J Head Trauma Rehabil
Vol. 12, No. 6, pp. 390–402

Violence, Abuse, and Neglect Among People With Traumatic Brain Injuries

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Background: Violence, abuse, and neglect (VAN) among people with physical and other disabilities has been reported; however, little is known about VAN experiences among people with traumatic brain injuries (TBI). **Methods:** Nine people who reported experiencing VAN post-TBI were interviewed for this phenomenological study. The data were analyzed to understand VAN as experienced by those with TBI. **Results:** Participants detailed many VAN experiences along with contributing factors, barriers in obtaining help, and recommendations for improving preventive and assistance services. **Conclusions:** Greater efforts are needed to identify and prevent VAN among people with TBI. Services following VAN must be improved. **Keywords:** *abuse*, *disability*, *neglect*, *prevention*, *qualitative research*, *traumatic brain injury*, *violence*, *victimization*

TRAUMATIC BRAIN INJURY (TBI) is among the most disabling injuries. It is defined as a blow or jolt to the head, or a penetrating head injury that disrupts the function of the brain.[1] While not all blows or jolts to the head result in a TBI, the effects of such an injury can cause a wide range of functional changes at varying magnitudes affecting thinking, sensation, language, and/or emotions.[2,3] The Centers for Disease Control and Prevention (CDC) reports that an estimated 1.4 million Americans sustain a TBI each year,[4] and at least 5.3 million people are living with TBI-related disabilities for which they require long-term or lifelong help with performing activities of daily living.[5]

In the United States, acts of violence and other forms of victimization of persons with disabilities are not uncommon events.[6] These persons are 4 to 10 times as likely to become victims of violence, abuse, or neglect (VAN) as nondisabled persons.[7,8] These estimates are more important when the size of the population at risk is considered. The 2000 US Census found that nearly 1 in 5 noninstitutionalized Americans, ages 5 or older, for a total of 50 million, have disabilities, and this number is increasing as the population ages.[9]

The World Health Organization defines *violence* as "The intentional use of physical force or power, threatened or actual, against oneself, another person, or against a group or community that either results in or has a high likelihood of resulting in injury, death, psychological harm, maldevelopment or deprivation."[10] Under this broad definition, victimization may be classified further into the categories of VAN.

Violence is defined as behaviors that intentionally threaten, attempt, or inflict physical harm on others.[11] For a person with a disability, threats of violence or acts of physical harm are primarily committed in their homes by family members serving as caregivers,[12,13] or by paid personal care assistants.[7,14,15] In either case, the perpetrators are usually men.[13,16,17] Also, institutional settings are high-risk environments for persons with disabilities because they may experience multiple episodes of violence by employees[18–21] and/or other residents.[22] Violence in these settings ranges from inappropriately applied physical restraints or sedation procedures[23] to acts of sexual violence,[16,17] which may include being forced, threatened, or deceived into sexual activities ranging from looking or touching to intercourse and rape.[24]

Abuse is defined as being threatened, terrorized, severely rejected, ignored, or verbally attacked.[24] Persons with disabilities indicate that emotional abuse by caregivers is common and may include being shouted

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The authors thank all of the participants who willingly and openly shared their personal experiences with violence, abuse, and neglect, and the friends and family members who supported them in doing so. We also thank the Georgia Brain Injury Resource Foundation support group leaders and Richard Aust, coordinator of the South Carolina Head and Spinal Cord Injury Drop-in Center, for their assistance in recruiting participants for this study.

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at, ridiculed, or ignored when they fall or have other needs.[15,25] Also, abuse may involve manipulation or coercion of a person's money or other financial resources.[19]

Finally, *neglect* is defined as a situation in which a person's basic needs such as food, clothing, hygiene, protection, or medical care are temporarily or permanently not met.[18] To date, studies of neglect of persons with disabilities include the withholding or destruction of assistive devices,[14,26,27] deliberate nonprovision or delay of scheduled medication,[14] inattention to bedsores or other characteristics of people with disabilities by healthcare providers or caregivers,[15,28,29] or withdrawal of assistance or inattention to basic hygiene tasks.[14] In addition, reports have described the characteristics of people with disabilities that increase the risk for victimization[8,12,18,30] and that create barriers to reporting to law enforcement or securing services.[8,19,31–34]

VAN research during the past 15 years describes the victimization of persons with physical,[35,36] learning,[16,17,37] and developmental disabilities[38]; mental illness[19]; and retardation.[12,18] It also describes the violence and victimization of women with a range of other disabilities.[13,14,31,39–41] Despite this research, no published studies, to our knowledge, have examined the victimization of persons with TBI. Thus, the objective of this study was to apply qualitative methods[42,43] to investigate the experience of VAN among a group of adults with TBI-related disabilities.

METHODS

Subjects

Nine people from Georgia and South Carolina participated in this study. They were recruited through support groups for people with TBI and a community program for people with head or spinal cord injuries. Eleven people volunteered to participate, but one was excluded because he identified himself as the abuser as opposed to being abused and another was excluded on the basis of a psychiatric diagnosis that decreased his likelihood of relating truthful and valid experiences with VAN. Participants in the final purposive sample had at least 1 TBI; several reported experiencing many. Each participant reported it had been at least 8 years since they had their first TBI. Before being interviewed, participants confirmed that they had experienced some sort of VAN post-TBI. Participants were asked to talk about instances in which they were the victims. The purpose of the study was to discover perceptions of VAN by people with TBI; thus, these terms were not defined for potential participants during the recruitment process.

