

The Intersection of Intimate Partner Violence and Traumatic Brain Injury: Findings From an Emergency Summit Addressing System-Level Changes to Better Support Women Survivors

Danielle Tocalino, MSc; Halina (Lin) Haag, MSW, RSW; Maria Jennifer Estrella, MScOT; Stephanie Cowle, BA; Pamela Fuselli, MSc; Michael J. Ellis, MD; Judith Gargaro, MEd; Angela Colantonio, PhD, OT, Reg (Ont.); and the COVID TBI-IPV Consortium

Background: Traumatic brain injury (TBI) occurring during intimate partner violence (IPV) is a largely unrecognized but significant public health crisis. One in 3 women will experience IPV in their lifetime, up to 75% of whom will sustain a TBI as a result. This article reports on the systems-level findings from a national summit to address barriers, needs, and priorities related to healthcare and support services for women survivors of IPV-TBI. **Objectives:** (1) To identify key needs, facilitators, and barriers to care for women survivors of IPV presenting with TBI; and (2) to cocreate ideas for resources and principles for identification, clinical care, and support for healthcare practitioners who treat women exposed to IPV and TBI. **Methods:** Using a community-based participatory research approach, we engaged 30 stakeholders—drawn from a national IPV-TBI Knowledge-to-Practice (K2P) Network including diverse

Author Affiliations: Institute of Health Policy, Management and Evaluation (Ms Tocalino and Dr Colantonio), Rehabilitation Sciences Institute (Ms Estrella and Dr Colantonio), Department of Occupational Science & Occupational Therapy (Dr Colantonio), and Dalla Lana School of Public Health (Dr Colantonio), University of Toronto, Toronto, Ontario, Canada; Lyle S. Hallman Faculty of Social Work, Wilfrid Laurier University, Waterloo, Ontario, Canada (Ms Haag and Dr Colantonio); KITE-Toronto Rehabilitation Institute, University Health Network, Toronto, Ontario, Canada (Mss Haag and Gargaro and Dr Colantonio); Parachute, Toronto, Ontario, Canada (Mss Cowle and Fuselli); Pan Am Concussion Program, Section of Neurosurgery, Department of Surgery, University of Manitoba, Winnipeg, Manitoba, Canada (Dr Ellis); and Ontario Neurotrauma Foundation, Toronto, Ontario, Canada (Ms Gargaro).

Author Contributions: This study was conceptualized and designed by Colantonio, Haag, Cowle, Fuselli and Ellis, who then organized the summit with the support of Tocalino and Gargaro. Data were collected by Haag, Tocalino, Estrella, and Cowle. Tocalino, Estrella, Haag, and Cowle coded and analyzed the data which was then reviewed and approved by the remainder of the research team. Estrella and Tocalino drafted the manuscript, which was then critically revised and approved by all authors.

This research was funded by the Community Foundations of Canada's Emergency Community Support Fund with support from a Canada Research Chair in Underserved Populations held by Dr Colantonio.

This work would not have been possible without the active participation and engagement of the stakeholders, included in the authorship as the "COVID TBI-IPV Consortium." These stakeholders include the following: Hilda Anderson-Pyrz, Manager, Missing and Murdered Indigenous Women and Girls Liaison Unit, Manitoba Keewatinowin Okimakanak Inc; Michelle Bartlett McLaughlin; Shirley Broekstra, MEd, RN; Nora Cullen; Tori

Dach, Geoffrey Sing, and Candace Stretch, The Cridge Centre for the Family; DAWN Canada (DisAbleD Women's Network of Canada); Kathleen Jodouin; Melissa Kimber, McMaster University; Sheila Macdonald, Director, Ontario Network of Sexual Assault/Domestic Violence Treatment Centres; Nneka MacGregor; Michelle McDonald, Brain Injury Canada; Nadia Noor, Pauktuutit Inuit Women of Canada; Kix Citton, Nanaimo Brain Injury Society (Nanaimo, British Columbia, Canada); Jade Byard Peek, Director of Advocacy, Kind Space (Ottawa, Ontario, Canada); Maud Pontel, L'Alliance des maisons de 2e étape pour femmes et enfants victimes de violence conjugale; Heather Imming, Survivor, Ontario Office for Victims of Crime; Jean Quinn, Survivor, Kingston Anti-Violence Advisory Council, Kingston Chapter of Women at the Centre; Deirdre Reddick, Kingston Anti-Violence Advisory Council, Kingston Chapter of Women at the Centre; Silvia Samsa; Reema Shafi; Leslie Spillett; Lyn Turkstra, McMaster University; Melissa Vigar; Ruth Wilcock; Catherine Wiseman-Hakes, McMaster University, KITE Research Institute, UHN-Toronto Rehabilitation Institute.

