Collaborating Center for Questionnaire Design and Evaluation Research

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Results from a Cognitive Interview Evaluation of Questions on Traumatic Brain Injury for the National Intimate Partner and Sexual Violence Survey

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INTRODUCTION

Staff from the Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS), Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) conducted a cognitive interview evaluation for questions to be included on the National Intimate Partner and Sexual Violence Survey (NISVS). This survey is conducted by CDC's National Center for Injury Prevention and Control (NCIPC). The questions under investigation for this project focus on traumatic brain injury resulting from intimate partner violence. The study received both Office of Management and Budget (OMB) and NCHS/CDC Human Subjects approval.

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BACKGROUND

NISVS

(https://www.cdc.gov/violenceprevention/datasources/nisvs/index.html) is a periodic survey that collects national and sub-national information on intimate partner violence, sexual violence, and stalking victimization. Questions on intimate partner violence, sexual violence, and stalking were previously evaluated by CCQDER (see Willson and Ryan, 2022 and Willson et al., 2022); however, NISVS plans to incorporate into the survey new questions on traumatic head injuries and anoxic brain injuries that result from intimate partner violence and sexual violence. Questions on traumatic head and anoxic brain injuries have been used in clinical settings but have, heretofore, not been evaluated in the context of the NISVS survey.

METHODOLOGY

Sampling and Respondent Demographics: As a qualitative method, cognitive interviewing employs a purposive non-random sample design whereby individuals are chosen on the basis of characteristics relevant to the questions under investigation. Recruitment criteria for this study included people who 1) have experienced intimate partner or sexual violence in general or 2) have experienced injuries to the



head or face as a result of intimate partner violence or sexual violence. Additionally, the goal of demographic variation for gender, age, race, and educational attainment was established for purposes of diversity, equity, and intersectionality. The CCQDER Operations Team recruited and screened respondents for interviews. Respondents were recruited from the CCQDER database and through word-of-mouth. Previous CCQDER studies for NISVS (Willson and Ryan, 2022 and Willson et al., 2022) have shown that utilizing the recruitment database helped facilitate the interview process and ultimately improve data quality by leveraging preexisting rapport between recruiter and respondent. Respondents' familiarity with the cognitive interview process and the recruitment staff translated into a certain level of comfort with and trust of the cognitive interviewer, which proved essential in discussing the sensitive topics of intimate partner violence and sexual violence.

A total of 20 cognitive interviews were conducted. The majority of respondents were Non-Hispanic Black (14) and there were more females than males (17 and 3, respectively). Most respondents (13) were between the ages of 30 and 49. The sample was roughly split on educational attainment. About half (nine) had a high school diploma or less. The other 11 respondents had some type of college degree, with most (8) having a 4-year degree. Table 1 summarizes the sample composition.

| Table 1: Sample Composition | Total (n = 20) | | | |
|------------------------------------|-----------------------|--|--|--|
| Race | | | | |
| White, Non-Hispanic | 5 | | | |
| Black, Non-Hispanic | 14 | | | |
| Asian | 1 | | | |
| Gender | | | | |
| Female | 17 | | | |
| Male | 3 | | | |
| Age | | | | |
| 18-29 | 3 | | | |
| 30-49 | 13 | | | |
| 50-64 | 2 | | | |
| 65 and older | 2 | | | |
| Educational Attainment | | | | |
| High School Diploma or Less | 9 | | | |
| Two-Year College Degree | 2 | | | |
| Four-Year College Degree | 8 | | | |
| Graduate Degree | 1 | | | |

Data collection: The cognitive interviews were conducted in two segments. Because the questions were designed for interviewer administration, the cognitive interviewer first read the questions to respondents and recorded their answers. The interviewer then followed up with retrospective probes to ascertain respondents' understandings of the questions and instructions, rationales for their answers, and whether any response difficulty occurred. Interviews were a maximum of 60 minutes in length and took place virtually using the Zoom internet meeting platform. A remuneration of \$50 was sent to respondents once the interview ended.

Due to the sensitive nature of the questions, the interview protocol included augmented safety measures for respondents. Respondents were reminded first by the recruiter and again by the interviewer that they could refuse to answer any question or end the interview at any time. Additionally, a list of toll-free help lines and internet website resources were made available to respondents who exhibited any distress or discomfort during the interview. Distress levels were categorized as mild, moderate, or severe. CCQDER staff was responsible for identifying and reporting any level of distress to the NCHS Ethics Review Board (ERB). Only one respondent displayed a moderate level of distress during the interview

and was offered the opportunity to end the interview but declined, citing the importance of work on the topic. Upon completion of the interview, the respondent was given a copy of the helpline telephone numbers and web resources.

Analysis: Analysis of interview data included a process similar to the constant comparative method pioneered by Glaser and Strauss (1967) and adapted to cognitive interviewing by Miller et al. (2014). Data analysis was carried out with the use of Q-Notes (https://wwwn.cdc.gov/qnotes/), a software application specifically designed for cognitive interview studies. The first stage of analysis occurred within each interview. This involved analyzing a respondent's narrative during probing and comparing it to their survey answers to assess internal consistency, identify response difficulty, and document the respondent's understanding of the questions and instructions. The second stage of analysis was a comparison of interpretations by question across interviews to identify larger patterns in the question-response process and forms of response error. Lastly, patterns and themes were compared for any systematic subgroup interpretive differences, for example, by gender or by types of experiences with intimate partner violence or sexual violence.

FINDINGS

The test instrument contains two substantive sections. (Demographic questions were included at the beginning of the instrument to establish interview flow with the use of non-sensitive questions. Those questions were not evaluated.) The first substantive section covers intimate partner violence and any traumatic head injury (blow to the head) and anoxic brain injury (being choked, strangled, or suffocated) that occurred as a result of that violence. The second section covers sexual assault (perpetrated by anyone, not just intimate partners) and any resultant traumatic head injury and anoxic brain injury. (The full test instrument can be found in the Appendix.)