Four of the participants were female and 5 were male, ranging in age from 38 to 51 years. They reported varying levels of independence. Some needed only occasional assistance with higher level cognitive tasks, such as making life changing decisions, while others needed daily assistance with tasks such as buying groceries, paying bills, and cooking. Some participants lived alone and others lived with family members and caregivers. A few participants held part-time jobs, but nearly all depended on additional financial support from other sources. All participants identified ways their lives had changed since the TBI. These self-reported changes included communication problems, emotional changes, decreased physical function and coordination, and changes in relationships. Nearly all participants identified having some sort of cognitive difficulty since their injury, including problems with memory, attention span, decision making, and problem solving. A few participants reported that they had become involved with alcohol and/or drugs since their injury resulting in further difficulties and challenges.

Precautions were taken to ensure the confidentiality and safety of both the participants and members of the groups where the recruiting occurred. During the recruitment phase, information about the study was given to potential participants verbally and was made available as hardcopy. The hardcopy information was attached to general TBI information so that potential participants could pick it up without specifically identifying themselves as being interested in the study. This measure protected their confidentiality at the time of recruitment and decreased the risk for the recipient should an abuser find the information. Other confidentiality protections included interviewing the participants at a time and place of their choosing and ending all contact with them at the completion of the interview, which included destroying their contact information. Participants were given informed consent forms to read and sign before starting the interview. As with a prior study,[24] they were told that they could sign using an "x" rather than their actual name as an additional protection to their confidentiality. Many participants chose this option. Institutional review boards at the CDC and the Medical University of South Carolina approved the protocol for this study.

Participants received $15 in compensation for their time. They were also offered a list of phone numbers for local agencies to assist them in dealing with VAN. Although many of the agencies do not provide services that are sensitive and adapted to the specialized needs of people with TBI, the agencies included in the resource list were assumed to be the most likely resources until such needs are better understood.

Qualitative approach

With the goal of exploring VAN among people with TBI, this study was constructed according to a phenomenological approach. The aim was not to determine causal relationships, but rather to uncover the nature of VAN from the participants' perspectives.[44] With detailed, personal descriptions of VAN from the participants, this approach allowed the researchers to determine the dynamics underlying the experience and to globally interpret what it meant to those who were affected.[45]

Data collection

Participants spoke with the lead investigator (Reichard), who also served as the interviewer, about their lives and VAN experiences during a single, one-on-one semistructured interview. They were permitted to bring a support person of their choosing to the interview, but only a few did so. One participant with a speech impairment had an acquaintance sit in to assist the interviewer in understanding what was being said. Interviews were conducted during 2002 in private rooms and tape-recorded. Field notes were taken throughout the interview to supplement information on the tapes.

Data analysis

Interview data were transcribed, and Atlas.ti[46] software was used to facilitate the data management and analysis processes. Prior to analysis, the data analyst (Reichard) followed the principles of phenomenological research and identified preconceptions in an effort to decrease personal involvement with the data. This included setting aside preconceived notions about what defines VAN. Next, the data were carefully reviewed and bracketed, allowing for grouping into thematic clusters and more specific subthemes. Another experienced qualitative researcher and coauthor (Sample) reviewed the assigned codes and themes to increase the reliability of the results. Finally, a comprehensive structural synthesis was developed to describe the experience of people with a TBI who encounter VAN.

RESULTS

Three dominant thematic categories emerged from the participants' descriptions of their lives and the VAN they had encountered: (1) living with a TBI, (2) experiencing VAN, and (3) continuing to live after VAN. In addition to the semistructured interview questions tailored to elicit insight and perceptions related to personal experiences, more direct questions were posed to gather participants' opinions about preventing VAN among people with TBI and how to assist those who experienced VAN. Responses to these questions generated the information found in a fourth theme of "Making it better." (Please refer to Fig 1 for a graphical depiction of the sequential connections and groupings among themes and subthemes.)

Theme 1: Living with a TBI

Regardless of the extent of their injuries, all participants expressed that having a TBI had affected their lives, and altered their abilities, lifestyles, and futures. It also challenged their perceived place in society in such a way that one participant defined "two different worlds," one for the "disabled" and one entitled "earth people" for people without disabilities that often accompany a TBI. Participants expressed that having a TBI defined a unique lifestyle and culture, forcing them to depend on others for things they had previously done independently, and compelling them to surrender control of aspects of their lives that had previously defined them as a person.

The participants' descriptions of living with a TBI fell into 3 subthemes. Each of these subthemes represents an ever-present component in their everyday lives and challenges, intertwined with each participant's identity.

Personal and life changes

All participants identified ways in which having a TBI changed their abilities and lives. Among the identified changes were changes in cognitive, emotional, mental, and physical abilities. The most commonly reported changes within themselves were difficulty controlling temper and decreased memory. They experienced changes in activities of daily living, in their relationships with others, and at work. Finances were identified as the most common area for which participants must depend on others for help. Many also talked about losing friendships, getting divorced, and being misunderstood by family members. A few participants stated that they had difficulty getting or maintaining jobs.

Current situation

TBI has dictated many participants' current living situations, including where they live, with whom they live, and how they spend their time. Whereas most participants led independent lives prior to their injury, they were left with fewer options in regards to where and how to live after the injury. Few participants lived by themselves at the time of this study. Most lived with family members and caregivers who assisted them, or were intended to assist them with various aspects of their lives. No participant lived with a spouse, although several had been married.