The authors also thank Vincy Chan, Amy Moore, Samira Omar, and Kristen Reilly for their support during the summits.

The authors declare no conflicts of interest.

This is an open-access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives License 4.0 (CCBY-NC-ND), where it is permissible to download and share the work provided it is properly cited. The work cannot be changed in any way or used commercially without permission from the journal.

Corresponding Author: Danielle Tocalino, MSc, Institute of Health Policy, Management and Evaluation, University of Toronto, 500 University Ave, Toronto, ON M5G 1V7, Canada (danielle.tocalino@mail.utoronto.ca).

DOI: 10.1097/HTR.0000000000000743

women survivors, service providers, researchers, and decision makers—in 2 half-day virtual meetings. Data were gathered through small group breakout sessions using semistructured discussion guides. Sessions were recorded, transcribed verbatim, and analyzed using thematic analysis techniques. Stakeholders contributed to the analysis and knowledge translation through member-checking activities. Ethics approval was obtained through the University of Toronto. **Findings:** Three main systems-level themes arose during these discussions: (1) the need for trauma-informed, anti-racist, and equitable health and social care systems; (2) the need for cross-pollination of knowledge between disciplines; and (3) the need for systems-level support for integrated and coordinated care. This article explores these needs and provides recommendations and suggestions for paths forward. **Conclusions:** The findings of this project enhance understanding of system-level needs among women survivors and provide a template for a national agenda for IPV-TBI research and practice. **Key words:** *care systems, intimate partner violence, traumatic brain injury*

ONE IN 3 WOMEN EXPERIENCE INTIMATE PARTNER VIOLENCE (IPV) in their lifetime.^{1,2} This public health crisis is a significant cause of physical injury, most commonly involving hits to the head, face, and neck, including nonfatal strangulation,³ a pattern of violence leaving survivors vulnerable to traumatic brain injury (TBI).⁴ Based on violence history and symptom reports, up to 75% of women survivors of IPV are living with probable TBI.⁴⁻⁷ Intimate partner violence can impact individuals of any gender; however, the majority of survivors are women, including cisgender and transgender women.⁸⁻¹⁰ This informed our focus on women survivors of IPV.

While women experiencing IPV are at a high risk of TBI, women with TBI and other disabilities are at an even greater risk of experiencing IPV.^{11,12} Indigenous women are at particularly high risk, reporting 2.5 times higher rates and more severe or potentially life-threatening forms of violence.¹³ In 2014, 93% of victims who reported incidents of IPV in Canada's northern territories suffered the most severe forms of spousal violence; that is, having been beaten, strangled, threatened with a weapon, or sexually assaulted.¹⁴ The National Inquiry into Missing and Murdered Indigenous Women and Girls determined violence against Indigenous women to be gender-based genocide.¹⁵ Black women, in addition to the increased risk of IPV, have been shown to have a particularly high burden of health and mental health concerns resulting from the violence.¹⁶ A 2014 review highlighted evidence of health inequities associated with both minority ethnicity and IPV, suggesting that an intersectional approach is required to mitigate disparities in health outcomes.¹⁷ However, there has been minimal inquiry to date considering these intersections.

Individually, both TBI and IPV are associated with substantial physical, cognitive, and mental health impacts, as well as significant negative economic and social implications.^{5,18-25} Combined, the impacts of both TBI and IPV are exacerbated and can lead to longer-term disability if left untreated.^{5,20,23,26-29} Despite the high degree of intersection, the significant implications of IPV and TBI, and women affected by TBI identifying

the intersection as a high priority,^{30,31} this intersection has been largely overlooked in research, practice, and policy arenas,^{6,7,32-34} with the majority of the work to date published in the last 5 years.^{6,7}

The lack of evidence regarding the intersection of TBI and IPV (IPV-TBI) is a long-standing problem and suggests that many survivors continue to live unaware of their brain injuries and thus lack the significant supports necessary for their well-being and recovery. Lack of awareness, gaps in screening for TBI, and unique challenges in accessing healthcare often leave TBI unidentified in IPV survivors.³⁵ This hinders identification and support⁶ and complicates the provision of and access to appropriate services.^{23,35-37}

With support of Parachute's project funding through the Community Foundations of Canada's Emergency Community Support fund and a Canada Research Chair in Underserved Populations held by Dr Colantonio, the research team convened a national emergency summit. This summit brought together service providers, survivors, and researchers from the IPV, TBI, and healthcare sectors to (1) identify key needs, facilitators, and barriers to care for women survivors of IPV presenting with TBI, both specific to the COVID-19 pandemic and more broadly, and (2) cocreate ideas for resources and principles for identification, clinical care, and support for healthcare practitioners who treat women exposed to IPV-TBI. As the discussions around these topics were rich, the findings from these summits are reported in 3 separate manuscripts: one focusing on COVID-19-specific findings (publication forthcoming), one on service implications, and one on systems-level implications. This article focuses on the systems-level implications.