Due to both the sensitive nature of the topic and a 60-minute interview time limit, all questions were not individually examined. Rather, retrospective probing was guided by specific research questions that applied to an array of survey items in each section. Issues with specific items are discussed as they arose during these broader discussions.

I. Determining Most Severe Injury

The entire structure of the test instrument centers on collecting information about the single most severe head injury and anoxic brain injury experienced by respondents. Section 1 focuses on intimate partner violence. Respondents are first asked a series of questions to establish whether a current or ex-romantic or sexual partner ever slapped, hit, kicked, or slammed them. If they answer 'yes' to any of these questions, respondents are asked if they ever had an injury to their head or face as a result of these actions. If so, respondents are then instructed to focus on the *most severe* head injury they sustained as a result of intimate partner violence. The second part of section 1 asks respondents whether an intimate partner ever tried to choke, strangle, or suffocate them. If so, they are again asked to focus on the *most severe* incident when answering all subsequent questions.

Section 2 focuses on sexual assault by anyone (including but not limited to intimate partners) and begins by ascertaining if respondents were ever made to have unwanted sex. If so, they are first asked whether their head or face was ever injured during such an event. Respondents who answer 'yes' are asked to identify the *most significant* injury and answer all subsequent questions in relation to this specific injury. Next respondents are asked whether anyone ever tried to choke, strangle, or suffocate them during

unwanted sex. If so, they are asked to think about the *most significant* time this happened. Table 2 displays the architecture of the two sections.

| Table 2: Question Architecture | | | | |
|---------------------------------|-------------|------------------|---------------------|--|
| Section 1 | | Section 2 | | |
| Intimate Partner Violence | | Sexual Assault | | |
| Head Injury Anoxic Brain Injury | | Head Injury | Anoxic Brain Injury | |
| Most Severe | Most Severe | Most Significant | Most Significant | |

The logical flow of the questions relies on respondents' ability to identify the most severe or most significant injury they ever sustained. Therefore, follow-up probing was designed to assess the extent to which respondents could identify the most severe/significant injury (or incident, depending on question wording) and then answer all the questions with this criterion in mind.

Only one respondent momentarily lost track of which incident she was supposed to be thinking about, due the excessive amount of violence she experienced in her life with multiple partners. The more she began thinking about these experiences, the more experiences she remembered. At one point she said, "The worst I can remember, I was tossed around the bedroom for a while by my throat. It was maybe 30 minutes...I just kind of let it happen. And then the cops showed up, I think. It was like 20 years ago." When asked if this was the incident she was thinking of when answering the questions, she could not definitively say. She said, "Yeah, that's what I was thinking of. I guess. It's all blending together." However, it was clear that this was not the incident she was initially thinking of because she earlier described a different incident to the interviewer (that resulted in a badly cut eyelid and injured eye) when answering questions on symptoms. At that point in the interview she said, "The one I was thinking of, it was my eyelid cut open. And so I was like blurry vision and I couldn't turn my eye all the way over to the side. I had to super glue it shut with nail glue in the mirror. Because you could see my eyeball through my eyelid. It was so cut open." In the end, it is impossible to say that the respondent was thinking of a single injury when answering the symptom questions. She, in general, had difficulty staying focused throughout the interview and explained to the interviewer that "I'm bi-polar." The respondent revealed this diagnosis as a way to contextualize how she processed her experience with intimate partner violence in particular.

Although the above respondent did lose track of the incident she was reporting, this was not the case for most respondents. Once respondents assessed their most severe injury or incident, they had no trouble answering all subsequent questions in relation to this injury. Rather than veer into thinking about different injuries when answering the questions, most respondents continued thinking about the injury they initially identified. Moreover, the terms 'most severe' and 'most significant' were not discernably different for respondents. Respondents took the overall intent to mean the worst injury or incident.

However, even though most respondents were able to determine their most severe injury, the process for arriving at this assessment did vary depending on respondents' experiences with domestic or sexual violence. For some respondents identifying the most severe injury/incident was easy. For others it was more challenging.

Easy Assessment of "Most Severe" Injury

Only One Head Injury: For one group of respondents, the task of identifying the most severe injury was easy because there was only one such violent event, which also happened to result in a head injury. For example, one respondent said, "I was scratched and punched in the face...One time." It was easy to

remember this single injury and posed no challenges in terms of thinking of the same injury across all questions.

Alternatively, some respondents had multiple violent experiences with a partner, but only one experience that actually ended with a head or anoxic brain injury. Despite having multiple violent experiences, that one head injury was easy to remember. For example, one respondent said, "It [violence] happened more than once, but the [head] injury happened at [only] one incident." Another respondent had a similar experience with multiple violent incidents but only one incident involving her head. She said, "Yeah. That's the only time he's ever busted my head open." For one respondent, having one head injury among many violent episodes was due to her partner – with the except of one time – intentionally hitting her in places that would not expose bruises. She said, "He didn't want to hit [where people could see]." It was, therefore, easy for her to remember the one time he hit her head.

Men reported similar experiences. One male respondent had a girlfriend who repeatedly hit him. In most cases this did not result in any injury. But on one occasion it did and that was the incident he thought of. He said, "Yeah, she tried it [choking him] multiples times, but she wasn't successful. But on this day, she caught me unaware." Another respondent said, "The worst [injury] was when she pushed me and I hit my head against a TV. The screen of the TV cracked. My friends came to check on me and they saw me. And my girlfriend, she left already. So, I went to the hospital and the doctor told me I had a head injury." While she was often violent towards him, there was only one time he sustained a head injury.

