

"Knowing what is wrong is like a million bucks"

**Perspectives of Survivors of
Domestic Violence on
Brain Injury Screening/Testing --
A Qualitative Study**

Report

April 2019

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**Submitted to Brain Injury Alliance of
Nebraska**

Acknowledgments:

- ❖ **Our sincere gratitude and thanks to the participants in the study who graciously shared their valuable insights and perspectives with us.**
- ❖ **We thank the Brain Injury Alliance of Nebraska for contracting with UNMC's College of Public Health for this project, and for Women Investing in Nebraska for their grant to the Brain Injury Alliance of Nebraska.**
- ❖ **We thank our community partners and research team for conducting the screening/assessment of brain injury and for helping us reach out to participants in this study.**

Suggested Citation:

Rajaram, Shireen (2019). "Knowing what is wrong is like a million bucks." Perspectives of Survivors of Domestic Violence on Brain Injury Screening/Testing -- A Qualitative Study. Report Submitted to the Brain Injury Alliance of Nebraska.

Disclaimer:

The views expressed in this report are those of the author and do not necessarily reflect the views of collaborating organizations or the funders.

Trigger Alert:

This report contains quotations and descriptions about the experiences of domestic violence survivors, which may be difficult for some readers.

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EXECUTIVE SUMMARY

This qualitative study was conducted by Dr. Shireen S. Rajaram, researcher at the College of Public Health at the University of Nebraska Medical Center (UNMC) and was funded by the Brain Injury Alliance of Nebraska.

This study is the first of its kind in Nebraska that included the voices of survivors of domestic violence who may have experienced a traumatic brain injury. The main objective of the study was to explore the perceptions of survivors of domestic violence (DV) of the brain injury (BI) screening/testing process through gathering systematic, in-depth qualitative data.

The key partners included the community-based organization, Brain Injury Alliance of Nebraska (BIA-NE), and three neuropsychologists who conducted a one-hour follow up neuropsychological assessment (NPA) of women who experienced trauma to the brain. Prior to the NPA, women were screened for a traumatic brain injury using the HELP screening tool by organizations that provide services to survivors of domestic violence.

Data were gathered through in-depth one-on-one interviews by Dr. Rajaram. The sample consisted of 10 women who were domestic violence survivors. The majority of the participants were between 19-45 years, unemployed, not married, lived in the Douglas County area, had children, previously or currently lived in either a domestic violence or a homeless shelter, and were white Caucasian. Five participants had a college degree.

Key Findings

- ❖ Women had varied reactions when they learned that they might have a brain injury resulting from the trauma of their domestic violence.
- ❖ Despite being angry, scared, and embarrassed, they were thankful that they now had an explanation for some of the cognitive symptoms they were experiencing.
- ❖ Most of them experienced memory loss and had problems with their concentration.
- ❖ These symptoms disrupted their daily activities, social relationships with family and friends and their overall quality of life.
- ❖ Most participants found the NPA to be challenging and difficult, but the experience also made them aware of the deficits in their cognitive functioning.
- ❖ Several participants followed up and took steps to seek more information on their condition.
- ❖ Women indicated that they would like more information on how they fared on the NPA and steps that they could take to help them better manage some of their symptoms. These included helpful tips and information on community resources that will help them improve their quality of life.

Recommendations

- ❖ Community based agencies that provide services to women (and men) who have experienced gender-based violence such as domestic violence, human trafficking, and sexual assault should *screen for brain injury* using an established tool such as the modified HELP screen tool.

- ❖ Following BI screening provide:
 - *Results* of the screening to women.
 - *All information in writing* since many of the women with a BI experience memory and concentration lapses.
 - Women with free- to low-cost *assessment services* such as neuropsychological assessment, brain scans, etc. for women who score high on a brain injury assessment.
 - Offer timely free- to low-cost *intervention programs* in the community, based on best/promising practices to help women better manage their symptoms resulting from a BI, through interagency collaboration.
 - Such classes could be offered as group or individual classes in the community, preferably by DV serving organizations in collaboration with BI organizations to provide women with tips to manage their symptoms to help women improve their quality of life.
 - Information on *community resources* that women can access at free- to low-cost for follow up on the results of the screening process.
- ❖ Develop, implement and evaluate *protocols* for screening and management of BI in DV serving organizations.
- ❖ Develop, implement and evaluate programs to *educate and train all employees* to screen for BI in DV serving organizations.
- ❖ Include the *voices of survivors* in all stages of program development, implementation and evaluation to help survivors better manage their brain injury and improve their quality of life.

PERSPECTIVES OF SURVIVORS OF DOMESTIC VIOLENCE ON BRAIN INJURY SCREENING/TESTING

“Knowing what is wrong is like a million bucks.”

INTRODUCTION

The Center for Disease Control defines a traumatic brain injury (TBI) as a disruption in the normal function of the brain resulting from a bump, blow, or jolt to the head, or penetrating head injury (1). Brain injuries (BI) can be mild, lasting for a short period of time or more severe resulting in serious physical or physiological impairments, coma or even death (2). TBI is a major cause of death and disability in the U.S. About 30% of all injury deaths are due to TBI (3). Symptoms of a BI can include problems concentrating, memory loss, irritability, nervousness and anxiety. Changes in behavior and daily routine can help in management and recovery from a BI. There had been increasing attention on BIs resulting from sports injury (1). However, there is inadequate information on the impact of BI on women who have experienced intimate partner violence (IPV). Preliminary data from a pilot project, screening 93 women at domestic violence shelters in the Midwest indicates that 60% of women had possible BI (4).

MAIN OBJECTIVE

The main objective of the study was to explore the perceptions of survivors of domestic violence (DV) of the brain injury (BI) screening/testing process through gathering systematic, in-depth qualitative data.

RESEARCH APPROACH

This study was based on principles of community-engaged research. The key partners included the community-based organization, Brain Injury Alliance of Nebraska (BIA-NE), and three neuropsychologists who conducted a one-hour follow up neuropsychological assessment (NPA) of women who experienced trauma to the brain.

We used a qualitative research approach and data was gathered through in-depth one-on-one interviews with survivors of DV who had undergone the BI screening/testing process.

The qualitative interview guide was drafted through a process of consensus among the project-partners. Please see Appendix A for a copy of the interview guide.

Key stakeholders assisted Dr. Rajaram in setting up ten interviews that were conducted in person, with women who were eligible to participate in the study. Inclusion criteria were women who: a) were 19 years and older; b) accessed domestic violence services in the Omaha/Lincoln area; c) had undergone a neuropsychological assessment (NPA) with a trained neuropsychologist; and d) were able to participate in a one-hour, face-to-face interview.

Their eligibility to participate in the NPA was determined by domestic violence service organizations, using an adaptation of the HELP TBI screening tool.¹ The tool assisted domestic

¹ The original HELPS TBI screening tool was developed by M. Picard, D. Scarisbrick, R. Paluck, 9/91, International Center for the Disabled, TBI-NET, U.S. Department of Education, Rehabilitation Services Administration, Grant #H128A00022. The Helps Tool was updated by project

violence service organizations to identify women who may have a brain injury, and they were given the option to do a follow-up NPA, free of charge with a trained neuropsychologists. Once the women completed the NPA, Dr. Rajaram followed up with interested participants and set up a face-to-face interview at a date and time convenient to participants.