METHODS

An emergency summit consisting of two 4-hour virtual meetings in November and December 2020 was convened with key stakeholders from the IPV, TBI, and healthcare sectors using a community-based participatory research approach.^{38,39} Approval for this research

was granted by the Research Ethics Board at the University of Toronto (protocol #39927).

Participants and recruitment

Participants included key stakeholders recruited directly from a Knowledge-to-Practice (K2P) Network and individuals identified using snowball sampling. The K2P Network is an informal, pan-Canadian network of service providers, persons with lived experience, decision makers, and researchers who have expertise in healthcare delivery, gender-based violence, IPV, and/or TBI. This network has been developed by members of the research team from the Acquired Brain Injury Research Laboratory at the University of Toronto since 2015.³⁵ Interested stakeholders were provided study information including the consent package, a demographic questionnaire, and discussion questions. Resources for emotional support were also provided. Participants provided written informed consent before participating in the summits and were able to stop their participation and/or remove their data at any point up to the publication of the manuscript. At the time of publication, no participants have withdrawn from the study.

Participants included stakeholders from the IPV, TBI, and healthcare sectors as well as population-specific advocacy organizations. Most stakeholders participated in one or both virtual summits, with 3 participating through written comments. Stakeholders predominantly self-identified as working in TBI or IPV advocacy or support, with an average of 17.4 ± 8.3 years of experience in their sector. As is common in advocacy

and support organizations, many participants identified as IPV and/or TBI survivors. Most participants were women (93%); 67% identified as White and 26% identified as having a disability. Stakeholder characteristics are displayed in Table 1.

Data collection and analysis

Members of the research team facilitated 40- to 60-minute breakout sessions and group discussions with guiding questions designed to obtain in-depth information on the following topics: knowledge and service gaps, knowledge transfer tools and approaches, service provision and implementation, and COVID-19-related impacts. An online polling platform, Mentimeter (<https://www.mentimeter.com>, herein “Mentimeter polling”), was used to collect feedback in real time to allow stakeholders to prioritize topics being discussed. Notes and syntheses were developed as the discussion was ongoing to allow for post-meeting review. Discussions were audio-recorded and transcribed verbatim by an external transcription service.

Transcripts, notes, and written comments provided by stakeholders were analyzed using thematic analysis techniques by 3 members of the research team trained in qualitative research methods (Toccalino, Estrella, Haag).^{40–42} Summit notes were first synthesized into one document (Toccalino). A master coding scheme was then developed from this document (Estrella), reviewed, and approved by all members of the research team. Data from summit transcripts were coded manually using this coding scheme (Estrella) and reviewed by the research

TABLE 1 Stakeholder characteristics

Professional characteristics	N = 27 ^a	%	Personal characteristics	N = 27 ^a	%
Sector ^b			Gender		
TBI direct service	9	33%	Women	25	93%
TBI advocacy/support	11	41%	Men	2	7%
IPV direct service	3	11%	Identity ^b		
IPV advocacy/support	10	37%	Black	3	11%
Other	9	33%	Indigenous	2	7%
Years worked in the sector ^c	17.35	8.25	White	18	67%
Focus of work/Primary clientele ^b			Non-Black or non-Indigenous POC	3	11%
Individuals with disability	10	37%	Immigrant	2	7%
Indigenous peoples	5	19%	LGBTQ2S	2	7%
Black community	4	15%	Disability	7	26%
Refugees or Immigrants	3	11%			
Other	8	30%			

Abbreviations: IPV, intimate partner violence; LGBTQ2S, lesbian, gay, bisexual, transgender, queer and questioning, and two spirit; POC, people of color; TBI, traumatic brain injury.

^aDemographic forms missing from 3 participants.

^bSome stakeholders represented more than once.

^cReported as mean and SD.

team. Transcripts were repeatedly read and discussed across several research team meetings. Data were continuously coded and recoded, and categories were revised as needed. Multiple versions of the files with comments were created to serve as an audit trail. Agreement on the final coding and themes was achieved across the research team. Synthesized member checking, a method of member checking where both raw and synthesized data are returned to participants,⁴³ was used during and after the summit meetings to ensure the credibility and the dependability of the analysis. Synthesized member-checking occurred throughout the analysis, including gathering feedback on a summary of the findings including quote material from the summit and drafts of the manuscript.