<u>Multiple Incidents</u>: Unlike the previous examples, another group of respondents had multiple experiences with intimate partner violence or sexual assault that often resulted in a head or anoxic brain injury. Despite having many incidents and injuries to choose from, most respondents in this group were still able to identify their most severe injury with little difficulty. Some respondents immediately identified their worst injury because it bled profusely, needed emergency medical attention, left an obvious scar, or took time to heal. The following are examples:

"I don't know how he did it, but I just felt like my feet were, like, off the floor. And my head hit the wall with force. And I had a really bad injury to the back of my head. I was bleeding and everything. I think that was the worst one."

"Well, I clearly remember getting punched in the eye and it being so bad with the blood coming out. But there was also a cut. The scar is still there. The cut in the eyebrow. And going to the hospital because the blood kept coming. So, I clearly remember that."

"There were many times. But there was one that, specifically in terms of injury, stands out. Because that's the one he ended up taking me to the hospital."

"The eye [injury] stands out as the worst just because I have a permanent scar...It [her eye] didn't work right for a while [she could not move her eye to the left] and it took a while for it to heal. That's why I say it was the worst one."

Some respondents had a violent experience that was an escalation from previous patterns of behavior. It was easy for them to quickly identify this experience and injury. For example, one respondent said:

"Yes. The reason why this is so severe, well, I can remember it because it was traumatizing for me. It was a time where I was finally ready to leave. And because I had been putting up with it so

long, he was like, you're not leaving me. And I remember that he put his hands around my neck and slammed me on the floor. And I was just so shocked."

Difficult Assessment of "Most Severe" Injury

Although most respondents who experienced multiple episodes of intimate partner or sexual violence were able to immediately identify the most severe head or anoxic brain injury, there was another group who found it more difficult. In these cases, the judgment phase of the question-response process was more complicated, and respondents employed different strategies to determine their most severe injury.

<u>Verbalization</u>: One strategy respondents used to determine their most severe injury was to talk it out with the interviewer. For example, one respondent initially thought about two incidents and had to verbalize each experience in order to decide which one was most appropriate to include. She said:

"Um, well, I don't know if you can see I have a scar right here [points to eyebrow]" *I can*. [Note: italics denote interviewer responses.] "I don't want to say HE did that because it was an argument that we were having, and I jumped out of the [moving] car...I was thinking we were going to make it [home] and he was going to get physical. So that wasn't one that HE did. I kinda did it to myself. But I do have a knot in my head because he bashed me and split it open right here from hitting me in the head with a phone." *So, you're wondering which incident to think about*? "Right." *Well, it's your call.* "Then I would just go with the knot on my head."

In this example, the respondent had to think through the actual cause of the injury. Both incidents involved head injuries that resulted from her partner's physical violence, but she ultimately chose the episode where he directly hit her versus her inadvertently sustaining an injury by trying to escape a fight.

Another respondent also mentioned that two incidents came to mind, and it was not immediately obvious which one she should choose. She had to verbalize each experience to the interviewer in order to arrive at a decision. She said:

"Okay, let me describe both of them. The one that happened in 2016 an ex-boyfriend of mine pistol-whipped me. Which resulted in two of my teeth being knocked out. And the most recent situation he got upset because I didn't want to have sexual intercourse with him. So, he began to beat me up and choke me until I was unconscious. And when I did wake up, he was still punching me. So, I had a major concussion, two almost-broken ankles, and a very bad sprained wrist. Those were the two that had the most impact and damage." So which would you choose? "We can say the most recent. Because of concussion and damage to the face."

Both respondents seemed to arrive at the most appropriate injury, but it took some cognitive effort to make that decision.

Most Recent Experience: Another strategy for respondents with multiple experiences with head or anoxic brain injuries was to think of the most recent one. This group of respondents could not identify a single worst injury because such experiences occurred frequently over the course of many years. For example, one respondent, who experienced many violent incidents from early in her life, decided to think about the most recent one rather than trying to remember the single worst episode that might have occurred long ago. About being choked she said, "It was a couple years ago. But it has happened several times in the past, before that incident. It happened many times." When asked if she was thinking about the worst incident when answering the questions she said, "The most recent one. Because I had it

happen [repeatedly] at the age of 18 and then recently a couple years ago." Another respondent had the same experience and was unable to point to the single worst episode. She said, "It was more of the same thing. So, there wasn't like a particular incident that stood out. I could just point to the most recent one."

Overall Experience: A third strategy respondents used was to think of noteworthy head injuries, group them together, and answer for those experiences overall. These were respondents who simply could not identify a single worst injury because they were all too similar. As one respondent said, "That [choking] was kind of a go-to [for him]. That was all the time. Sometimes to where I literally cannot breathe. And I have not blacked out [because] he'll let go. He can see I'm about to pass out and let go." When pressed on whether she could identify the one worst episode, she could not. She said, "It's like it's so many...I've been about to pass out many times." She answered on the basis of those experiences overall. Another respondent offered a similar story. She said, "That was for a whole entire year. I was beaten every day. I didn't even go to my junior year of high school because he wouldn't let me." Another respondent said, "I'm just thinking about all of it. He done hit me plenty of times. So, I just think about all the times."

II. Reporting of Symptoms

After establishing the most severe injury/incident, respondents are asked a battery of questions about symptoms they experience after (and because of) this injury/incident. Respondents were mostly able to answer these questions with ease, however, a few difficulties and complications did arise.