Only a few participants said that they had many activities that occupied their time during the day—others were limited. A few participants held 1 or more part-time jobs. All participants were involved in some sort of structured activity that allowed them to interact with people outside of their immediate household. These activities

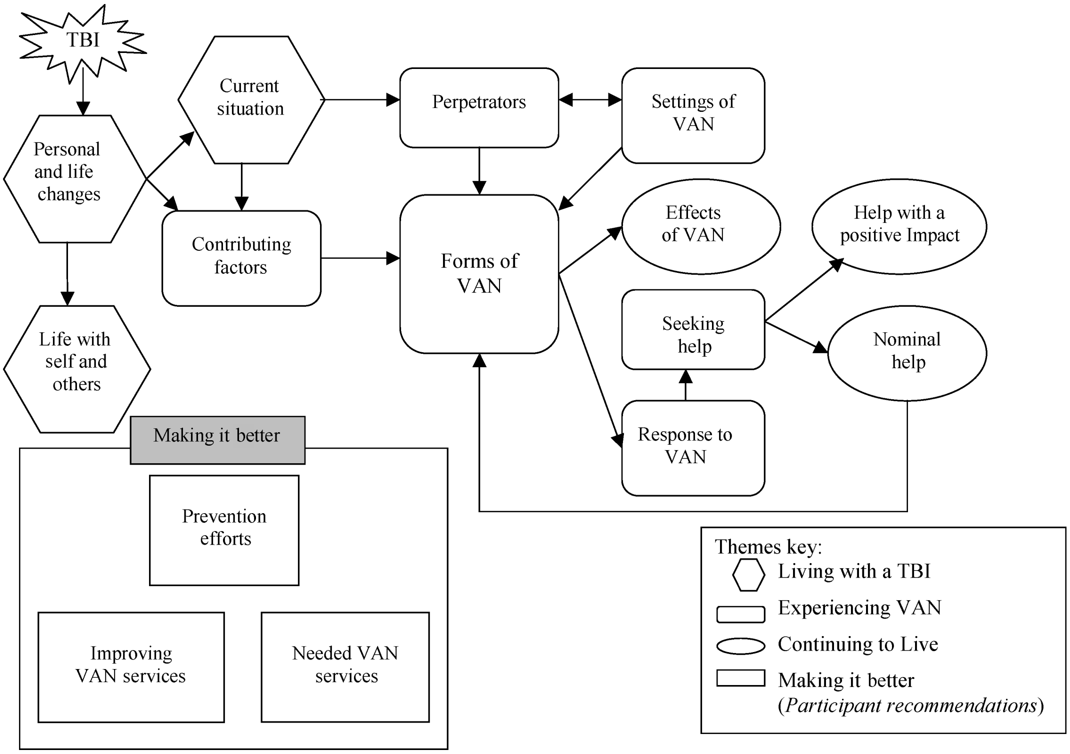

Figure 1. Violence, abuse, and neglect (VAN) among people with traumatic brain injury (TBI): Sequential connections and groupings among themes and subthemes.

included attending 1 or more support groups and participating in a community program geared toward people with disabilities.

Life with self and others

In addition to regularly facing new challenges and adapting to life changes since their TBI, participants had to conquer biases and challenges from others. To avoid some of these obstacles, one participant warned that a person should not let others know about a TBI saying, "If you acknowledge a handicap, then you're targeted in many ways . . . Nobody works with you to see if you can become the best you [can be]. You may not be able to do what you used to do, but many of us are able to do quite a lot, and nobody works with you."

Several participants were acutely aware of how others perceived them because of their disabilities. One participant stated that "People just meet me and are unaware. They just think I'm retarded or–and I can't comprehend." Another stated, "I just wish that people would realize that just because you have a brain injury doesn't mean you're retarded or stupid. A brain injury doesn't make you less intelligent. You know sometimes we see the world a little differently, but it doesn't mean that we don't see the world at all."

Despite encountering negative attitudes and beliefs from others, many participants related plans to persevere towards new goals allowing for improvements and successes in their lives. One participant declared her determination stating, "I'm constantly changing. I'm metamorphosing. I hope I become a butterfly."

Theme 2: Experiencing violence, abuse, and neglect

Participants generally described experiences of VAN not as discrete events, but rather much more broadly, integrating them with the challenges of daily life, experiences in searching for help, and attempts to cope with the impact. Some of these experiences proved to be cyclical as the act of seeking help resulted in additional exposure to VAN. A few experiences were described as single episodes, having little to no reported impact on participants' lives thereafter. Male participants generally reported one-time incidents in relation to a single perpetrator, while female participants reported both one-time and multiple incidents from a single perpetrator.

Contributing factors

Many participants described TBI-related disabilities as being influential in their VAN exposure. A few participants described physical disabilities, including being unable to yell or move, that prevented them from defending themselves. Some also identified that since their TBI they had become too trusting, too passive, or less intuitive, potentially increasing their likelihood of exposure to VAN. These characteristics contributed to participants' difficulty observing standard safety precautions, such as not walking alone at night and not allowing strangers access to financial information. The same characteristics further contributed to their delayed identification of abuse. Reflecting the sentiments of other participants, one participant stated, "Right from the first time he did that, I should have thought something was wrong here, but I didn't." Another participant, acknowledging her difficulty identifying situations leading to VAN offered, "I've still got [an] intuitive ability but this is a blind side." She went on to say that when identifying VAN, "I just haven't relearned I guess the signs to look for." Finally, a participant voiced that often people with TBI have difficulty controlling tempers and frustrations that "we have to overcome . . . sometimes I think I overcame too much by letting other people walk on me."

In addition to contributing factors related directly to having a TBI, several participants identified that drug and/or alcohol use may have caused their exposure to VAN. When the participants used such substances, they commonly reported that they lost control of themselves and their environment. One participant, subjected to long-term violence and abuse, attributed her use of alcohol to the idea that "It faded out the reality of it all . . . . It would eliminate the facts. . . . That I was being abused."

Almost half of the participants related stories indicating they had experienced some form of VAN before having a TBI. They frequently cited a parent as being the perpetrator. However, not all participants identified these actions as being violent or abusive. One subject denied a history of childhood VAN, yet related that his father threw tools at him and "was not allowed to come back into [the state] because of the way he treated my mom and me and my brother . . ."