FINDINGS

Throughout the 2 days of the summit, stakeholders emphasized several systems-level needs and priorities for IPV survivors with TBI. Stakeholders also provided suggestions for ameliorating existing systems and developing new ones. The findings of these discussions are reported here, organized into 3 main themes: (1) the need for trauma-informed, anti-racist, and equitable health and social care systems (supporting quotes in Table 2); (2) the need for cross-pollination of knowledge across disciplines (supporting quotes in Table 3); and (3) the need for systems-level support for integrated and coordinated care (supporting quotes in Table 4).

Trauma-informed, anti-racist, and equitable care

A common theme identified throughout both days of summit discussions was the need for systems of care that are attuned to the intersectional and diverse needs of survivors of IPV-TBI across the country. Trauma- and violence-informed resources ranked as a priority among the top resource gaps, and inclusive and diverse research ranked as the primary research gap that should be addressed based on Mentimeter polling during the summits. Stakeholders spoke of the systemic racism experienced by Black and Indigenous women, including survivors of IPV-TBI; the underaddressed and undetected needs of immigrant and refugee communities; the lack of healthcare in rural, remote, and Indigenous communities; the lack of understanding of trauma and disability; and the basic needs of survivors that are currently not being met. Racist and prejudiced assumptions by service providers were reported to create barriers to access and negative experiences with healthcare. Women survivors who experience other intersecting marginalizations, such as identifying as Black, Indigenous, immigrants, or refugees, are often either not seen or dismissed altogether, which can discourage them from seeking care in the future. It was further identified that symptoms of TBI can be used to reinforce systemic racism, stigma, and discrimination, impacting survivors' access to care. One example provided was assuming intoxication when a survivor presents with the symptoms of TBI.

TABLE 2 Stakeholder quotes—Trauma-informed, anti-racist, and equitable care

- “One of the key things that we have found [within Black youth engagement] was an inability to have Black health professionals, or people who represent or are from their community [...] and so specifically if their injury or the aspect of the gender-based violence that they’re experiencing is in regards to race, often that is dismissed [...] past experiences with racism within the healthcare system often prevents Black women from ever wanting to return.”
- “With all that pre-judgment and prejudice and discrimination and micro-aggressions that happen, how something then gets documented and qualifies somebody for services, can be completely skewed, based on that reaction or judgment.”
- “There is that fear that with the trauma that women aren’t going to be able to care for their children or that sort of thing. So recognizing the effects of both trauma as well as TBI and how as long as we’re supporting the women and having them—that they’re getting the care that they need that they can still care for their children, that this is not something that they should be further victimized by. Or that their children should suffer either from having their family broken apart even further.”
- “This is now a critically important consideration, intersectionality of race and gender, and how this—I have to say it—how colonial Canada is complicit in so many ways around creating a set of social circumstances [...] the history of Canada and its impact, particularly on gender violence that Indigenous women experience.”
- “And to also, you know, come from a holistic care model that there’s a circle of care surrounding this individual once it’s been identified that they have a TBI [...] if we’re just going with saying to them, you know, this is what we’ve noted, but also if we have a really empowering and strengthening approach to this, it will make a world of difference to the individual. Because this is overwhelming news, right, to learn that you have a brain injury and how that will impact your life.”

Abbreviation: TBI, traumatic brain injury.

Stakeholders called for a person-centered, trauma-informed, culturally sensitive, and nonjudgmental approach when identifying and supporting survivors that involves understanding the dynamics of IPV. Systemic changes to services and programs are needed to recognize existing group disparities, intersections (eg, race/ethnicity, mental health, substance use), and challenges that are amplified among marginalized groups (eg, poverty, trauma, lack of resources, social and state violence, lack of infrastructure, geographic isolation) and, more specifically, the colonial history of Canada and its impact on IPV among Indigenous women. Building diversity and accountability structures into healthcare systems was identified as a priority. Concrete suggestions to build diversity into systems include ensuring that services are trauma-informed, culturally relevant, and available in minority languages. Stakeholders also called for practices and structures that would facilitate increased diversity among healthcare professionals so that women can see themselves reflected in those providing their care. Recommendations regarding accountability structures include introducing complaint mechanisms or evaluations on service standards that are measured and acted upon to ensure that diversity and intersectionality remain at the forefront of IPV-TBI care.

While many of the conversations centered upon systems of care and services directly related to IPV and/or TBI, stakeholders also emphasized the importance of systemic support for survivors in meeting basic needs more broadly to ensure equitable access to services, most notably for survivors living in rural, remote, and Indigenous communities or who are experiencing poverty.