Memory Lapses

Some respondents did not have full memory of their experiences. Ironically, this was often due to the injury itself. One respondent remarked, "Well, it wasn't that easy to remember...And for me, I feel very bad...and the memories aren't coming back." Another respondent also continues to struggle with long term memory loss due to her most severe head injury. What she knows about the incident she essentially learned from the person who assaulted her. She said:

"I've gone over this with my therapist. I don't remember. He [her partner] actually told me that he took my head – we were in a back alley – and he slammed me against the wall. And I don't actually remember him hitting me. What I do remember is laying on the ground and I had blood coming out of my head. And then I went to the hospital. When I got released, I remember putting my hand here [touches side of head] and it was literally the size of a baseball...We were traveling in a city. And I was still trying to put everything together and I couldn't. I don't even remember him slamming me [on the ground]."

Other respondents do not have clear memories of their most severe injury due to what they often described as being in "fight or flight mode" during the assault. Loss of memory was due less to physical causes (from the injury) and more to the psychological distress that comes from living through intimate partner violence. As a result of the emotional trauma, it was not always easy for respondents to report the nature of the symptoms they had at the time of the episode. Cognitive awareness of their symptoms at the time of the injury was simply not the priority; surviving was the priority. The following are examples:

"I remember him hitting me, but you don't really think about it [what your symptoms are] at the time."

"You can't diagnose yourself while you're having the experience."

"I think it was more because I was in 'fight or flight' mode trying to get away and figure out what to do. So, I think that's why I don't remember directly what happened after."

"In the moment I think I was just, I don't want to say 'fight or flight,' but I think I was just in frozen mode. I wasn't crying. I was just in shock."

"When you're being attacked, it's all about surviving...When you're in those situations, your priority is to live. And you don't think about your symptoms. You think about what you need to do to survive."

In these cases, some respondents took their best guess about whether they had a particular symptom. For example, one respondent relied on logic over memory. She said:

"I don't remember. But I'm going to speculate... If somebody takes your head and bashes it into wooden stairs six or seven times – my face was three times the size that it is now – there's no way in the world you don't have blurred vision... When I think about it, I do recall barely being able to hold onto the railing to walk down the stairs. So, I'm confident I had some level of dizziness."

Other respondents, rather than guess, chose the 'don't remember' option. As one respondent explained, "Immediately after I can't remember. That's why I was unsure [about how to answer]."

Timeframe Judgments: 'After the Incident'

The list of questions asking about symptoms (for both traumatic head injury and anoxic brain injury) are preceded by a timeframe of 'after the incident.' This timeframe is somewhat vague, and respondents interpreted it as symptoms experienced either in the moment or long-term, depending upon the nature of the symptom. Sometimes respondents admitted to being uncertain of the intent of the timeframe. One respondent asked, "Okay, is this question right then or within a time limit?" After the interviewer repeated the question (and the timeframe) she understood the timeframe as short-term and said, "Within 24 hours, yes." In another example, one respondent had such a severe injury that her symptoms were both immediate and long term. Seeing the potential for differences in symptoms over time, she explained her response dilemma:

"I know when I got home [from vacation where this event happened] you asked 'afterward.' After the injury. And I said 'no' to one of them, but I think it's because once I got home and checked by the doctor days after the incident happened, [she no longer had the symptom]. And then the ones that I answered 'yes' to, it was because it was literally in the timeframe of the incident. Right after it happened. Not days after. So that's why I said 'no' to one of them. But now that I'm hearing all the questions, I'm like, did I answer that right? Was that supposed to be when I got home or right after the situation happened?"

She was initially thinking about symptoms she had during and immediately after the incident. But as she heard the complete list of symptoms – including those that are noticed more in the long-term – she questioned and readjusted her initial understanding of the timeframe.

<u>In the moment</u>: Many respondents did not need to ask for clarity on the timeframe. They simply answered many of the symptom questions in terms of their experiences during (or shortly after) the episode. To a large extent this is because some of the symptoms are inherently transitory. For example, one question asks about feeling dizzy, clumsy, or having balance problems – symptoms likely to occur immediately after blunt trauma to the head. One respondent said, "Right afterwards, yes. You mean trying to get back on your feet after someone's punched you in the eye and you're laying out on the floor? I would say yes."

Some respondents sensed the timeframe ambiguity and felt the need to clarify to the interviewer the timeframe they were referencing. Usually this was because the symptoms were short-lived and no longer relevant. One respondent replied to 'feeling dazed, confused, or having trouble thinking straight' by clarifying, "I would say I did. But it was like immediately after the injury [not long term]." Similarly, another respondent mentioned several symptoms that were specifically experienced as immediate and short term. She said, "I did feel dizzy. I did feel clumsy. And blurry vision. I did feel that, but it wasn't for long. It was just when it happened."

<u>In the Long Term</u>: While many of the symptoms are associated with short term effects, others are more likely to be felt over an extended period of time. Symptoms related to memory and cognition fell into this category. For these questions respondents tended to think beyond the immediate violent attack and include long-term symptoms of the injury. For example, several respondents had 'trouble concentrating' well after the incident, saying, "Yes, I still do." Being 'dazed, confused, or having trouble thinking straight' is another example. One respondent said, "Well, it wasn't that easy to remember. It was a long time [ago]. And for me the memories [still] aren't coming back."

'Learning or remembering new things' was another example of a long-term symptom. One respondent has difficulty remembering dates and appointments among other things. She said, "Like now, still. I can't remember the whole early 2000's. My older kids talk to me about things that happened, and they have to keep on giving me details because I can't remember." Another respondent who answered 'yes' to this symptom was asked about the timeframe. She said, "That's what I was thinking – long term. Because four years ago I applied for disability, and they had me go meet with all these people. And I suspected I had memory loss. And they said you have short and long term [memory loss]. I've seen a neurologist."