The University of Nebraska Medical Center' Institutional Review Board (IRB) deemed that this study was not research and hence no further permission from IRB was needed to carry out the study. Informed consent was obtained before interviews began. Participants had the option to not answer any questions and they could terminate the interview at any time. Women were given a \$20 gift-card upon completion of the interview as a token of appreciation for their participation in the study. At the time of the interview, all women obtained services from domestic violence serving organizations that provided mental health services at free or low-cost.

All interviews were conducted by Dr. Rajaram and were recorded with permission from research participants. Interviews were professionally transcribed, verbatim. Transcripts were coded, and analyzed for key themes, using a qualitative research software. Pseudonyms are used in the report, and the names of people and organizations have all been redacted. The pronoun "she" is used to reference the neuropsychologists who conducted the follow up NPA even though both male and female neuropsychologists did the NPA.

RESULTS

Sample

The sample consisted of 10 women who were domestic violence survivors. The majority of the participants were between 19-45 years, unemployed, not married, lived in the Douglas County area, had children, previously or currently lived in either a domestic violence or a homeless shelter, and were white Caucasian. Five participants had a college degree. See Table 1 (Appendix B) for socio-demographics of participants.

Key Findings

The following are key themes that emerged from the qualitative data analysis.

A. Emotional reactions to possible Brain Injury – *“And I think, wow, all that damage!”*

Participants had varied reactions when they heard that they might have a brain injury. These reactions were both at the initial stage when they scored high on the HELP screening tool, as well as when they did the follow-up neuropsychological assessment (NPA) with a trained psychologist. Their reactions ranged from being scared, angry, dejected, not surprised, relieved, and ashamed.

Scared – *“A little scared”*

Some participants were scared and concerned about what the diagnosis meant and the extent of damage they suffered.

personnel to reflect recent recommendations by the CDC on the diagnosis of TBI. See http://www.cdc.gov/ncipc/publications/tbi_toolkit/physicians/tbi/diagnosis.htm.

Donna: You know the brain's scary. So scared that, I don't know if they can fix it, or what's gonna happen.

Jessica: A little scared coz it kinda -- I started thinking of like dementia and stuff like that, but for as young as I am, I didn't wanna think that I could have dementia at my age.

Sandra: Kind of spooky, I guess. Kind of worried about the damage that could have been done, just because of the abuse at the time...at the time... didn't think something like that...could cause me so much...so much damage.

Betty: More concerned definitely, because with my short-term memory loss as it was, even when I thought it was minimal.

Angry – “Made me mad”

Some participants were angry at the person who caused the injury.

Connie: Made me mad. I'm angry at the men that put me in that type of situation. I think I was more angry, than I was anything else....Knowing what is wrong is like a million bucks. I feel mad at all the stuff that has happened to me, but that is like a million bucks to know what is wrong.

Gina: I felt very angry, very angry at him, you know. Like you knew that I was abused before and you did it again. You know I was already broken when I met you, and then I -- because I was very open with him, and then he just took that and ran with it.

Dejected – “Made me feel bad”

A couple of participants were also sad and dejected to learn that they might have a brain injury resulting from the physical abuse that they had experienced.

Sandra: This man had done to me in our relationship....And I think, wow, all that damage! Just to think that I thought that, you know, once...once the abuse was over that it wasn't going to stop hurting. But yet, it doesn't stop hurting, because it's the abuse that he did that's caused the injury...the brain injury already.

Jessica: It made me feel bad because if he wouldn't have beat me up, then I wouldn't have probably had the problems that I'm having... it made me look at myself, if that makes any kind of sense. What I let myself go through and how really I, I don't deserve that.

Not surprised – “I wasn't surprised”

Some participants previously suspected that something was wrong with them and, therefore, they were not surprised to learn that they might have suffered a brain injury.

Abby: I wasn't really surprised, because I felt like I have had brain injury... I probably have had some brain damage at some point in my life, because I felt some fluctuations in my own ability to focus and concentrate and think clearly...from the injuries I've had, it felt like I might have some level of brain damage. So its been a thought from before.

Connie: I wasn't surprised...I thought I had dementia....I thought I had Alzheimer's...I'm not surprised because, I've never had an answer for why somethings elude me and, different things I can't remember right away....I am glad I had an answer.

Sandra: And what used to scare me was the fact that I thought that it was dementia. I was sure it was dementia... so I was, I should say, I wasn't surprised.

On the other hand, a few participants were surprised that they had a brain injury. They were not aware that domestic violence could have such far reaching consequences.

Betty: I knew it could, like you know, whiplash when you get in a car crash, because I know the effects. I've only had one bout of whiplash, and I know you can get it from that to an extent, depending on how hard but, I never once thought domestic violence could do it.

One person was not sure what was meant by a head injury.

Kathy: I don't know what's considered a head injury, if someone hits you in the head or if you're banged against the wall with your head....my husband banged my head against the wall, and then he's hit me several times in the head so -- Yeah, in September in '17 and then 2010 and then 2006.

Relieved – “A little relieved”

Participants felt relieved and thankful that they finally had a possible reason for the symptoms they were experiencing.

Betty: Oddly enough, a little relieved. I thought I was crazy. I thought I was imagining it. Imagining the part, what I was going through...imagining that my short-term memory loss was getting worse, but when I heard that it was quite possible I wasn't imagining it, that's when I felt relieved.

Sandra: I can't remember some things, and some things are really easy to remember...I am glad I had an answer.

Jessica: I feel relieved and frustrated at the same time, because its like – it was like, why am I having this, but I [now] know why I'm having it you know, cause I do have some kind of brain issue...

Abby: You know there's a reason that isn't just aging, stuff. I can't help, stuff I couldn't prevent you know.

Connie: Knowing what is wrong is like a million bucks. I feel mad at all the stuff that has happened to me, but that is like a million bucks, to know what is wrong.

Also, a couple of participants had previously seen healthcare providers, who were unable to provide an explanation for their cognitive challenges.

Abby: I tried. I went to the ER and the ER doctor was not very helpful. He pretty much ignored me while I was in the ER, said there was nothing wrong with me on the CAT

scan -- they gave me some kind of MRI or something, and he said there was nothing wrong, that I -- my symptoms were so bad, I had temporary blindness, projectile vomiting. I couldn't walk...That one doctor just didn't wanna help me.

Sandra: Yeah. Relief because, maybe four years ago – no like three years ago, I asked my doctor...I asked my doctor, I asked her, I said, "Doctor XX [name redacted]," I said, "Is there any way that...that...that I could have symptoms of dementia?" And she said, "Oh, no, Sandra. You're too young to have it...You can't have dementia right now."

They were now relieved to learn that their symptoms might be related to their brain injury and that someone would take them seriously.

Ashamed – "I was ashamed"

One person was ashamed to share the information as she thought she would be blamed for subjecting herself to the injury.

Sandra: No, no. Because at first, I didn't know, and I was ashamed. I was ashamed because my daughter's gonna tell me... "See...we told you, you shoulda left a long time ago." And that's something that I didn't wanna hear from them, so.

B. Experience of symptoms – "I feel like I am going to go crazy"

Participants experienced multiple symptoms including memory loss, problems with concentration, and anxiety and depression. Often they did not have an explanation for why they were experiencing these symptoms.

Memory – "I forget everything"

Participants experienced memory loss that kept them from functioning in their day-to-day lives.