Stakeholders explained that survivors who have limited financial resources may not even consider treatment if they do not have the capacity to meet daily living needs, such as food, shelter, and transportation. Without housing and accompanying supports, women are left unable to leave violent living situations and unable to access services. Stakeholders called for policy changes that would facilitate immediate financial assistance or guaranteed income, the inclusion of rehabilitation costs in the national healthcare plan, and a national strategy for addressing homelessness. Technological barriers, specifically the lack of availability and affordability of suitable technological devices and Wi-Fi, were also noted as hindering survivors from receiving virtual care. This was noted as particularly problematic during the pandemic due to increased reliance on virtual care, which is further discussed elsewhere (forthcoming data from the authorship team). Furthermore, stakeholders reported many survivors are without access to primary care and most are without access to extended health benefits and rehabilitation. These healthcare-related barriers are felt even more profoundly in rural, remote, and Indigenous communities due to the lack of infrastructure, with many of these areas having limited to no physicians, community health centers, or hospitals.

“Cross-pollination”: Increasing intrasectoral education and training

The need for cross-pollination, or more general awareness of the IPV-TBI intersection at the systems level across sectors, was emphasized to enable better support

TABLE 3 *Stakeholder quotes—Cross-pollination: Increasing education and training*

- “Even if you work in the emergency department, you don’t always get this information, but it wasn’t until after I left the nursing field that I learned about this. So I think that this is something that really needs to be brought forward to the frontline workers. Be it in healthcare, be it in shelters, I think it’s an area that’s missing and there are some opportunities through the professional organizations.”
- “I think one of the things that is very difficult in terms of connecting with the medical community is just getting your foot in the door to who to have the conversations with [. . .] I think it’s really about those like upper-level bodies that are doing the educating, that are doing the training.”
- “You have to understand the context, the dynamic of the violence to understand why and how. So for me, I really see like the need to put the IPV and TBI together [automatically] when it comes to training for people to understand that it’s not a separate situation. It’s a combined situation and we have to work through it.”
- “I also think primary care providers, family physicians, nurse practitioners, community health centers where—yeah, because lots of people won’t be coming to the emergency department, but they might say at some point, the primary care provider who could be asking about, you know, symptoms and—etcetera, or whatever the person’s presenting in, and so I think there’s a broader reach into healthcare.”
- “I mean we’ve just heard from previous speakers that every professional is going to come in contact with someone who’s been impacted by IPV if they’re a frontline healthcare provider [. . .] I think there needs to be a multilevel approach here to education and how we disseminate the education and resources, because I think what I’m increasingly learning—and it’s very frustrating—is that if we don’t tell people they have to worry about this and make it required in some way, it’s not going to happen.”

for survivors both through education and cross-sectoral referrals. Stakeholders identified specific educational needs, such as awareness of possible IPV among women and its indicators, an understanding of the dynamics of IPV and its relation to TBI, and training on how to ask about IPV-TBI. Stakeholders stressed the importance of aiming broader by formally educating and training the many different professionals who are likely to interact with women survivors of IPV and TBI. These included physicians (eg, family doctors and emergency department doctors), allied health professionals (eg, nurses, rehabilitation professionals), shelter and case workers, professionals from youth protection services, mental health professionals in both public and private sectors, probation or parole officers, paramedics, hotline workers, and government officials. Frontline healthcare workers in particular were ranked as the highest priority audience after survivors for education based on Mentimeter polling from the summits.

There was general agreement among participants that “every professional is going to come in contact with someone who’s been impacted by IPV if they’re a front-line healthcare provider.” Often, healthcare providers (eg, paramedics, emergency department personnel, community health clinic staff) are a first point of contact for survivors within the health system and can therefore serve as a gateway to appropriate services, if properly informed. However, stakeholders noted the challenge of getting appropriate education to these professionals, noting the need for buy-in from appropriate decision makers and sessions that extend beyond optional lunch-and-learns. A multipronged strategy was proposed to embed IPV-TBI-related education and training in early and continuing education requirements and encourage cross-sectoral education through community networks. Early education would involve including IPV-TBI content in the curriculum for students or training for new employees, and continuing education would involve opportunities for affordable professional education, facilitated workshops with follow-up consultations, and research refresh. Endorsement from leadership and upper-level bodies, such as professional organizations or colleges, may be helpful in implementing these cross-pollination education activities.