Perpetrators

People from all aspects of the participants' lives were identified as being the cause of VAN. The most commonly identified perpetrators were significant others, strangers, healthcare workers, and mental health workers. Other perpetrators included family members, acquaintances, coworkers, and personal care assistants.

Several participants, identifying that they knew the perpetrator before the VAN began, held an initial admiration for that person and a desire to have a relationship with them. One participant, abused by her significant other, stated that he "was [a] knight in shining armor" when she first met him. Given the supervised lifestyle she was leading due to her TBI, she felt as though she was being controlled and this man offered her a lifestyle that "was not being guided in any direction other than the way he wanted it to be." In regards to another relationship that turned abusive, she said, ". . . all I wanted actually, true enough, was his companionship. That's all I was looking for." Another participant related her initial feelings, "I thought [he] was so attractive. I'd never had this in a relationship. Calm, cool, collected, supportive, non-judgmental. What's not to like in that?"

Participants described their perceived reasons why perpetrators subjected them to VAN. In several instances committed by family members, significant others, or strangers, money was thought to be the motivating factor. Others speculated that the perpetrators thrived on being in control. One participant stated, "He didn't drink and he didn't do drugs, but that's how he got high was being violent and being abusive and being controlling. That's how he got his high. To him, that was his drug." Another stated, "When they start seeing me take control and be responsible, they don't want to talk to me anymore." Noting the contribution of substance use by a perpetrator to ongoing VAN, a participant stated that "the alcohol just made him madder" causing him to be "more violent." Several participants reported that they had no insight into what triggered the perpetrators to commit acts of VAN.

The way the participants felt they were perceived by their perpetrators may have also been a key component as to why they were targeted for VAN. All female participants conveyed that they felt that the perpetrator perceived them as susceptible because of their TBI. Participants commonly described that they were perceived as "stupid." This was corroborated by a participant who stated, "He perceived my being slow as being stupid, and being stupid, I would be very malleable, very easily formed to whatever he desired." Another stated, "I'm just a babbling idiot to them." In comparison, another participant described, "I was an easy target. Because I was a nice person, brain damaged." She continued that "He wouldn't think that I knew what was going on."

Forms of VAN

Participants identified a wide range of VAN experiences, including those that are compatible with standard definitions used in the general population and those that are more exclusive to people with TBI. It was not uncommon for participants to relate experiences that could be classified as physical, psychological, or sexual abuse. However, they also reported VAN in the form of abuse of their finances, lack of understanding of TBI or TBI-related disabilities, and being used. One participant also mentioned self-abuse as a part of VAN, defining it in terms of thinking less of herself because of her dependence on others and, consequently, lowering her own self-esteem.

Nearly all participants reported at least 1 experience with physical abuse ranging from being intentionally hit by a door while passing through, to being beaten to the point of sustaining a concussion and needing immediate medical attention. Both strangers and acquaintances engaged participants in physical altercations on the street and in bars. One participant related that he had been walking down his street when a neighbor called out to him. When he walked over, his neighbor hit him, knocking out some of his teeth. Medical and mental health professionals also subjected participants to physical abuse, including the use of unnecessary restraints and harsh medical procedures. One participant who depends on a wheelchair for mobility told of a caregiver who deliberately took him outside, pushed him out of his wheelchair, and left him lying on the ground while she took a seat nearby and observed. Males most commonly attributed episodes of physical abuse to casual acquaintances or complete strangers. Conversely, female participants referred to spouses, significant others, and family members when they were relating stories of physical abuse. One participant described an experience with her husband at the time, resulting in hospitalization:

> He had the scissors and he got mad and I took the scissors away from him . . . and that's when he pounded me in the head . . . . I dropped the scissors, and that's when the dog bit him, and that's when he picked up the scissors and stabbed the dog. . . . He continued to kick me then, and the dog, even though he stabbed him once, the dog got up and went after him again. . . . He was kicking the scissors in, trying to kill the dog, and needless to say, he succeeded in killing the dog.

More than half of the participants reported experiencing psychological abuse ranging from doubting to insults and criticism to threats of additional VAN. A participant described the psychological abuse she endured:

> He'd wake me up in the middle of the night cussing me out. And I was like what? What'd I do? Maybe I was snoring wrong or laying wrong in the bed or I threw my arm around or–it didn't matter. It didn't matter. He just woke up and decided he needed a fix, so it was my turn to get cussed out. . .

Another related an encounter she had with a mental health worker who had already mistreated her in other ways, ". . .[she] told me I better never tell anybody anything because I was the sick one. She wasn't. I'd never be believed."

Both male and female participants who experienced sexual abuse most commonly identified the perpetrator as a stranger or casual acquaintance. One participant reported that soon after his TBI he was transferred to a rehabilitation facility. At that time he was awake and alert, but unable to speak or move. He described how 2 male orderlies came into his room one night and masturbated in front of him as he was forced to be a captive audience. Another participant described her experiences at a mental health facility with 2 orderlies, ". . .they put me in restraints and one of them went over to the door and the other one stayed with me and fondled me and then they changed places and the other guy did it." Still another participant related that while traveling with a boyfriend, they ran out of money. Their solution was for her boyfriend to sell her as a prostitute. Despite being scared, she felt she had to follow the instructions of her boyfriend because "He had control, and I didn't, and I had to bow to his wishes or I'd get my other eye black, you know." Another experience involved coercion into sexual activities for cigarettes and for cab fares. In reference to paying for cab rides from a regular driver, she stated, "Instead of giving him money I'd [perform oral sex on him]."

Several of the participants reported that family members, significant others, and strangers abused their finances. One participant related that he had a savings account at a bank, but believes he gave the wrong person the account number as all the money was withdrawn via the Internet. Another participant said that family members had moved into her home under the premise of assisting with finances, but instead used her credit and now she is being threatened with lawsuits for bills they promised to pay.