It should be noted that Question 20 captured a variety of timeframes as well. This question asks whether respondents were examined by a doctor, nurse, paramedic, or other health professional 'after the injury.' Respondents included answers that were in the immediate aftermath ("Yeah, same day."), the next day ("I went to urgent care the following day."), several days later ("I had went to the doctor but probably a few days after it occurred."), or even a week later ("It was like a week later. I needed stitches but I didn't get them [right away]. I just superglued it shut.").

Emotional versus Physical Cause of Symptoms

There were some questions about symptoms that tended to direct respondents' thoughts away from the injury as the cause of a symptom and toward psychological distress as the cause of a symptom. In other words, while respondents may have had certain symptoms, these symptoms were not always understood as having their origins in the physical injury itself. This was especially true of the last two symptom-based questions (18 and 19 for intimate partner violence (section 1) and 47 and 48 for sexual assault (section 2)), which are:

Questions 18/47: Did you experience a change in mood or temperament such as irritability, or feel more emotional than usual?

Questions 19/48: Did you have trouble sleeping or were you more tired than usual?

Sometimes respondents interpreted these questions as relating to the emotional toll that this type of violence takes on a person, instead of focusing on the physical effects of the actual injury. The emotional toll was expressed several ways, including anger, sadness, shock, and fear. When respondents experienced these feelings, they often answered 'yes' to these two symptom questions in particular.

Anger: One pattern was for respondents to answer 'yes' to 18/47 because they were angry at and blamed themselves. One respondent explained that she answered 'yes,' "Because I was blaming myself instead of putting the blame on him. I guess I learned how to block things [his previous assaults] out of my brain. So, when you come back around, I'm not thinking, oh, he pretty much raped me before. That's why I was blaming myself." Another respondent who answered 'yes' expressed a similar feeling. She said, "I was just more irritated. I got kind of meaner. I shouldn't have let it get that far but I did, so I was mad at myself."

<u>Sadness and shock</u>: Other respondents expressed not anger but sadness or shock over what happened, both in the moment and long term, and answered 'yes' on this basis. One respondent said, "After that [experience] even to this day I still battle depression...There were times I thought my life was over because I left [him]. This was a high school sweetheart, turned fiancé, and we have two children together." Another respondent said, "Like I said, I was shocked, dazed and realized he'd hit me. So, I picked myself up off the floor and ran to the bathroom and cried. Men aren't supposed to hit women."

<u>Fear</u>: Some respondents answered 'yes' to 18/47 because it was fear that made them more emotional than usual. One respondent explained, "Because before and after of all of the emotions and thoughts. My mind was going 100 miles a minute of all those different emotions. Fear, being upset that this happened, and then the sad part thinking, oh my God, did my kids see this? And then the panic – what if I can't get away from him?" Another respondent answered, 'yes' to 19 and said, "You don't sleep [out of fear of being attacked]."

Other respondents also reported having trouble sleeping (question 19/48) due to emotional trauma, not necessarily the injury itself. One respondent said, "Um...I would say 'yes.' Just from tired of being abused." Another respondent said she had trouble sleeping for at least a month afterward because, "I was still thinking about all the events that happened."

Even other questions sometimes prompted respondents to think about the emotional fallout of interpersonal violence. For question 8 ('dazed, confused, or have trouble thinking straight'), a male respondent said, "Yes. I was a bit confused and dazed. And I think mostly because it wasn't her striking me. I think it was because that it actually happened. And it's, like, emotionally rough. And it's, like, the pain gets to be ten times more when you realize it's actually happening and who it's happening from." Overall, constructs measured by certain symptom questions included symptoms due to a specific physical injury *and* symptoms due to the emotional trauma of experiencing interpersonal violence in general.

III. Issues with Specific Questions

Questions 10 and 24: 'Were you knocked out or did you lose consciousness, even briefly?'

It can be difficult to understand the parameters of certain physical symptoms and, therefore, whether one has experienced them. This was evident for the notion of 'losing consciousness.' Some respondents had to piece together bits of information to arrive at the conclusion that they did in fact lose consciousness. One respondent ended up answering 'yes,' but expressed uncertainty with her answer. She said:

"That's the accident in the kitchen where he hit me so hard that I went against the refrigerator and just slid down on the floor. And that was a sense of just seeing stars...So when you see stars it's almost kind of like you're out of your body. So that's why I hesitated [when answering]. It's almost like you're losing consciousness in a way, but you still are aware to some extent."

She decided to answer 'yes' because she felt she was on the edge of consciousness, which was close enough to the intent of the question. Another respondent expressed similar hesitancy. When asked about it she said:

"I'm 90% [sure] that at one point I did pass out. Because I remember him slamming me against the door, choking me. And the part where he starts choking me, almost you start blacking out. You see colors. And then I don't remember much."

Because she does not remember the entire episode, she assumed her lack of memory was enough evidence to suggest that she did, indeed, lose consciousness.

Questions 21 and 50: [If respondent answered 'no' to 'After this injury, were you examined by a doctor, nurse, paramedic, or other health professional?'] 'Why not?'

One question asks whether respondents were seen by a doctor or other type of health care professional for the most severe injury they sustained. If they answer 'no,' the next question asks, 'Why not?' and includes a set of reasons, from which respondents may choose as many as applicable. The response categories are as follows:

- a. Didn't think the injury was serious
- b. Difficulty paying for it
- c. Did not have transportation
- d. Could not take time off work
- e. Prevented from seeking care by current or ex-partner
- f. Unable to seek care because of COVID-19
- g. Some other reason

Two reasons could be added to this list. The first is embarrassment. Multiple respondents mentioned this as their reason for not seeking medical attention for their injury. As one respondent said, "I guess at the time it happened I was too embarrassed to go out [to see a doctor]."