Stakeholders also flagged the lack of healthcare professionals in remote and rural contexts and highlighted the importance of education for individuals in community support roles. Local librarians, school support, individuals from religious organizations, and community officers were identified as key audiences. Stakeholders also called for the need to educate professionals from the law enforcement and legal systems to better support survivors who are going before the courts and who may be suffering from trauma and/or TBI symptoms. Professionals need to recognize the impact of

IPV-TBI on survivors’ behaviors (eg, not appearing for appointments, memory lapses may be consequences of IPV-TBI, lack of engagement in the process) to increase understanding and counter stigma so that women do not become further disadvantaged in the criminal and family law systems.

Although there were many audiences identified requiring IPV-TBI education, stakeholders emphasized the need for a unified message:

“There is no one messenger, but we all need to have the same message [...] we’re educating based on evidence, we’re educating based on the voice of those that live with this. But I think when we’re all sending different messages, and everyone is getting a different communication or different education that’s a disservice.” (Participant in breakout group 3; day 1, session 2)

Integrated and coordinated care

Integrating care and breaking down silos/building bridges was one of the highest priority service gaps that needed to be address, based on Mentimeter polling during the summits, second only to empowering survivors through knowledge. Building on cross-sectoral education and training, stakeholders emphasized the need for systemic change to develop a centralized and coordinated network of IPV-TBI services to address the currently fractured and siloed care that women survivors receive. Stakeholders spoke about the value of collaboration between IPV and TBI sectors, clarifying that the goal is not to make IPV service providers experts in TBI, or vice versa, as this would only strain service providers and do disservice for clients who should be receiving specialized care from the appropriate sector when needed. Instead, they recommended leveraging existing knowledge and expertise and building on the aforementioned suggested cross-pollination efforts to develop collaborative care systems to support survivors holistically.

It was noted that current systems do not have “gaps in services” but rather “massive chasms”. One contributing factor was the requirement of a formal diagnosis of TBI in order to receive many forms of TBI support. Stakeholders noted the challenge in obtaining a diagnosis of TBI. The 2 noted pathways for obtaining a diagnosis included a physician assessment, which was noted as particularly challenging for survivors who were unable to access care right away, or a neuropsychologist assessment, which was financially inaccessible for many. Stakeholders explained that complex conditions such as IPV-TBI cannot be treated as separate conditions and instead require integrated care that includes all the key care providers. Various strategies that could be embedded within this system of care were discussed including having a centralized number for survivors to call or having

TABLE 4 *Stakeholder quotes—Integrated and coordinated care*

- “Let’s stop saying gaps in services, we’re dealing with massive chasms. They are swallowing people whole and we expect them to just kind of be able to step over the gap and keep on their recovery journey. These are not gaps. We are not calling things what they are, and so what we’re doing is basically rescuing people from these massive chasms that you fall into as an injured person, as someone who has a history and experience of trauma.”
- “Everybody knows that traumatic brain injury is a team approach, it’s a multidisciplinary team approach, and in order to meet the complex needs of our patients [both] outside of IPV and inside of the IPV setting. So there needs to be more resources so that a primary care provider can say I recognise this, here’s the initial education, but this is outside of my scope now and I need to be able to pass you onto a coordinated process to provide more comprehensive care. It’s the same as stroke, cancer, everything else that we can, you know, all these other big Public Health issues.”
- “I really believe that we’re doing a great disservice when we hand somebody a business card and say call this person, especially when folks are dealing with so much trauma and brain injury and relationship and taking care of their kids [. . .] Like oh my gosh, can we do better, can we please do better than placing the burden of care and navigation and figuring this all out on the injured person? It breaks my heart.”
- “In our rural context again, to add that voice, that often there’s a lack of professional support or services and so we see a lot of informal or community type services stepping in. And so I think that just speaks to the need for a bit of universality around a tool, because you know, sometimes it might be the local librarian or somebody at the school or maybe someone in a religious organization who’s providing that support to family or is noticing something where there isn’t sort of that more professional stream that would pick it up or people would have access to.”
- “I think in our system we have to cast a pretty wide web. There’s no standard pathway for one person through any aspect of our healthcare system. So we never know who that touchpoint is going to be and maybe someone will only ever seek one resource, whether it be the librarian or their pastor or they, you know, whether it’s a shelter [. . .] It has to be a sort of all hands on deck to make sure that no matter where that touchpoint is within the system [. . .] those touchpoints have the information to get the proper supports to these individuals.”
- “If they are identified—and I would just trouble the piece around being officially diagnosed, because it is very difficult to get an official diagnosis of a brain injury if it’s not a severe brain injury, or you don’t have access to a neuropsychological assessment, which can be six, seven thousand dollars [. . .] So I think that we want to be careful too that we’re not requiring official diagnosis, because that will not happen for many people. But if they have experienced these types of situations [. . .] chances are they do have a concussion or brain injury.”