Reports of VAN included descriptions of episodes that occurred specifically because participants had a TBI or related disability, with perpetrators demonstrating either a lack of understanding of TBI or knowingly taking advantage of TBI-related disabilities. There were instances of neglect related to medical professionals not diagnosing a TBI, "I was told there was nothing wrong with me, but I couldn't even tie my shoes. I couldn't walk across the floor because my balance was so out of whack. My eyes weren't focusing. I couldn't read. I couldn't talk very well, but there was nothing wrong with me." Another participant related recurrent neglect because she was unable to drive to obtain the medications she needed; family members who lived in her home would not stop at the pharmacy despite promises to assist her financially and otherwise.

> I will tell them I am out of medication, the refills are at the pharmacy, they need to be picked up, and I get this, "Okay, we'll go tomorrow." Well tomorrow never comes. I usually have to get my fiancé to pick them up and have to get my brothers or I'll have to get my dad. At one point I had to literally call my daughter who lives way over in [another town], which is a good 30 miles away, to come all the way down here to get me to go a half mile down the road to pick up my medication. A half a mile. Nobody would go and they pass it on their way to work. They pass it coming home. But they won't pick it up because it costs $26. Because I have no money, they won't pick it up because they don't want to spend $26 because I have no

> money, because I'm fighting for my disability, and I have no money. They don't want to put out 26 damn dollars.

Other participants reported that perpetrators took advantage of their disabilities by exploiting a memory deficit to take their money or by taking advantage of decreased judgment skills to gain their trust or to coerce them into sexual activities.

Several participants reported that incidents of VAN occurred because their physical disabilities influenced the way others perceived them. As a result of his TBI, one participant has an atypical gait that he reported causes him to stagger when he walks regardless of whether he has been drinking. He related a time when he had been arrested for being "an intoxicated pedestrian." While the participant admitted he had been drinking prior to his arrest, he reported that the officer based his arrest solely on the fact that he walked as if he were drunk and performed no additional testing. Immediately following his arrest, he spent 3 weeks in jail. He was released directly to his court hearing at which time the arresting officer again accused him of walking like a drunk, not considering that he had no access to alcohol during his time in jail.

In addition to experiencing multiple incidents of VAN against them as individuals, several participants reported that the TBI community as a whole regularly incurs abuse by systems that should provide or assist in the provision of employment, education, training, or medical services. One participant related that she felt the system is neglectful because options for retraining following a TBI are very limited. Another suggested that employers were unwilling to consider her for employment because they felt she "should be responding like all the other brain injured." A participant related what she considered to be a frequently occurring problem of medical professionals not treating people with TBI respectfully:

> . . .they think all brain injured people are the same. We're all deaf. We all don't understand English . . . everybody was talking to [my mom] like I wasn't even in the room, asking her what I thought, how I felt, you know–what I was capable of doing, what I was doing there, and it was totally–it was like I wasn't there.

Settings of VAN

The settings for VAN and the reasons participants were there varied widely. VAN occurred in homes and assorted public places, including healthcare facilities, bars, places of business, hotels, and city streets. Excluding the episodes of VAN that occurred within residences, participants were at these locations because they were participating in daily life activities such as seeking healthcare, participating in social or leisure activities, purchasing goods sold by a business, or working. In some instances, the person was en route to another location.

Response to VAN

Participants' immediate responses to VAN varied widely from reacting physically or verbally toward the perpetrator to ignoring the situation. A few reported that they requested police assistance to get them out of the situation, but most did not request help or immediate assistance.

Participants experienced anger, panic, hurt, confusion, and self-blame during VAN. One person described how she faulted herself for recurring VAN, ". . .during the [first] month, I felt I deserved it, and then after awhile, after it had been going on for a week or two, I knew–kind of knew that I didn't deserve it but I was stuck. I felt I was stuck in the relationship." Another described her urgent need to flee the situation, "so inside I mean I was panic city left and right. And my thoughts were to run. That is what I wanted to do. I wanted to run out of there as fast as my legs could carry me."

In the midst of the VAN, a few participants found the means to empower themselves. A participant proudly reported that she successfully stood up to her perpetrator, "he and I went eyeball to eyeball and I didn't back down. . . . I can take him mentally, even damaged." Other participants reflected on having a sense of empowerment when they took control of a situation by standing their ground against their perpetrator or removing them from their environment.

Some participants initiated the use of individual coping mechanisms. One participant reported that her long-term memory deficit actually serves as one, "I just don't remember the bad parts. And that's probably good." Another participant identified, "I was able to re-channel my brain away from my feelings. . ." Conversely, many participants indicated that they were unable to initiate coping mechanisms needed to fully face the impact of the VAN.

Seeking help

Many participants wanted assistance for dealing with at least 1 of the episodes of VAN they described. In seeking help, they told various people about their experiences including police, counselors, healthcare professionals, family members, and friends. However, actually finding help was deemed "extremely difficult." Some participants needed to first find an individual willing to assist them in finding help. A few participants were unable to identify any place or person to whom they would turn to seek help.

Most participants who sought help reported at least 1 barrier. Financial constraints were commonly reported: "I'm in group therapy because–since I don't have no money, the county's got to pay for me, and the county's not willing to pay for individual counseling, so they only got me in group therapy." Another emphasized, "The paying is always the hard part for us. We always need services but we can't get the services because we don't have the money." Another barrier was the limited availability of services that could accommodate the needs of people with TBI and related disabilities. For instance, one participant was unable to accurately remember the details of a sexual assault and therefore could not provide the rape prevention service with needed information so that they could help. Another stated, "Well, they didn't help me because I was trying to speak, and it's still a problem for me. My mind is fine, but [my TBI] happened, and speech is still a problem for me. So they did not help me because they did not care."