Jessica: Because I would have memory problems and not remembering certain things and walking into rooms and not knowing what to -- why I walked in to the room. In the middle of a conversation, not knowing words to say, so I knew something maybe was going on.

Sandra: Like you can give me a name, and two seconds it's gone already from my memory unless I write it down... I mean I'm watching TV, but yet at the end of the movie, I really don't know what it was about, because I'm sitting there listening to it...but I can't remember anything. And it's scary. It's scary. [Laughter]... Like going to my brother's house...going to my brother's house, the first time I went there. And somebody asked me where...where it was at and, I couldn't tell them where it was at...I should know where it's at.

Connie: My doctors I work with. You know, sometimes I forget...forget things that they told me not to do or, or to do. And then later, I'll try to recall it, and I can't. Isn't that weird?

Gina: You know I forget everything. Like I said, I have to write everything down. I'll go up and down the stairs because I'm forgetting.

Some participants were better with long-term memory, while others did better with short-term memory.

Donna: Like I can remember like long-term stuff, but short-term stuff, I have to write it down, or I have to put it in my calendar, or people have to remind me over and over about stuff.

Betty: My -- I have pinpoint long-term memory that has not changed, even with everything I've gone through...[But] I've had to ask people when meeting them, people I see every day, what their name is and apologize to them like the next day. Sorry, but I forgot your name. After I've heard it about the tenth time, now I'm remembering it.

Connie: My memory trouble. Yes, I do have trouble with like, some people say – back in 1982, in November I'm doing this, and I just have no concept of that. Does that make sense to you? I - yeah, I, I have no concept of it at all.

One participant indicated that she felt like she was going crazy because she could not remember much.

Sandra: "Yeah, I said, "But forgetting so much," I said, "That's scary." I said, "It's really scary to me." I said, "Because I feel like I'm going to go crazy. Like I'm going crazy or something." I said. And I just, it scares me."

A couple of participants stated that they felt stigmatized either because of the memory issues or their inability to concentrate.

Betty: I'll get called slow. And that's not really right. All it was I was -- I'd try to remember something, or sometimes someone would have to repeat themselves over and over again...my short-term memory loss... there's already people thinking I had some kind of mental problem. No, it's not mental. It's brain injury.

Concentration – "It's hard to concentrate"

Participants experienced many challenges with their ability to concentrate.

Sandra: Yeah, focusing on one thing is really hard. Really hard. It's hard to concentrate...The concentration's really bad. I used to read a lot and I can't read anymore.

Betty: Somebody could be talking to me. Yesterday I was reading a book. I had been reading that same book for three days...But after so long, my concentration wasn't there. I couldn't even focus on it enough to even pick -- you know read the words out of it.

Abby: I've been kind of -- I've lacked focus like I used to have ever since then, and it's slowly coming back but very, very slowly. Over the course of years, my focus has slowly been come back...It couldn't be like bills or grocery shopping or anything administrative like that. It had to be what I was focused on. What was important to me.

Connie: It's hard for me to focus. It's real hard for me to concentrate and focus...It gets really frustrating. Like I'll be in the middle of telling somebody something, and next thing I know, I, I'm not there. Not that I'm not there, but I have no idea what I was talking about.

Anxiety/Depression – “I have a lotta anxiety”

Several participants experience anxiety and depression.

Sandra: Yeah, there's a lot of depression...a lot of depression and I've been struggling with it for quite a while. I forget to eat. I forget to eat...because of the depression, I was down to 83 pounds.

She also stated that she has a lot of anxiety.

Sandra: So when I get to a point...instead of being able to think...my thoughts start racing really fast, and I start to get scared because I can't remember and it scares me. It scares me a lot...Yeah, I have all of that [anxiety and depression]. I take medication for it.

Donna: I'm on anxiety pills right now for my anxiety, but I don't do good in real big crowds, like concerts and real big crowds. I just -- I don't do good in them. It gets where I can't breathe and stuff like that.

Betty: The memory, the anxiety and the concentration...With the anxiety, I'm actually afraid of meeting people after everything I've gone through....And even -- and it's like talking to men in general, I get real leery. My anxiety levels go up...So if I find somebody I can talk to that happens to be a guy to me, that's a miracle.

Gina: Like mentally. I get up every night throwing up you know in the middle of the night, just anxiety, really bad anxiety.

Mary: I might have some anxiety, too, because of the abuse that I just went through with their dad.

C. Impact of symptoms – “I pushed a lot of people away”

Their symptoms had an impact on their work, daily activities and their social relationships with family and friends.

Daily activities and work – “I struggle to do any of the daily activities”

Their symptoms had an impact on their daily activities including work.

Sandra: I struggle to do any of the daily activities that I'm supposed to do. There's things that I'm supposed to call and check on my mom to make sure that she's okay or see if she needs help and sometimes I forget about that.

Mary: I never really – I don't know. I guess I didn't even stay at a job long enough, but once I started struggling, I just end up just leaving.

Connie: I try to work and it gets too stressful and the stress gets there. My head starts to spin, you know, and I would call it my "committee in the head," it's like, you know, all that stuff goes on...and just gets stressful...it's real hard for me to work. Yeah, the "committee in my head" starts to go off...I did work at XX [name redacted] for a while, but they, they were very nice to work with. They said you can't – they just, they understood.

Jessica: Yeah, because if -- I'll miss a day or not do something, miss something, miss -- Like miss meetings.

Donna: Coz right now I can't work so I felt a little less hopeful. My headaches and my anxiety prevent me from working.

Social impact – "I isolated myself a lot"

Their inability to function well in their daily lives often strained their relationship with their family members. Family members sometimes got frustrated with participants and, often could not deal with their symptoms.

Sandra: Like my family, like they'll tell me something and they'll be like, "Alright, Sandra, I told you. I told you at this time." It's like, "Well, I'm sorry. I forgot." Or they tell me what the address is.

Jessica: Yeah, with my friends sometimes coz they're like, "Can't you remember this? Why do you not remember this?" And I'm like, "I can't."

The disruptiveness and embarrassment of their symptoms caused many of them to withdraw and decrease contact with friends and family.

Sandra: She [daughter] lives in Oklahoma. And I used to go and see her quite a bit, you know, on the bus. But then, afterwards, maybe about the last couple of years, I've stopped going because it's...it's really difficult to...like change buses...you got to stop here, get off this one and wait for the other one...It's like too many transfers for me and they were too much... that's put me off from going to visit her a lot because of that.

Indeed, some women isolated themselves from family so they did not have to deal with explaining the impact of their symptoms such as anxiety and forgetfulness.

Betty: Before it was like, I was afraid to. Being around people used to scare me, because if I think they're going to ask me something, my...my...my thoughts would start racing really fast, fast, fast and...and it would scare me. And that's what would...that's what would make me isolate myself from everybody.

Abby: That was very bad for a long time. I became extremely isolated to the point that I only just barely saw my dad, and we lived in the same house. He was the only person in the world, and then I eventually found a therapist, so it was like my dad that I would see sometimes, but I didn't get along with him, and my therapist whom I saw, because I needed someone else to talk to. I had nobody, nobody for like a year. It was very bad.

