and makes engaging participants in data analysis, interpretation, and dissemination of findings more feasible and equitable. In this study, visual-narrative methods enabled participants to reflect on and articulate experiences related to TBI and community reintegration that may have otherwise

been challenging to put into words. These methods also allowed participants to convey their views to policy-makers, program managers, and members of the wider public. Photovoice holds great promise as a research approach that can be led or co-led by military servicemembers, veterans, and their family members to challenge misconceptions about and misrepresentations of their experiences. Furthermore, we see photovoice and other forms of PAR as a potential tool for veterans and military families affected by invisible injuries, helping them to move toward healing and develop a new sense of mission and purpose through engaging in critical reflection on their reintegration experiences and advocating for social change in their communities.

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