Several participants did not seek help for VAN due to fear, shame, self-blame, and potential retribution. One participant said, "[It] never came to my mind [to look for help]," but also added he was afraid that seeking help would simply incite his caregiver to be more abusive. Elaborating on the feelings of fear, another participant said:

> I too have seen the different places say one thing and turn around and do the opposite thing, and they say that they're for you, but then there's a control issue. Okay? And it's the fear of always having them come in and say you're not capable, because it's already happened to them once. You know, they've already been declared not capable and people have been in their face, doing things for them or telling them stuff or whatever. So the last thing they want to do is risk going to another place that has the authority to take that control away from them again. And going to a county mental health, calling a county mental health that can trace your phone number or whatever, even if it's unlisted. The county mental health gets the police department to authorize the operator to trace your number. I mean there's no escaping, and we know this. Control is such a big issue. We know this. So that's why. It's a control thing.

One participant who blamed himself for an incident of VAN offered, "Ain't no sense in making anyone go to jail for my mistake."

Theme 3: Continuing to live after VAN

Participants were forced to deal with both short-term and long-term effects of exposure to VAN. Those who found a person who said they would help, either had a positive experience or additional feelings of helplessness or distress when the help never came to fruition or resulted in additional VAN.

Help with a positive impact

Help from others was found in the form of physical and verbal defense, protection from additional VAN, and removal of the perpetrator from the environment. One participant expressed her appreciation that those who helped her recognized "I was [a] human being. I was respectable." Many participants reported they found help through the support they received from certain people who allowed them to talk about the incident and provided verbal reinforcement indicating that they believed what was being told to them. A few participants identified that there was someone in their lives to whom they could consistently turn for this type of support and that this is how they dealt with incidents of VAN.

Nominal help

While many participants struggled to find help, most who found it cited that it had no positive impact on them. For example, "I went to a psychiatrist. It seems like he fell asleep while he was talking to me." Several even reported negative consequences as a result of seeking help, including additional incidents of VAN. Suspicion and disbelief from helpers was not uncommon, "they basically told me I was a good storyteller, imaginative." Following her reports of sexual abuse by a medical professional she did not see regularly, a participant related:

> I did attempt to tell [my regular doctor], and he had me come back in and he told me that he knew it was hard for me but he needed to do a pelvic exam and so he did do a pelvic exam. He saw evidence where it looked like I could have been raped, but he was convinced I was raped by someone I was dating or some acquaintance or someone like that. . .

Several participants reported that the persons they turned to for help simply took no action or performed no follow-up.

Because of their TBI, participants faced additional challenges in finding help who could understand and accommodate special needs, including physical disabilities, decreased memory, speech impediments, and decreased independence in activities of daily living. One participant, requiring medications and regular medical monitoring, described how she tried to find help to escape an abusive living environment and was told by police to leave the state. She told them that solution was impossible as she did not drive and could not afford to find a place to live on her own. They then offered to find a shelter she could go to, but again gave her no realistic way of getting there and making sure her medical needs were accommodated. She said, "I felt like they didn't give a damn . . . they just didn't care. They wanted me to go away." Another participant sought help for issues related to TBI and VAN from "23 different places at least," many of which were unprepared or unaware of how to accommodate her disabilities. For example, she received guidance from a psychiatrist who demonstrated no understanding of the extent of her disabilities and suggested she return to college. Following his advice, her first attempt to return to school resulted in her disappearing with a newfound male acquaintance. The psychiatrist insisted that she try again, resulting in the participant disappearing again and ending up in jail. Another participant related that her speech impediment, causing stuttered and garbled speech at times, had been misunderstood by law enforcement officers and resulted in unfair treatment:

> . . .they get huffy with me, it's like they get pissed off, like they've got better things to do. It's like I'm wasting their time, and that's not the case. And I don't do it on purpose, and I don't know why they think that or why they act like that. So and they actually–some of them get downright out angry. I've even had one of them one time–one of them one time do a breathalyzer because they thought I was drunk.

Effects of VAN

All female participants readily identified ways in which VAN affected them psychologically. These effects included claustrophobia, depression, posttraumatic stress disorder, and decreased self-esteem. Internalizing the blame for what happened, one participant stated, "There had to be something wrong with me. What am I doing wrong?" Both male and female participants identified a loss of trust in others, which affected their ability to develop relationships with others. A participant stated, "The only person I can trust is me and God. . . . All kind of wolf be coming in sheep's clothing." Male participants identified few emotional or psychological impacts of the encounter, but more physical injuries resulting from an event.

A few participants verbalized that they just had to accept what happened. After experiencing VAN from a family member, a participant offered, "today I realize he was the sick one, not me . . . but I still love my [family member]. There's no doubt about that. He was just sick." Another stated, "It's just another day of life. I have been through too much to go back now."

Theme 4: Making it better

During the final portion of each interview, participants were asked for their suggestions to prevent VAN among those with TBI and to help those who already experienced it. Most participants appeared to put careful thought into answering these questions and voiced responses that would have helped them as individuals or the TBI community as a whole.

Improving VAN services

Many participants suggested improving existing services that provide assistance to people who experience VAN. Several offered that providers such as first responders, medical personnel, and mental health professionals could benefit from training to increase their understanding of how to interact with and best help people with TBI. Participants suggested enhancing and promoting currently existing support resources from national and local brain injury groups. Some participants reported that local brain injury groups were a valuable source of support for them, but that it had taken quite awhile to discover them after having a brain injury.

A few participants restated the need for affordable or even pro bono services that provide quality counseling invested in their well-being. Expressing her disappointment with her current counselor, a participant sarcastically remarked, "The county [needs] to pay her a little bit more so at least she can sit there and pay attention because she's so broke she can't even pay attention." Another suggested that more people are needed to assist in a timely manner rather than waiting until insurance or other financial assistance can be found.