Donna: Well, I pushed a lot of people away. I didn't get the help I needed at first. I really -- so now I'm allowing people to help me, allowing [myself] to get the support I need...I'm

really just learning how to, like I said, live again like socially, mentally, physically. Everything has taken almost four years to come around and just kind of learn a new way of living.

Sandra: I isolated myself a lot...I isolate myself so as to not have to answer questions. Because it seems like when somebody asks me something or I go to try to remember something or to do something, my...my brain starts like...It seems like everything starts going really fast like and I can't catch up because. So I'd rather isolate myself, so this way I'm by myself, and I don't have to answer to anybody.

Also, family members became frustrated about the domestic violence that participants experienced.

Connie: I really don't have interactions with friends and family...It's hard... don't know if I told you, but I'm estranged from my family, really...my family just doesn't understand how come I keep going from an abusive relation – it scares them...And my daughter couldn't take it any longer, so they want to know, why keep going back to the same type of person? If I knew that answer, I wouldn't go back! I tried really hard to screen them, but sometimes, some of them are really good at what they do.

Despite the tension of dealing with the symptoms, family members were often a source of support to participant. Overall, they received support from people they shared the information with.

Sandra: Yeah, because what I've told them...I've told them. I've finally shared with my children about my [NPA] session with XX [name redacted], and I've told them that it wasn't just because I'm being...getting old and being forgetful, you know. But the good thing was they were...happy to the fact that it wasn't the dementia because, that, they were scared about. Because my daughter kept on telling me, "Mom, you need to go to the doctor."...So, they were happy about it. [To hear about the possibility of the brain injury causing symptoms].

Family members often provide support in helping women deal with their cognitive symptoms.

Gina: My mom. Yeah, she was like, "Well," she had said she probably thought that there was a possibility...she was just like, "Okay, you know, what do you gotta do?"

Sandra: She [her daughter] told me, she said, "Just write everything like XX [name redacted] told you, Mom. Just, you know, things you need to know, just write everything. Keep a daily active...I mean a book on your activities and what you need to know. Your appointments and things you don't want to forget." She says, "Just like [the neuropsychologist who conducted the NPA; name redacted] told you." She says, "And you know, this'll help you along until you can get to a doctor to actually do the testing on you to see how much activity, how much there is up there.

D. Experience of physical abuse – “Pounding my head into the wall”

Participants experienced several instances of physical abuse in their lives.

Betty: Because I had one ex that repeatedly pounding me in my head. And like every angle of my head, including my face. And I still have problems with my left eye, on this side, from the last time which was in 2015.

Mary: I got hit in my temple, in the back of my head that last time, so...I've been in probably bigger fights, too, where I got hit in my head or I hit my head on the ground or something. So that was really why, I was like, let me figure out if I got hit in my head so many times.

Sandra: It was a relationship that was 15 years. And the abuse was pretty much...all through the relationship...I remember him one time getting me and pounding my head into a wall...It knocked all my front teeth out...he'd grab me and he'd pick me up by the hairs and slam my head against the wall and hit me...He's a big man, so he hit me with a lot of force...he used to hit me a lot or he'd pound my head on the ground. Bang me into a window and things like that.

Connie: You know, they knock you on your head, they knock you into the wall...coz when someone punches you, and they're that much bigger, your whole head just swivels...And when they hit right there [points to the side of her face], you, you, you, go way to the side. And the head, they'll hit you in the head...some reason, he liked to hit my head a lot...he was one that kept punching me in the mouth, but my whole head would hurt by the time we got done. And then he would kick me in the back of the head...he was bouncing my head off the cement.

Although, the physical abuse was ubiquitous, often, participants could pinpoint specific incidents of abuse after which they felt they began to experience negative cognitive and emotional symptoms.

Abby: I had a very severe concussion about 11 years ago I think, and I just didn't really quite feel the same after that.

Gina: And I noticed my memory really bad within -- it's about a year...I think I noticed more with the last -- well, the last two hits, you know he ruptured my eardrum two times, two places in this ear, one in this one...and then the second time when he hit me so hard, I mean like gradually, and it's been about a year since he did it. I mean he hit me hard. Like full force...But I think it was that -- just that last time that just really just got me...

Donna: So it's been an ongoing issue since he beat me up. He's beat me up numerous of times, but 2014's probably the worst time...I got a concussion and I've just never healed from it.

A few participants were not sure what might have caused their brain injury.

Sandra: Like I started to get the injuries. Um wow. I got beat so much that I really can't...I really can't pinpoint when I started noticing it [symptoms].

One person had other physical trauma in their life.

Jessica: And then after I got beat up from [him] -- I had a car accident, and then I got beat up, so I don't know which one it was correlating with, but putting the two together, I think made it worse so -- [that was] ten years ago.

E. Why they did the follow-up NPA session? – “I wanted to know”

Participants in this study decided to follow-up and do the neuropsychological assessment (NPA) after they scored high on the HELP screening tool and were informed that they might have a brain injury. They did the follow-up NPA session because they wanted to see if they did have a brain injury, to find out more information on what they could do to get better, and to help others through participating in the research study.

To see if they had a brain injury – “I wanted to know if I did have brain injury”

Participants wanted to know if they did in fact have a brain injury.

Betty: I wanted to do the follow-up assessment because I wanted to know if I did have brain injury, I wanted to know the extent...I do know the extent now. I couldn't -- when she read all those words [in the NPA session], and it's like my mind would wander off after I heard the first six to eight of them.

Mary: I just was trying to see if I actually had an issue...I wanted to know if I really did have issues because of head injuries that I have had. 'Cause it just never came up at all, so I kind of just wanted to know more about it, and to see if there actually was an issue.

Connie: I wanted to know if I did have a brain injury and if I did, how sensitive it was, and maybe get some background on how, how these things happen.

Sandra: Because she was going to give me these tests and then these tests, it was gonna prove the fact that I was able to -- that there is damage in there. There is damage. So that's why I wanted to talk to her.

Participants wanted to learn more about brain injury.

Mary: And I was like wow, I really want to know more about it, so...I want to do more research about it, too. I mean just based off of what they told me that the head injury could cause these things, and I'm like, could be other things, too, so maybe if I had more [information].

Abby: Sure, I am curious to know. I like science a lot. I like medicine. I like learning about myself and how the body works, and I wanted to talk to him about what I experienced.

Sandra: I wanted to know is there any way to find out exactly how much about...how much damage he did to me, to my brain to see if -- I know it probably can't be repaired, you know. It's something I'm just gonna have to live with now for. I just was wanting to know, you know, what all he caused...how much injury was caused...what suffering I'm going to go through because of him.

They were glad they could get a professional opinion and that they would be taken seriously. They were thankful that finally they could get answers for some of their symptoms.

Abby: It -- yeah, it's just -- it's nice to hear from a doctor, from a professional you know that you're not broken...And that is enough to heal somebody sometimes. Just hearing from a professional that it's possible could sometimes make it happen for you.

One participant (Shannon) stated that the NPA was, "...almost like a second opinion." [probably relieved...his exam is almost like a second opinion. So it just made me feel that I'm on the right track of doing what I was supposed to be doing.]

Sandra: Because it was a chance. It was a chance that probably that somebody would finally listen to me and understand that what I'm going through.

What could be done to get better – "What do I do to get better?"

Participants were interested in knowing what steps they could take to get better. They felt that now that they knew they might have a brain injury, they needed to move ahead and figure out how to get better.