Abbreviation: IPV, intimate partner violence.

an information-sharing center where service providers can inform each other about the work they are doing. Key recommendations to begin this initiative included looking at different support structures across the country and having discussions at the provincial/territorial level to increase awareness of the complexity of IPV-TBI and the need to create a system of care and funding to support this initiative.

Stakeholders further emphasized the need for support in navigating the system, so as not to leave the burden of care and navigation on survivors. Some suggestions focused on removing barriers and simplifying access to services (eg, removing requirements, having a one-page informational sheet). There were also several suggestions for creating linkages between existing supports. For example, utilizing local, provincial, or national brain injury associations as linkages between TBI screening and service provision was suggested. Survivors typically do not need a referral or formal diagnosis to receive support from brain injury associations, whereas much medical support requires a formal diagnosis, the lack of which was noted as a common barrier to receiving TBI care for survivors. This does not suggest that brain injury

associations would provide a medical diagnosis or all the care that survivors need but rather, would be directing them to places or providers that can deliver vital TBI-specific care. Others suggested building partnerships through local health integration networks with primary healthcare providers as liaisons or using a structure such as the Acquired Brain Injury navigator program (in place in Ontario, Canada) as a model for community connection and one-on-one navigation support. Peer support was also noted as a potentially beneficial form of support for women survivors and highlighted the value of having peer navigators who have a shared understanding of women survivors’ experiences. Stakeholders also spoke about considering other systems at play where women may benefit from navigation support, such as the family law system.

Regardless of the approach, having an organized systems-level network was identified as critical such that survivors connect to it by design and not only by accident. The need for multiple points of entry to such networks or to coordinated care pathways was deemed particularly important for survivors of IPV-TBI, as needs vary by survivor and available resources vary by

community. These systems of care must also be developed to ensure survivors living in rural, remote, and Indigenous communities receive equitable access to comprehensive multidisciplinary IPV-TBI care.

DISCUSSION

This virtual summit, held over 2 half days in late 2020, brought together 30 stakeholders from across Canada representing the IPV, TBI, and healthcare sectors. Participants, many of whom self-identified as survivors of TBI and/or IPV, shared their thoughts and experiences from the perspective of direct service provision, personal or shared lived experience, and advocates for survivors. While the conversations across the 2 days were rich and varied, the findings reported here focus on systems-level discussions. Three main themes arose from these discussions: (1) the need for trauma-informed, anti-racist, and equitable health and social care systems; (2) the need for cross-pollination of knowledge between disciplines; and (3) the need for systems-level support for integrated and coordinated care.

As a foundation, stakeholders emphasized the need for trauma-informed, anti-racist, and equitable care systems. Retraumatizing experiences, systemic racism and discrimination, and financial or bureaucratic hurdles were all noted as barriers to survivors accessing care in the current system. These findings are echoed by the literature. Systematic reviews published in the last few years have highlighted the importance of equity-oriented, culturally safe, accessible, and survivor-centered services for survivors of violence.^{44–46}

Building on that foundation, stakeholders highlighted a need for cross-pollination across sectors. A general increase in awareness of the intersection of IPV-TBI is needed for all the various providers who are likely to encounter survivors in their practice. At the very least, stakeholders identified this cross-pollination as an opportunity for providers to be more understanding of the intersecting implications of IPV-TBI (eg, the cognitive impacts of trauma and brain injury) and lead to increased identification of survivors with TBI and cross-sector referrals to get them the care they need. This would begin to address the acknowledged difficulties in supporting survivors with appropriate services.^{6,23,36}

Stakeholders shared an ultimate goal of having integrated and coordinated care pathways for survivors built on the principles already discussed. A systems-level and systemic change to the ways we provide health and social care for women survivors of IPV-TBI that sees all of the woman's needs, enables her to access care from a multitude of touchpoints, and assists survivors in navigating and overcoming the bureaucratic and accessibility barriers that are often encountered in the current system.

Stakeholders discussed the urgent need for support from government/policy makers. They noted that, at present, there is very little funding support and a disconnect in how federal and provincial governments recognize brain injury. Stakeholders determined steps to facilitate policy change, the first being to build a case on the intersection of IPV-TBI that is informed by objective evidence (ie, service gaps), voices of individuals with lived experience, and a health economic lens. Occurring concurrently with this step is forging partnerships and bringing together everyone involved in the area of IPV-TBI, along with endorsements from community organizations to lobby for proper support and funding for IPV-TBI care.