Needed VAN services

Several participants identified new services that could be developed to assist people with TBI who had experienced VAN. Justifying the need for a new system, one participant stated,

> There's not much trust in going to your traditional systems of sheriffs or even telling a pastor or anything like that because of the stigma that comes with any kind of neglect or abuse and a fear of retribution. I think there needs to be trained mental health people that know about brain injury, that isn't prejudicial, thinking that all people with brain injury are the same. . . .

Training brain injury support group leaders or even "higher functioning peers" to provide assistance was also suggested. Finally, a few participants felt that a hotline or even Internet support would be helpful.

Prevention efforts

Participants had many suggestions for preventing VAN among people with TBI. Four themes emerged: (1) need for support systems, (2) anger management, (3) prevention of drug and alcohol abuse, and (4) increase in awareness among the public about brain injury. The concept of support systems included use of support groups as well as individuals outside of the TBI community who were consistent and reliable. One participant perceived that she was exposed to fewer dangerous situations because of her carefully arranged support system. Others reported that because they had people in their lives who regularly inquired about them, they felt that if they were in a situation of potential VAN it was more likely that it would be discovered and addressed. A few participants conveyed the need for anger management education citing that their own anger could provoke VAN. One participant stated, "we can easily become violent ourselves . . . but in order to prevent it from happening to us, we need to make sure that we don't do it to others also. It's a two-way street." Another prevention effort suggested was decreasing drug and alcohol use, as it contributes to the initiation and involvement of VAN from both the victim and perpetrator perspective. More than one participant suggested increasing public awareness about brain injury, hoping to enhance general understanding and acceptance. Emphasizing this need, a participant stressed, "Police, the schools . . . don't realize the struggles that I go through every single day, every single day."

A participant suggested a prevention effort that involved making stricter laws to punish perpetrators. Another suggested improving the quality of caregivers and providing financial means to hire them, rather than being forced to rely on family members. She cited that forcing family members to serve as caregivers could result in resentment of the individual with the TBI. Finally, day programs were also suggested as a means to provide appropriate and safe social outlets for people with TBI and a respite for their caregivers.

DISCUSSION

This study shows that the experiences of VAN (inclusive of contributing factors, response to the incident, and seeking help) by persons with TBI can be similar to VAN experiences of persons with other types of disabilities. It also revealed that TBI-related disabilities create specific susceptibilities to VAN and challenges to finding help. Finally, it increased the understanding of how people with TBI perceive VAN and its contributing factors. This study suggests that VAN prevention and assistance services for this population must be given special consideration so that they reach the desired community and are tailored to accommodate their unique needs.

This study is limited in generalizability as the results are based on only 9 participants from 2 selected states and may not be representative of the experiences of others with TBI. Also, all study participants had a TBI and many reported related cognitive deficits that could potentially affect recall and/or reporting, so caution should be used when interpreting the results. At times these deficits may have also contributed to a more concrete reporting style when relating VAN experiences, resulting in limited inclusion of details that would have provided greater meaning to the essence of the experience. Information from the participants was not corroborated by other sources. However, the interviewer used several recommended techniques to help minimize recall bias and to promote the accurate verbal expression of events. These techniques included prioritizing questions to gather the most important information first, wording questions in a manner to prompt autobiographical recall, limiting external stimuli during the interview, and offering breaks, especially if the participant appeared fatigued or distracted.[47] Despite the potential for minor inaccuracies, participant information was rich in detail and provided in-depth insight into their perceptions and experiences with VAN.

Sobsey developed an integrated ecological model of abuse to explain the interaction of different factors leading to abuse and to ground practical guidelines for prevention among people with disabilities.[20] This model was designed to be consistent with the nature and the extent of abuse that occurs in this population. Emphasis is placed on the interaction between the potential offender and potential victim and any related power inequities. This dyadic relationship is examined within the contexts of the environment and the culture in which it exists. The environment includes the family and/or social unit that encompasses the relationship while the culture encompasses the attitudes, beliefs, and ideology that surround the environment, including attitudes and beliefs related to people with disabilities.[20]

As suggested by the model, the unique characteristics of the interaction between offender and victim must be considered when looking at factors leading to abuse. Many participants reported that they can now identify characteristics of themselves, the perpetrators, and the situation that contributed to acts of VAN; however, at the time of the incident they were unable to do so.

People with TBI frequently experience unique combinations and degrees of physical and/or cognitive disabilities,[3] a phenomenon that was described by many participants. These disabilities were cited as contributing factors to VAN as they markedly affected participants' functioning in their daily lives and were commonly unrecognized or misunderstood by people with whom they interacted. In addition, they often contributed to the participants' own difficulties identifying or preventing VAN, a problem that has also been identified among people with mental retardation.[12] Sobsey identified that skill limitations, whether they are cognitive and/or physical, may increase the probability that a person will be perceived as vulnerable by a potential perpetrator, reducing their ability to protect themselves.[8]

One of the most notable changes in many of the participants' lives following TBI was decreased independence due to physical and/or cognitive disabilities, creating a need for them to rely upon on others. Examined within Sobsey's model, such a need can lead to the adoption of compliant behaviors in interactions with a wide range of people without discriminating their appropriateness, thereby increasing susceptibility to abuse. In addition, dependence among people with disabilities can necessitate interactions with potential offenders who provide assistance with activities of daily living.[20]