Gina: I was willing to go do what I gotta do...like if I did have that [brain injury], like what do I do to get better?

Abby: I wanted to know if there was any medical treatment that could be done to improve brain chemistry or whatever was damaged from my concussion or my traumatic experiences.

Sandra: So I realized that...that there was [a brain injury] and that I did need...that I did need to get help for it. To see a doctor for it.

Donna: Maybe how to get help...I felt hopeful that there might be a cure...or maybe some help with it, so I can get back on my feet and get back to work....or maybe some help with it, so I can get back on my feet and get back to work.

Gina: Coz I'm all about getting better...I wanna get better.

Mary: I have been fully involved in trying to move forward with my life, and being mentally stable was one of my goals, is one of my goals, so this...happened to be one of those things that would help me reach that goal. So I was more willing to do that....if this is an issue...then what can I do to improve that or if there is anything that I can do to help me.

Another person (Shannon) stated that the session made her feel like she is on the right track to getting better.

Help others – "I like helping people"

Several women indicated that they wanted to do the follow up NPA to help others through participating in research that would impact other people's lives.

Abby: I also wanted to help with the research side of things so...it felt very helpful and of use to society to you know have my results tacked in to the community's results and to

see what the research can do for others in the future. It was really nice to be a part of that. I felt like I could -- was able to give back a little bit.

Kathy: Just curiosity I guess...I would say the main [reason] is to help other people or help them find their research, so they can come up with a conclusion or a way to find the answer, and what happens when someone's been hit in the head several times.

Donna: I'm always looking for opportunities to help myself but also help other individuals, that have suffered from the same thing that I have or, you know -- research -- to hopefully come up with a cure, so.

F. Reactions to the NPA process – “As hard as I try to concentrate”

Many participants were overwhelmed and frustrated that they were not able to complete many of the tasks from memory recall to drawing. Despite the challenges, most participants found the NPA to be quite interesting and challenging.

Frustrating and challenging – “A lot of them were frustrating and challenging”

Jessica: And it was like, wow! I really am not remembering, so it really got to me that I didn't remember these things...I kinda was frustrated with myself because I couldn't remember some of the words that she was wanting me to remember....Because I realize that I'm not remembering as much as I feel I should for my age.... And I think I should be remembering more...it just kinda throws me off you know why I'm not.

Mary: It made me surprised that there were some of the things that I could not do. I was like wow, like...frustrated me a little bit, but there's absolutely, as hard as I try to concentrate and think about the patterns or remember those things, I couldn't, and I was like, wow.

Connie: Drawing that thing is the hardest thing I had to do that picture of – I don't know what it was, it looked like half of a house or something. I struggled with that really hard.

Some found the session to be anxiety provoking, and embarrassing since they were not able to do well of many of the tests.

Abby: A lot of them were frustrating -- and challenging and mostly because of the anxiety aspect...like messing up was my biggest concern...but it was you know anxiety-inducing, a little bit every time, because I was just afraid of goofing up.

Donna: I had a lotta anxiety. It was a little overwhelming. It was -- yeah, it was just a little overwhelming and a lot of anxiety.

Another person stated that she has a learning disability and that made the process more difficult.

Kathy: It was difficult. It was fun and difficult, because I already struggle with ADD [Attention Deficit Disorder], so remembering is quite difficult for me, so that was difficult.

One participant stated that the process was exhausting.

Kathy: Um it was kind of mentally exhausting.

Embarrassing – “And it’s embarrassing”

A few participants stated that they NPA session was embarrassing because they struggled with the activities, and were not able to do as well as they hoped.

Jessica: I don’t know why, I got...out of that session [NPA session], I was like, ‘cause I had to keep saying, I don’t remember, I don’t remember. And, it’s embarrassing, but that’s – but I think it’s – having an answer meant a lot to me.

Connie: It made me look at myself, if that makes any kind of sense. What I let myself go through and how really, I, I don’t deserve that. I don’t know why, I got that out, out of that session, I was like, ‘cause I had to keep saying, I don’t remember, I don’t remember. And, it’s embarrassing, you know.

Abby: Like embarrassing myself was my biggest concern.

Insights into their injury – “It was kind of mind-opening”

Participating in the NPA provided them with insights into the impact of their injuries on their brain functioning.

Jessica: Yeah, coz I didn’t realize that I couldn’t remember that much stuff, and it just -- it kinda -- to me, it was kind of mind-opening to realize that I don’t know as much as -- you know my brain’s not working as well as I thought it was.

Sandra: Well, it showed me how much damage there really is in there I think because there was a lot of things that I wanted to remember... when XX [name redacted] did the testing it was like, yeah, I knew that there was something wrong. That there was damage to my brain somehow.

Another person knew she had short-term memory loss, but after the NPA, she realized that she had more problems beyond the memory loss.

Betty: So finding out, it was real big -- well, it was bigger than that [short-term memory loss], yeah, that part was new.

Kathy: Yeah, it just signified that my confusion wasn’t just because of ADD. It could have been because of head injuries.

Confidence boost – “Gave me a really big boost of confidence”

For three participants the NPA testing gave them a boost of confidence since they no longer felt that there was something wrong with them.

Abby: It gave me a really big boost of confidence, actually. Yeah, she made me feel so great about my results so....Totally. Yeah, I mean, she just -- he made me feel like I was more intelligent than I realized, and that was very exciting to me.

For two participants, the testing session helped decrease her social inhibitions to be around other people, since they now felt they had a better understanding of their cognitive challenges.

Betty: And now I feel like I'm...I can do it. I can, you know. Don't have to isolate myself. That I can...I can function daily life like, you know, like anybody else can.

Sandra: Now I don't hide in my room. I don't hide in my room. I'll come out and I'll watch TV with the girls and talk with them. I'll go to my son's and and watch the kids for him or just go visit just to be with the kids. I'm not just hibernating like always because I, that's what I used to do, is hibernate....So, yeah, it's helped me a lot because now I realize it wasn't just my forgetfulness...Yeah, after I seen XX [name redacted]. Yeah, more confidence.

Good experience – “It was really great”

Many found the NPA experience interesting and enjoyable.

Connie: And I thought it was interesting. I thought the session was interesting.

Gina: It was cool coz, like, to know what actually could be wrong with me was nice. I enjoyed it.

Abby: I just thought it was so fantastic. I thought it was great. I thought it was really unique, a unique experience.

Even though many struggled with the NPA, most participants did not find the session to be too long.

Gina: It wasn't long. Just the things were frustrating for me 'cause I couldn't remember.

One participant stated that although it was long, she felt that was necessary so the process could be thorough.

Mary: It was long, but thorough. I felt like the things that they did to test me, were legit. So I knew my results would come out legit, too. So I was like okay.

Two participants stated that they found the session to be quite long.

Kathy: It was longer than I expected. Yeah.

Shannon: It was what I expected. I mean it was a little long. Sometimes it was annoying because she...[kept] repeating the numbers and the objects, and it just went on, and on, and on and by the time she finished, it was like okay, I can't remember the first one. Yeah.

Another participant stated that the neuropsychologists gave her breaks. All participants felt that the instructions were very clear and the neuropsychologists were very supportive throughout the test.

Abby: Yeah, like clear as day, I knew that -- like his directions were very clear, and I had no trouble understanding anything that he was describing so it was great.