A second reason that could be added as a category is fear of involving the authorities. One respondent said, "I don't want to go through making it a domestic situation. Give me some pain killers, throw some ice on it and let's roll. It's a whole thing [to report incidents like this at the hospital]." Some respondents specifically mentioned the fear of potentially involving Child Protective Services if they went to the hospital. In a twist to involving authorities, one male respondent said he did not seek medical care because he was worried that HE would be blamed for the violent episode. He said, "I would've

probably been looked at as the bad guy. I just left it alone and left her alone and left it in the past and moved on with my life."

Question 34: 'You reported that someone used physical force or threats of harm to have, or try to have, vaginal, oral, or anal sex with you. Was your head or face ever injured during any of those incidents?'

Question 34 made a false assumption for a couple respondents who understood the term 'reported' as 'reported to the police.' For example, when answering, one respondent confirmed, "I did report it to the police." But another respondent with the same interpretation pointed out the false assumption she thought was being made by the question. She said, "No. Go back. I didn't." *Didn't what?* "With my husband forcing himself on me after threatening to kill me...and then wants to have sex with you, I didn't report that [to the police]."

This ambiguity might be alleviated by using the words 'you said' instead of 'you reported' in the question stem.

Question 35: 'How did you know the person who did this to you? Was this person... a current or former romantic or sexual partner or someone else?'

This is another question that makes a false assumption. The word 'person' suggests that the respondent was sexually assaulted by a single person, but some people experience more than one attacker. One respondent had this experience and said, "It was what I would call like a gang rape or something. Me in the middle with, like, eight guys." Even though the respondent did make that clarification to the interviewer, he chose the second option ('someone else') which he saw as reasonably accurate. However, that option may not be as appropriate for respondents who have had a sexual partner *and* 'someone else' sexually assault them at the same time.

IV. Unnecessarily Lengthy Instructions

In an attempt to ensure that question intent is accurately conveyed to survey respondents, the test instrument contained lengthy instructions prior to certain sections and questions. However, these instructions sometimes had the opposite of their intended effect. The lengthy wording was problematic in two ways. First, extensive reading by the interviewer sometimes causes respondents to mentally disengage until they heard an actual question. Second, emotionally laden topics were often repeated to the point that the survey came across as somewhat blunt and insensitive. As a result of these two issues, some of instructional language was shortened during testing.

The first example is the instruction between questions 6 ('In your lifetime, did you ever have an injury to your head or face because of the things your current or ex-partner did to you?') and 7 ('Approximately when did this injury occur?'). The instructions after question 6 read:

We are interested in learning about times in your lifetime when you experienced an injury to the head or face because of what a current or ex-partner did to you. Please think about the most severe injury to your head or face because of what a current or ex-partner did to you.

About halfway through testing the last clause of the last sentence was dropped so that the sentence simply read: 'Please think about the most severe injury to your head or face.' There was no observed decrease in respondent understanding as a result of this change.

A second modification was made to the instructions that precede the symptom questions, which begin at question 8 ('Were you dazed, confused or did you have trouble thinking straight?'). The instruction was:

Please continue thinking about the most severe injury to your head or face. In the next set of questions, I will ask about what you might have experienced soon after this injury. For each question, please indicate if it happened to you or not. We only want to know about things caused by the injury to your head or face or made worse by this injury. After this injury...

In the middle of testing, the second-to-last sentence ('We only want to know about things caused by the injury to your head or face or made worse by this injury.') was omitted altogether. This change did not have any effect on respondents' understandings of the symptom questions.

Third, the battery of symptom questions contained a repeated script between questions 19 ('Did you have trouble sleeping or were you more tired than usual?') and 20 ('After this injury, were you examined by a doctor, nurse, paramedic, or other health professional?'). The instruction before question 20 read: 'Please think about the most severe injury to your head or face because of what a current or ex-partner did to you.' This instruction proved unnecessary, as respondents had already been thinking of the most severe injury. It was omitted with no deleterious effect on respondents' understandings – they continued to think about their most severe injury.

Finally, question 22 asks: 'In your lifetime, has a current or ex-romantic or sexual partner ever put their hands around your neck, put something over your mouth, or done anything else that made you feel choked, strangled, suffocated, or like you couldn't breathe?' Respondents who answer 'yes' are then read the following instruction before hearing question 23:

Please think about the most severe time that this happened. That is, when a current or exromantic or sexual partner put their hands around your neck, put something over your mouth, or did anything else that made you feel choked, strangled, suffocated, or like you couldn't breathe.

This was both lengthy and potentially insensitive due to its literal repetition of the question that had been asked only a moment prior. Therefore, the instruction was shorted to: 'Please think about the most severe time that this happened.' Similar to the previous modifications, the deletion of the second sentenced had no ill effect on respondent comprehension.

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APPENDIX: COGNITIVE INTERVIEW TEST INSTRUMENT

| [DEMOGRAPHIC (| DUESTIONS: | NO PROBING |
|----------------|------------|------------|
| | | |

| First, how | old are | you? | Age | |
|------------|---------|------|-----|--|
|------------|---------|------|-----|--|

Are you:

- a. Female
- b. Male
- c. Transgender, non-binary or another gender identity

Are you Spanish, Hispanic, or Latino?

- a. Yes
- b. No

What is your race? You may choose more than one category.

- a. White
- b. Black or African American
- c. Asian
- d. Native Hawaiian or Other Pacific Islander
- e. American Indian or Alaska Native

Are you now...?