There is limited potential to examine the perspective of those who abuse people with TBI within this study as participants could only hypothesize about the reasons perpetrators acted in the manner they did. One similar factor among several of the perpetrators was the use of alcohol and/or drugs. Sobsey's model suggests that drug and alcohol use can indicate a lack of control over impulsive behavior and potentially relate to acts of VAN against people with disabilities.[20] Participants reported perpetrators came from all aspects of their lives, highlighting that they can be susceptible to VAN, regardless of the status or familiarity of the perpetrator. This corresponds to Sobsey's conclusion that while there may be similar traits among offenders, they take on a variety of roles in victims' lives and the potential for someone to become an offender must be considered within existing environmental, cultural, and situational contexts.[20]

The impact of environmental factors was seen in the participants' descriptions of VAN. Some described environments that facilitated or forced them to interact with the perpetrator–a few participants were "cornered" into complying with the VAN. Mental health and other healthcare settings, which should undoubtedly be deemed safe, were the most notable environments providing the impetus for VAN. Considering this, Sobsey notes that environments can be prone to enhancing already existing power inequities and consequently facilitating VAN.[20] Such power inequities have been historically seen in paternalistic relationships between healthcare providers and their patients.

In addition to the environment, cultural and value systems can increase the likelihood that VAN will occur. For years, people with disabilities have struggled with the falsehood that they are lesser members of society and have had to face attitudes that devalue their worth. These societal attitudes, which participants reported to be common in their daily lives, can contribute to an increased risk of VAN.[20]

The unique forms of VAN within the TBI community are reflected in several incidents described by the participants. While some types of VAN experienced are also common among people without TBI, others were specifically related to TBI disabilities. These generally involved the perpetrator not understanding TBI-related disabilities or, conversely, knowingly taking advantage of such disabilities. In these instances, the victim was often forced or manipulated into situations of VAN.

Participants detailed many incidents of VAN, including descriptions of factors that were previously cited for increased vulnerability to sexual assault among people with various physical or mental disabilities. These contributing factors include the denial of basic human rights, perception of increased vulnerability by the offender, social isolation, difficulty taking preventive measures or resisting assaults, and placement into "mainstream" situations without regard for the individual's capacity for self-protection.[35]

VAN among people with TBI is a public health problem due to its potential impact on morbidity and mortality, as well as its long-term health and economic effects on survivors, families, friends, and society. As shown in this study and reflected in the Sobsey model, incidents of VAN often have multicausal explanations and may be unique to their environmental context.[20] Thus, comprehensive public health prevention and intervention approaches should be developed, including risk factor identification, community empowerment, training, and evaluation.[48] Adopting such holistic approaches will help foster the development of a positive environment, promoting early identification of potentially harmful situations, encouraging help seeking behaviors following VAN, and strengthening social networks that can serve as both preventive and supportive mechanisms.

In the context of services currently available, participants who chose to seek help to deal with their exposure to VAN generally reported the help they found had little to no positive impact on their ability to cope with or eliminate the VAN in their lives. Several participants were unable to find help, while some who had were exposed to additional VAN. The US Department of Justice Office for Victims of Crime has identified reasons people with disabilities have difficulty or are unable to find help to deal with VAN.[32] They include the physical or social isolation people with disabilities often endure that prevents them from learning about available services or their legal rights.[32] In addition, they are faced with services that are physically or attitudinally inaccessible, making no effort to welcome and serve those with disabilities.[32] Associated with attitudinally inaccessible services, participants conveyed they had difficulty finding personnel who believed their credibility. This challenge was previously cited as a deficit of some service providers in meeting the needs of people with disabilities who had been sexually assaulted.[35]

Much work is needed to improve the current quality and availability of help for those with TBI who have experienced VAN. Not only were services inaccessible, but they were also unaffordable. No participant held a full-time job, thus making it difficult, if not impossible, for them to pay for quality counseling services. In general, they found that service providers who would accept what they could offer financially did not understand the needs of people with TBI and did not provide good quality care. Improved community-based services need to be developed through collaboration and coalition building between law enforcement, social services, healthcare, mental health, and public health.

Given the variety of perpetrators cited in this study, it is evident that there continues to be a need to educate the general public about understanding, interacting with, and respecting people with TBI. However, multiple events suggest a more urgent need to target TBI education to public service officials (eg, law enforcement officers), and healthcare and mental health professionals who may react neglectfully, disrespectfully, or abusively toward the people who turn to them for help and support. These educational efforts should be implemented not only to improve their knowledge about TBI but to incite them to become useful resources and advocates for people with TBI who seek their help. Along with education, building partnerships between the TBI community, the professionals providing services to those with TBI, and the professionals providing services related to VAN would be most beneficial. Such links would increase the availability of reliable support for the TBI community, increase the likelihood of prevention and/or early identification of VAN, and strengthen the quality of services provided by VAN service providers.

On the basis of participant data indicating difficulty identifying potential or ongoing situations of VAN, people with TBI could benefit from education to help prevent VAN. While recognizing that VAN is not the fault of the victim, education should empower people with TBI to recognize potential risks and to protect themselves. Finally, it is important that people with TBI identify both personal and community support systems on which they could depend should they encounter VAN or potential VAN. Several participants suggested that having such support systems as a means to protect themselves from VAN or to cope with it was invaluable.

This study shows that people with TBI are at risk for VAN and consequently exposed to multiple forms of VAN. Despite this, there are few efforts to understand and prevent VAN in this population or to provide supportive services to those who have experienced it. Our results suggest that future efforts in this area, including additional studies, should focus on (1) building community-based coalitions, promoting knowledge and services related to how to prevent, identify, and intervene in VAN occurring among people with TBI; (2) empowering people with TBI to identify and prevent situations of VAN; and (3) providing good quality, affordable services to people with TBI attempting to cope with VAN. By targeting these areas for further research, development, and improvement, a positive impact should be seen in preventing VAN and providing services to persons who have been exposed. Ultimately, these improvements could strengthen the confidence of persons with TBI, and increase their positive ties to the community in general.

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