Gina: And she's very thorough. You know what I mean? And she'll -- I think she'll -- she's a good person. That's all I can say is she'll -- she's good at what she does.

Abby: It was great. It was really great. She's really a kind person to work with. I was nervous because it was -- it's awkward, because it's quiet, and you're being tested on your logic and that's embarrassing if you mess things up or if you say a stupid answer...but she was extremely comforting to work with. She's just very kind and gentle and you know not intimidating in any way.... Yeah, she was wonderful. She was truly wonderful.

They felt that going through the NPA would definitely benefit others and that they would wholeheartedly recommend it to other women in a similar situation.

Jessica: That it's a good thing to go through because you see where you're at and if you need more help, then you can get it...Yes, it could definitely benefit.

G. Reaction to the first screening process -- "Its just kinda foggy"

Most participants recalled the 1-hour NPA session vividly, but were not able to recall much of the first screening session with the HELP screening tool.

Jessica: And I think just my memory, is just not -- it's just kinda foggy but the one with XX [name redacted; the NPA], I really remembered a lot. Not everything that she was saying to me, but I remember her, and I remembered doing it...I talked about XX [name redacted] screening and my mom -- I talked to my mom about it. The first screening I didn't really tell anybody about....But the second one I did 'cause I was just wowed by it and realizing how much I don't remember, and I talked to my mom about it, and she's like, "Well, maybe we should have something looked in to more."

Four participants shared the first diagnosis with their friends or a family member.

Connie: I did tell my friend, yes, I did tell my friend. I just shared with them that, maybe that there was a brain injury.

Some participants were a bit confused about the HELP screening questions they were asked, and were not sure what the results of the HELP tool signified.

Mary: They said, "Somebody will be following up with you to do the survey or to speak with you after we're done with this. Here's his number and here's his name. He'll finally be calling you." I'm like okay.

For some participants the HELP tool was administered within a group setting at the domestic violence serving organization.

Shannon: [We were] in [a] group and then when we were done with group, she [the group facilitator] had some time to sign people up. So she was really vague on what the outcome would be.

One person said that it was a long time between the first screening and the scheduling of the NPA, as well as the follow-up one-on-one interview.

Shannon: No, I just -- I was given the questions, and I signed the paperwork...I don't know what happened, but it took so long for them to get back with me in regards to it....And then even when you called me, there was quite some time between when I saw XX [name redacted] and when you called me, and I was like, you know, I didn't think it'd ever come about.

H. Perception of information provided following NPA – “Well, she said I did remarkable, but I'm not sure what that [meant].”

Result provided of the NPA – “I don't remember him telling me”

A couple of participants recalled receiving the results of the testing.

Abby: I didn't ask for the results [laughs] because I thought I didn't do very well, but XX said, “Well, don't you wanna know what your results are?” And I said, “Uh not really.” You know and she actually gave me very good feedback. She said that I did a lot better than I thought I could possibly have done, so I was very pleased to know that I did well so. I mean considering [laughs] but yeah, so she was very nice to offer to tell me the results.

Connie: Well, she said I did remarkable, but I'm not sure what that [meant] – I, I'm not sure. That's really all she said.

However, most participants stated that they did not receive the result of the NPA or information on how they performed.

Donna: None. She didn't give me any results.

Shannon: Yeah, but I don't know the conclusions of them [NPA].

Kathy: I don't know if I got any results, really. I don't remember her telling me if any of my answers helped, or I think -- yeah, now I'm thinking about it. She did say I did a good job on some of it so -- but I don't know if I did suffer from the head injuries or not. I don't know for sure.

Gina: She told me she thinks I have PTSD, which I probably already do know...I mean she -- I mean if she wanted to, she could go more in-depth with me you know, but yeah, I do.

Betty: That I do have short-term memory loss. To me, I already knew I did.

A couple of participants stated that they might have received the results of the NPA, but felt that, because of memory issues, they were unable to recall this information.

Connie: I know she said something about attention. Yes, she did. Isn't that terrible? I can't even remember.

Tips to manage symptoms – “I didn’t really get any tips”

A couple participants indicated that they did receive helpful hints on how to manage their symptoms.

Jessica: Well, I did like, write the things down, make lists, basically make lists, really think about -- try not to overthink things you know coz sometimes I can overthink like a word and then not be able to get it... Yeah, coz now I got a whiteboard on my fridge...And I got a whiteboard in the kids’ room for their stuff that they gotta do...I find it very helpful... and then putting stuff in my -- on a calendar on my phone. To make sure that I’m doing everything and getting to the places that I need to be every day, too. That’s been very helpful, too.

She stated that this behavior change came about following the suggestion by the neuropsychologist doing the testing – “Just telling me about it.” (Jessica)

Jessica: Writing down things...what I should do is things that are important or things that I need to know that to, you know, document them, so that way it would help a little bit in the ways. You know, that way for my appointments...for my appointments that it would help like that.

However, most other participants stated that they did not receive any tips or helpful hints on how to manage their symptoms.

Mary: No, I felt like it was just pretty straight and narrow, just doing the assessment, giving our answers...and then s/he gave me my results...I don’t think there was discussion about what can I do to help improve those things? She didn’t really give me any resources or how to help those things...I don’t know about helpful hints...I didn’t really get any tips on like... how to help those things that I scored low on.

Again, participants wondered if they were provided information on tips to manage their symptoms, but due their memory issues, they were unable to recall any of this information.

Abby: You know we didn’t discuss a whole lot of techniques, so I don’t -- unless I’m forgetting, which isn’t impossible with my memory, but I don’t believe we really went over techniques per se or like coping mechanisms.

She stated that if coping skills were discussed, that would be something she would remember.

Abby: If coping skills were discussed, that would have been something that I would have liked to know. That’s why I’m thinking that they probably weren’t discussed, because I would have probably remembered that.

Pamphlets -- “She gave me a brain pamphlet”

A few participants indicated that they received a pamphlet, but stated they did not have the time to read it and access more information on the web.

Betty: She gave me a pamphlet of who to get a hold of...I just haven’t been able to call or email or anything yet... I would know more as soon as I was able to read what she gave me.

Abby: I got a BIA [Brain Injury Alliance of Nebraska] pamphlet. Yeah. It is at home. I haven't read through it yet. I've been so busy since then, but I have it on my desk. You know I haven't read -- I just realized that I haven't read it [laughs] so I'm gonna have to do that soon but -- and I'm gonna go to the website and peruse that too, but other than that, I don't know that I was given anything other than that.

Donna: Yeah, he gave me a brain pamphlet...I read a little bit of it. I haven't read the whole thing yet though...he just said it's a support group --

Gina: I think there's one [pamphlet] and it's upstairs...It's been very busy for me. I apologize. [laughs] I have a paper or something she -- I don't remember...It was late in the evening too, like 7:00 or something like that, so I was trying to get back home.

One participant indicated that she did not get any pamphlets.

Jessica: I didn't get any pamphlets.

I. Steps taken following the NPA – “I went and had some more testing done”

Even though many participants felt that they did not receive much information on how to manage their symptoms such as poor memory or problems with concentration, they took steps on their own to better their situation. For example, following the testing with the NP, several participants changed their behavior to better manage their symptoms such as forgetfulness and inability to concentrate, or made plans to or reached out to professionals to get better.

One person indicated that although she did not get any helpful tips on symptom management, nonetheless, participating in the NPA provided her with insights on better managing her condition.