- a. Married
- b. Divorced
- c. Separated
- d. Widowed
- e. Not married but living with a partner
- f. Never married

[SECTION 1: INTIMATE PARTNER VIOLENCE - TRAUMATIC BRAIN INJURY]

The next set of questions ask about experiences that can directly impact your health or may have resulted in injury. You may find that some of the questions are sensitive. Remember you may choose not to answer any question for any reason. If you do not want to answer a question, say so, and we will move on to the next one. You may also stop the interview at any time. In your <u>lifetime</u>, has a current or ex-romantic or sexual partner ever done any of the following things to you on purpose?

| 1. | Slapped, pushed, or shoved you? | Yes | No |
|----|--|-----|----|
| 2. | Hit you with a fist or something hard? | Yes | No |
| 3. | Kicked or stomped on you? | Yes | No |
| 4. | Slammed you against something to hurt you? | Yes | No |
| 5. | Hit you in the head or made you hit your head on another object? | Yes | No |

[IF YES TO ANY OF THE ABOVE, CONTINUE; IF NO TO ALL, GO TO ANOXIC BRAIN INJURY]

- 6. In your lifetime, did you ever have an injury to your head or face because of the things your current or expartner did to you?
 - a. Yes
 - b. No [go to anoxic brain injury section]

Collaborating Center for Questionnaire Design and Evaluation Research

[Head/Face Injury Section Intro] We are interested in learning about times in your lifetime when you experienced an injury to the head or face because of what a current or ex-partner did to you. Please think about the most severe injury to your head or face because of what a current or ex-partner did to you.

- 7. Approximately when did this injury occur?
 - a. Within the last 12 months, since (date)
 - b. 1-3 years ago
 - c. 4-7 years ago
 - d. More than 8 years ago

[Signs/Symptoms Intro] Please continue thinking about the most severe injury to your head or face. In the next set of questions, I will ask about what you might have experienced soon after this injury. For each question, please indicate if it happened to you or not. We only want to know about things caused by the injury to your head or face or made worse by this injury. After this injury...

- 8. Were you dazed, confused or did you have trouble thinking straight?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 9. Did you have difficulty remembering what happened just before or after the head injury?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 10. Were you knocked out or did you lose consciousness, even briefly?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember

After this injury...

- 11. Did you feel sick to your stomach, or did you vomit?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 12. Did you have a headache?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 13. Was there ever a time when you were dizzy, clumsy, or had balance problems?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 14. Did you have blurred or double vision, or other changes in your vision?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember

After this injury...

- 15. Did you have trouble concentrating?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 16. Did you have difficulty learning or remembering new things?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 17. Were you more sensitive than usual to either light or noise?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember

After this injury...

- 18. Did you experience a change in mood or temperament such as irritability, or feel more emotional than usual?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 19. Did you have trouble sleeping or were you more tired than usual?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember

[Follow-up / Contextual Questions (if they said yes to any of the symptoms)] Please think about the most severe injury to your head or face because of what a current or ex-partner did to you.

- 20. After this injury, were you examined by a doctor, nurse, paramedic, or other health professional?
 - a. Yes
 - b. No (go to #21)
 - c. Not sure/Don't remember
- 21. Why not? (Check all that apply)
 - h. Didn't think the injury was serious
 - i. Difficulty paying for it
 - j. Did not have transportation
 - k. Could not take time off work
 - 1. Prevented from seeking care by current or ex-partner
 - m. Unable to seek care because of COVID-19 (?)
 - n. Some other reason

[INTIMATE PARTNER VIOLENCE ANOXIC BRAIN INJURY]

Now I will ask you about other experiences you might have had with a current or former intimate partner.

- 22. In your <u>lifetime</u>, has a current or ex-romantic or sexual partner ever put their hands around your neck, put something over your mouth, or done anything else that made you feel choked, strangled, suffocated, or like you couldn't breathe?
 - a. Yes (go to Q23)

- b. No (go to sexual violence section)
- c. Not sure/Don't remember (go to sexual violence section)

Please think about the most severe time that this happened. That is, when a current or ex-romantic or sexual partner put their hands around your neck, put something over your mouth, or did anything else that made you feel choked, strangled, suffocated, or like you couldn't breathe.

- 23. Approximately when did this incident occur?
 - a. Within the last 12 months, since [fill date]
 - b. 1-3 years ago
 - c. 4-7 years ago
 - d. More than 8 years ago

[Signs/Symptoms Intro] In the next set of questions, I will ask about what you might have experienced soon after this happened. For each question, please indicate if it happened to you or not. We only want to know about things caused by the incident or made worse by it. After this incident...

- 24. Did you lose consciousness or pass out, even briefly?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 25. Were you dazed, confused or did you have trouble thinking straight?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 26. Did you have difficulty remembering what happened just before or after the incident?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 27. Did you experience a seizure, not explained by a pre-existing seizure disorder?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember

After this incident...

- 28. Did you lose control of your bladder or bowels (accidentally pee or poop on yourself)?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 29. Did you see stars or spots or have blurred, double or tunnel vision?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 30. Did you have ringing in your ears or experience decreased ability to hear?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember

- 31. Did you feel dizzy, clumsy or have balance problems?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember

[SEXUAL VIOLENCE: NO PROBES]

Next are some detailed questions about times in your life when you may have experienced unwanted sexual situations with anyone, including strangers or someone you knew such as a romantic or sexual partner, a family member, a friend, teacher, co-worker or supervisor, or someone you have known for only a short time. These questions are detailed, and the language is explicit, which some people may find upsetting. It is important that the questions are asked this way so that you understand what we mean. Remember you may choose not to answer any question for any reason. If you do not want to answer a question, say so, and we will move on to the next one. You may also stop the interview at any time.

Some people are threatened with harm or physically forced to have sex or sexual contact when they don't want to. Examples of physical force are being pinned or held down, using violence or threats of violence, or not physically stopping after you said no. To be clear, the next questions are asking only about times in your life when sex was unwanted, and you did not give consent.

Females only:

- 32. In your LIFETIME, has anyone ever penetrated you by putting their penis in your vagina, mouth, or anus when you did NOT consent to it, and it was not wanted, by using physical force or threats of physical harm? (Examples of physical force are being pinned or held down, using violence or threats of violence, or not physically stopping after you said no).
- a. Yes
- b. No
- 33. In your LIFETIME, <u>has anyone</u> EVER used physical force or threats of physical harm to TRY to put their penis in your vagina, mouth, or anus, but it DID NOT happen? (Examples of physical force are being pinned or held down, using violence or threats of violence, or not physically stopping after you said no).
- a. Yes
- b. No

[IF YES TO 32 OR 33, THEN CONTINUE TO NEXT SECTION; IF NO TO BOTH, END SURVEY]

Males only:

- 32. In your LIFETIME, has anyone ever penetrated you by putting their penis in your mouth or anus when you did NOT consent to it, and it was not wanted, by using physical force or threats of physical harm? (Examples of physical force are being pinned or held down, using violence or threats of violence, or not physically stopping after you said no).
- a. Yes
- b. No
- 33. In your LIFETIME, has anyone EVER used physical force or threats of physical harm to TRY to put their penis in your mouth or anus, but it DID NOT happen? (Examples of physical force are being pinned or held down, using violence or threats of violence, or not physically stopping after you said no).
- a. Yes
- b. No

[IF YES TO 32 OR 33, THEN CONTINUE TO NEXT SECTION; IF NO TO BOTH, END SURVEY]

[SECTION 2: SEXUAL VIOLENCE TRAUMATIC BRAIN INJURY]

- 34. You reported that someone used physical force or threats of harm to have, or try to have, vaginal, oral, or anal sex with you. Was your head or face ever injured during any of those incidents?
 - a. Yes [go to next question]
 - b. No [go to anoxic brain injury section pg. 9]

[Head/Face Injury Section Introduction] Please think about the most significant injury to your head or face that happened because someone used physical force or threats of harm to have, or try to have vaginal, oral, or anal sex with you.

- 35. How did you know the person who did this to you? Was this person...
 - a. a current or former romantic or sexual partner
 - b. someone else
- 36. Approximately when did this injury occur?
 - a. Within the last 12 months, since (fill date)
 - b. 1-3 years ago
 - c. 4-7 years ago
 - d. More than 8 years ago

[Signs/Symptoms Intro] Please continue thinking about the most significant injury to your head or face. In the next set of questions, I will ask about what you might have experienced soon after this injury. For each question, please indicate if it happened to you or not. We only want to know about things caused by the injury to your head or face or made worse by this injury. After this injury...

- 37. Were you dazed, confused or did you have trouble thinking straight?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 38. Did you have difficulty remembering what happened just before or after the head injury?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 39. Were you knocked out or did you lose consciousness, even briefly?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember

After this injury...

- 40. Did you feel sick to your stomach, or did you vomit?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 41. Did you have a headache?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember

- 42. Was there ever a time when you were dizzy, clumsy or had balance problems?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 43. Did you have blurred or double vision, or other changes in your vision?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember

After this injury...

- 44. Did you have trouble concentrating?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 45. Did you have difficulty learning or remembering new things?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 46. Were you more sensitive than usual to either light or noise?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember

After this injury...

- 47. Did you experience a change in mood or temperament such as irritability, or feel more emotional than usual?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 48. Did you have trouble sleeping or were you more tired than usual?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember

[Follow-up / Contextual Questions (if they said yes to any of the symptoms)] Please continue thinking about the most significant injury to your head or face that happened because someone used physical force or threats of harm to have, or try to have vaginal, oral, or anal sex with you.

- 49. After this injury, were you examined by a doctor, nurse, paramedic, or other health professional?
 - a. Yes
 - b. No (go to #50)
 - c. Not sure/Don't remember
- 50. Why not? (Check all that apply)
 - a. Didn't think the injury was serious
 - b. Difficulty paying for it
 - c. Did not have transportation

- d. Could not take time off work
- e. Prevented from seeking care by current or ex-partner
- f. Unable to seek care because of COVID-19 (?)
- g. Some other reason

[SEXUAL VIOLENCE ANOXIC BRAIN INJURY]

You reported that someone used physical force or threats of physical harm to have, or try to have vaginal, oral, or anal sex with you. Now I will ask you about other experiences you might have had when this happened. This might be a different experience from what you reported earlier.

- 51. In your lifetime, did someone ever put their hands around your neck, put something over your mouth, or do anything else that made you feel choked, strangled, suffocated, or like you couldn't breathe during unwanted vaginal, oral, or anal sex?
 - a. Yes [go to next question]
 - b. No [End survey]
 - c. Not sure/don't remember [End survey]

Please think about the most significant time that this happened.

- 52. How did you know the person who did this to you? Was this person...
 - a. A current or former romantic or sexual partner
 - b. Someone else
- 53. Approximately when did this incident occur?
 - a. Within the last 12 months, since (date)
 - b. 1-3 years ago
 - c. 4-7 years ago
 - d. More than 8 years ago

[Signs/Symptoms Intro] In the next set of questions, I will be asking you about what you might have experienced soon after this incident. For each question, please indicate if it happened to you or not. We only want to know about things caused by the incident or made worse by it. After this incident...

- 54. Did you lose consciousness or pass out, even briefly?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 55. Were you dazed, confused or did you have trouble thinking straight?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 56. Did you have difficulty remembering what happened just before or after the incident?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 57. Did you experience a seizure, not explained by a pre-existing seizure disorder?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember

- 58. Did you lose control of your bladder or bowels (accidentally pee or poop on yourself)?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 59. Did you see stars or spots or have blurred, double or tunnel vision?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 60. Did you have ringing in your ears or experience decreased ability to hear?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember
- 61. Did you feel dizzy, clumsy, or have balance problems?
 - a. Yes
 - b. No
 - c. Not sure/Don't remember