Mary: I don't know about helpful hints, but it made me more aware, aware of the areas that I need to look at or pay attention to... Yeah, I actually reached out to XX [name redacted of local community based organization], the health navigator and she was able to give me some resources on psychiatrists to see or to maybe even get a psychiatric eval...I'm probably gonna have to look into the resources that the XX [community based organization] gave me but it -- just doing this assessment and it made me more interested and concerned about maybe I should look into this and see. You know, exactly what's going on with me.

Also, she stated that she might need to see a psychiatrist as well

Mary: Yeah. I think I have to go see a really...a well-educated psychiatrist that I'll probably have to meet with, just 'cause this could be a factor in my mental stability as well as other things and they would kind of have to weigh those things to help me out at the same time.

Connie: Yes. I tried chunking. I read this little book on different memory things you can do, and so I've been chunking and it seems to work with numbers anyway, especially. But I've been chunking and, I thought I was doing one more thing... Yes, I've read a

memory thing, I've been chunking and something else. But it seems to work, the chunking does. It does. The other one doesn't work as well.

Kathy: It was kind of mentally exhausting, but I think I did learn that if I practice some of those tests they gave me by myself at home on -- on my own time, that I could improve my mental capacity and my mental strength, which you just have to spend time and do it. There's no way around it really.

Jessica: Because, I felt after XX testing, I realized there was a lot more that I wasn't remembering, and so I went and had some more testing done...I think I'd need to have the brain scan done just to see what comes out of that just because I think there is some trauma there, and I wanna know what kind of trauma it is...So -- and maybe compare it to the one I had you know ten years ago....See what the difference is now to then.

A couple of participants were already actively managing their symptoms.

Jessica: If I don't write it down in my phone that I'm doing something, I don't remember.

Other participants stated that they did not do anything differently following the testing.

Donna: I just live my life day to day.

J. Information they would like to receive – “How to fix myself”

Participants stated that they would like more information including the extent of damage to their brain, guidance of how they could better manage their symptoms, their performance on the NPA, and resources in the community that they could access to improve their condition.

Extent of damage -- “To know how much damage there is”

Participants indicated that it would like more information on how much damage to their brain had occurred.

Sandra: To know, I guess, how much damage there is there, and just what it did to me and what...the extent of the damage, is what I want to know. Yeah.

Connie: If I do have something wrong, and to an extent, to what extent is there damage done.

Betty: But I gotta find out more as to the extent of it.

Donna: I don't know. Maybe kinda where my brain is, and what scale my brain -- you know where my brain is.

What can be done – “What do I do to get better”

Participants stated that they would have liked more feedback on helpful hints on managing symptoms and what might be next steps they could take to get better. They indicated that being provided with the information would be very beneficial.

Sandra: I mean come out with the information that XX [name redacted] gave me. That they would benefit quite a bit from it because, yeah, she was very, very helpful.

Betty: Yeah, is there anything I can do by myself to improve? On my own. I know there's ways I can do that with help out in the community, but for me to do, individually.

Connie: And what can I do to help myself? I would like to know where I should emphasize.

Shannon: Well, I don't remember getting any information about how I did it. How well I did or how poorly I did, but if that information is given and resources in regards to what they can do to try to get their memory back or their strength or... Well, I know each person is different. I just feel that they should -- we should have gotten something to you know, help us more...I just wanna know when I'm gonna get back to halfway normal.

Donna: What we could do from here to help me. I think if XX [name redacted] at the end would kinda give them their results and kinda tell them where they kinda stand, it would be helpful... because it would give them a better understanding of where they're at.

Mary: Well, I'd like to have my results in areas I scored low in. And maybe some things, some information about ways that I could improve that on my own. I didn't get into that. I wanted, I wanted to have a copy of my results. Just so that I would know what areas that I scored low in...[I'd like to] improve those things that I scored low on.

Gina: How to fix myself. You know -- What I mean? Like if I did have that, like what do I do to get better?

Abby: That would be good you know. Coping mechanisms would be good.

Jessica: Yeah, I'd like maybe more tips to manage what I'm going through...Because I mean yeah, I'm trying to do the best I can with what I know. Like I've made the lists of everything. I mean I have lists everywhere. [laughs] You know but then sometimes it's like I forget to look at the lists. But I want -- I don't -- it feels like I want -- I need more.

Resources – “What services can I use to get better”

A few participants indicated that they would like more information on community resources.

Gina: You know what I mean? Like that's my automatic thought was, what services can I use to get better. You know what I mean?

Abby: Sure, yeah, community resources and maybe, medical treatments that are being tested for the purpose of brain recuperation just to know what technology is coming up, if there is anything -- any medical treatment coming up, that's going to be -- Community resources are always very helpful. It's good to know what's out there.... Yeah, or community resources, like a list of just -- you know a packet of community resources, coping skills, the pamphlet from BIA. That would be great, those three things.

She indicated that a newsletter would help her keep in touch with local services.

Abby: I just would love to hear more news about -- like if you guys have a newsletter or something that goes out, that would be really cool to know just what's going on in the world of brain injury science....It's just interesting to me. I used to subscribe to Scientific American Mind magazine...And so it's just interesting to me...I kinda geek out about that stuff...So I would just like to be kept in the loop of any research that you need a volunteer for, just let me know.

Shannon: If that information is given and resources in regards to what they can do to try to get their memory back or their strength or even the XXX [name of community based organization redacted] helping you know.

She indicated that she needs motivational support that could be provided by a local organization.

Shannon: I would say support in regards to motivation...I just know I need the support, and I need people to make sure I get it done until it becomes a regular routine for me to do it...Or even the XX [name redacted of local community based organization, providing services to DV survivors] helping you know...I just have no motivation, because I don't have anyone to motivate me....So even a phone call, say, "Hey, you need to do your meds," or, "do your exercises."

Written information – “Maybe writing it out”

Some participants said that they would like to have information in writing, because they have memory problems and may not remember what was said.

Shannon: I don't remember getting any information about how I did it. How well I did or how poorly I did. You know what? I can't remember because I have a memory problem and if you don't give it to me in writing, I'll forget it.

Abby: I'm wondering if for other people who don't -- who aren't as interested in brain science as I am, maybe writing out a -- making a pamphlet or a brochure or something that explains what the session with XX [name redacted] would entail. Like you're gonna be tested on various things....that would get people interested in...I thought maybe it might just be some talking and like therapy style...it was just very different, but if you can somehow describe what a session is going to be like on a piece of paper for potential candidates to look over, that might be useful.

One person indicated that she is glad that she is no longer in contact with her abuser, and she has all the information from the testing, and there is nothing more that she needs.

Kathy: Well, I mean I pretty much -- I think I got the answer. They told me the repercussions and the outcome of getting -- being hit, so I pretty much concluded that -- I mean I got my answers so -- but there's nothing more that I feel like I need to know.

DISCUSSION

This study is the first of its kind in Nebraska that included the voices of survivors of domestic violence who may have experienced a traumatic brain injury.

Women had varied reactions when they learned that they might have a brain injury resulting from the trauma of their domestic violence. Despite being angry, scared, and embarrassed, they were thankful that they now had an explanation for some of the cognitive symptoms they were experiencing. Most of them experienced memory loss and had problems with their concentration. These symptoms disrupted their daily activities, social relationships with family and friends and their overall quality of life. Most participants found the NPA to be challenging and difficult, but the experience also made them aware of the deficits in their cognitive functioning. Several participants followed up and took steps to seek more information on their condition. They stated that they would like more information on how they fared on the NPA and steps that they could take to help them better manage some of their symptoms. These included helpful tips and information on community resources that will help them improve their quality of life.

RECOMMENDATIONS

- ❖ Community based agencies that provide services to women (and men) who have experienced gender-based violence such as domestic violence, human trafficking, and sexual assault should *screen for brain injury* using an established tool such as the modified HELP screen tool.
- ❖ Following BI screening provide:
 - *Results* of the screening to women.
 - *All information in writing* since many of the women with a BI experience memory and concentration lapses.
 - Women with free- to low-cost *assessment services* such as neuropsychological assessment, brain scans, etc. for women who score high on a brain injury assessment.
 - Offer timely free- to low-cost *intervention programs* in the community, based on best/promising practices to help women better manage their symptoms resulting from a BI, through interagency collaboration.
 - Such classes could be offered as group or individual classes in the community, preferably by DV serving organizations in collaboration with BI organizations to provide women with tips to manage their symptoms to help women improve their quality of life.
 - Information on *community resources* that women can access at free- to low-cost for follow up on the results of the screening process.
- ❖ Develop, implement and evaluate *protocols* for screening and management of BI in DV serving organizations.
- ❖ Develop, implement and evaluate programs to *educate and train all employees* to screen for BI in DV serving organizations.

- ❖ Include the *voices of survivors* in all stages of program development, implementation and evaluation to help survivors better manage their brain injury and improve their quality of life.

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APPENDIX – A

Interview Guide

Introduction

Thank you for meeting with me today.

As you know, I work with a research team at University of Nebraska Medical Center and the Brain Injury Alliance of Nebraska. I work in public health in Omaha.

We would like to learn more about your thoughts on the screening session you had with _____, and also your more recent assessment session on brain injury with _____ (insert name).

The information that you provide us will help us learn more about what is important to you and how we can better conduct the screening process, and also provide you with suggestions that may help you in your life.

I have a few questions for you. Please feel free to skip or not answer any questions if you do not wish to do so.

Questions

1. So let me start by asking you a little bit about the first screening process you had with _____. Can you share with me how you felt when you were told that you might have a brain injury and were requested to do the follow-up with assessment to learn more?
 - a. Probes: Were you surprised to learn that you might have a brain injury? Do you find yourself wanting more information? What things did you want to know more about?
2. Can you share what you might have told family, friends, and staff about this experience?
3. Prior to this screening with _____ can you share with me any struggles in your day-to-day functioning that you may have had?
 - a. Probes: with memory, concentration, anxiety, grief, depression, problem solving, recreational activities, work/job skills (performance), interactions with friends and family (social skills), managing your emotions, etc?
4. Was there a specific time in your life that you recall when you began to experience some of the symptoms that you mentioned?
 - a. Probe: Is there a specific injury or episode that you can remember after which you began to experience of these symptoms?
5. Can you share your thoughts and feeling when you learned that some of your symptoms you mentioned might be related to a brain injury?
 - a. Probes: Did you feel relieved in being able to finally have a possible explanation (i.e., brain injury) for these symptoms.
 - b. Probes: Did you feel scared or anxious knowing that you might have a brain injury?
6. Are there things you have been able to do differently as a result of the screening session with _____?

As you know please, feel free to skip any questions that I ask.

7. Please, can you share with me your thoughts on why you decided to do the follow-up assessment with ____?

8. Please, can you share with me more your thoughts and feeling about the assessment session you had with ____?

Probes: How was the process? Tell me more about some of the tasks that you go to do in the session?

Probes: Were they easy/challenging and what aspect of it was easy/challenging; were the instructions clear?.

9. Can you share with me your thoughts and feelings about some of the results that you were given in this assessment session with ____?

(robes: What information did you learn from that session? Was any of the information new to you? Did it help explain some of the questions you might have had in the first screening session with ____? Did it make you feel more relieved or scared?

10. Please, can you share with me your thoughts and feelings about some of the feedback or helpful hints that ____ gave you at the end of the assessment session.

a. Probes: Did the helpful hints that ____ gave you, help explain some of the questions you might have had after the first screening session with ____?)

11. Please can you share with me how you might use the information that you learned in your daily life? What might be specific things that you can do to assist you?

a. Probes: with your memory, anxiety, grief, depression, work, social skills, managing your emotions.

12. Can you tell me a little bit about any challenges or barriers that you might face that would keep you from using any of the information or helpful hints that was provided by ____?

13. Now that you know this information about brain injury, what other things would you like to know or any additional help you may need?

a. Probes: community resources, tips to manage symptoms, etc.

14. Overall, what did you think about the session?

a. Probe: The location? Duration?

15. If there are other DV survivors who are interested in going through this session with ____, what would you tell them?]

a. (robe: How do you think this session might benefit them?

That is all the main questions I have for you, and we now have a few background questions. (Again please feel free to skip or not answer any questions if you do not wish to do so):

16. Where do you currently live? Before you lived in the shelter where did you live?
- a. Probe: Which county [state] do you live in?
17. Do you live...or have you lived in a domestic violence shelter?
- a. Probes: When, where and for how long?
18. Do you have any children?
- a. Probe: What ages and gender? Do they live with you...in the shelter?
19. How old are you?
- a. Probe: Let me read you a few categories and you tell me which one might best describe you: 19-25; 26-25; 36-45; 46-55; over 55 years?
20. What gender best defines you: Male; Female; Transgender?
21. Have you ever been married?
- a. (Probe: Legally, civil? How many times?)
22. What is your education level?
- a. Probes: Let me read you a few categories and you tell me which one might best describe you: High school/GED; Trade School _____ (months/years); Associate Degree; Some college ____ (years); College degree; Post-graduate (Masters and above).
23. Are you currently employed?
- a. Probes: Here are some categories: part-time, full-time, unemployed (if unemployed, how long)
24. Which category might best describe your racial/ethnic background?
- a. Probes: Would you consider yourself to be Latino/Hispanic? Would you consider yourself to be any one of the following: African American, Asian American, Native American, White/Caucasian or of a mixed-racial background?
25. Any other thoughts you would like to share?
26. And, finally, would you be willing to visit with us at a future date?
- a. Probes: (If yes, what might be the best way to reach you? Email, phone, etc.?)

Thank you so much for your time and for sharing your thoughts with us.

Appendix - B

TABLE - 1
Participant Demographics (N=10)

Education	N	%
No GED	1	10
GED/High School	1	10
Trade School	1	10
Associate Degree	2	20
Some College	5	50
Employment		
Unemployed	6	60
Employed (part- or full-time)	3	30
Disability	1	10
Married		
Yes	1	10
No	9	90
Race/Ethnicity		
White Caucasian	7	70
African American		
Native American	1	10
Latino/Hispanic	1	10
Mixed Race	1	1
Area		
Douglas County	7	70
Lancaster County	3	30
Shelter		
Domestic Violence Shelter	5	50
Homeless shelter	3	30
No shelter	2	20
Children		
Yes	9	90
No	1	10
Age		
19-25	1	10
26-35	2	20
36-45	4	40
46-55	2	20
>55	1	10