Strengths and limitations

To our knowledge, this summit is the first pan-Canadian effort bringing stakeholders together to share their experiences, discuss the gaps in access to care and the need for a coordinated systems approach, and to suggest approaches for mitigating these gaps. While we would consider the diversity of the participants a strength in this research, we acknowledge that there are voices that may have been missed or opinions from the communities and sectors represented that differ from what we have discussed here. Ongoing dialogue with diverse stakeholders, including the voices commonly overlooked in developing services and structures, is necessary for work in this field to progress in a trauma-informed, anti-racist, and equitable way with a greater number of stakeholders. We also acknowledge that the time limitations, virtual modality, and group setting of the discussions may also impact the depth of discussion possible. Further exploration using other methods may be warranted.

CONCLUSION

The findings from this virtual pan-Canadian summit highlight many areas for action at the systems level to better support survivors of IPV-TBI across Canada. We encourage decision makers working in healthcare, the IPV sector, and the TBI sector to consider systemic changes they can make within their institutions or organizations to improve service provision for IPV-TBI survivors. We further call on the provincial, territorial, and federal governments and policy makers at all levels to support system-wide change in support of survivors and survivor-led solution both through funding and policy change. IPV-TBI is a global healthcare crisis and should be situated and addressed as such.

DEDICATION

We would like to dedicate this work to Michelle Bartlett McLaughlin. Michelle was an advocate for

survivors of brain injury across Canada, particularly those facing IPV. She was an active supporter and regular contributor to our IPV-TBI research and continuously advocated for survivors' voices to be

centered in this work. Her contributions to brain injury and IPV research, education, and advocacy and her impact on us as a team will not be forgotten.

REFERENCES

1. Statistics Canada. *Family Violence in Canada: A Statistical Profile*. Statistics Canada; 2011.
2. World Health Organization. *Violence Against Women*. World Health Organization; 2021.
3. Sheridan DJ, Nash KR. Acute injury patterns of intimate partner violence victims. *Trauma Violence Abuse*. 2007;8(3):281–289. doi:10.1177/1524838007303504
4. Valera E, Kucyi A. Brain injury in women experiencing intimate partner violence: neural mechanistic evidence of an “invisible” trauma. *Brain Imaging Behav*. 2017;11(6):1664–1677. doi:10.1007/s11682-016-9643-1
5. Roberts AR, Kim JH. Exploring the effects of head injuries among battered women: a qualitative study of chronic and severe woman battering. *J Soc Serv Res*. 2005;32(1):33–47. doi:10.1300/J079v32n01_03
6. Haag HL, Jones D, Joseph T, Colantonio A. Battered and brain injured: traumatic brain injury among women survivors of intimate partner violence—a scoping review. *Trauma Violence Abuse*. Published online June 6, 2019. doi:10.1177/1524838019850623
7. Kwako LE, Glass N, Campbell J, Melvin KC, Barr T, Gill JM. Traumatic brain injury in intimate partner violence: a critical review of outcomes and mechanisms. *Trauma Violence Abuse*. 2011;12(3):115–126. doi:10.1177/1524838011404251
8. Bukowski LA, Hampton MC, Escobar-Viera CG, et al. Intimate partner violence and depression among black transgender women in the USA: the potential suppressive effect of perceived social support. *J Urban Health*. 2019;96(5):760–771. doi:10.1007/s11524-019-00355-3
9. Garthe RC, Hidalgo MA, Hereth J, et al. Prevalence and risk correlates of intimate partner violence among a multisite cohort of young transgender women. *LGBT Health*. 2018;5(6):333–340. doi:10.1089/lgbt.2018.0034
10. Statistics Canada. *Family Violence in Canada: A Statistical Profile, 2013*. Statistics Canada; 2015.
11. Barrett KA, O'Day B, Roche A, Carlson BL. Intimate partner violence, health status, and health care access among women with disabilities. *Womens Health Issues*. 2009;19(2):94–100. doi:10.1016/j.whi.2008.10.005
12. Chirwa E, Jewkes R, Van Der Heijden I, Dunkle K. Intimate partner violence among women with and without disabilities: a pooled analysis of baseline data from seven violence-prevention programmes. *BMJ Glob Health*. 2020;5(11):e002156. doi:10.1136/bmjgh-2019-002156
13. Sinha M. *Measuring Violence Against Women: Statistical Trends*. Canadian Centre for Justice Statistics; 2013.
14. Burczykca M, Conroy S. *Family Violence in Canada: A Statistical Profile, 2015*. Statistics Canada; 2017:1209–6393.
15. National Inquiry into Missing and Murdered Indigenous Women and Girls. *Reclaiming Power and Place: The Final Report of the National Inquiry into Missing and Murdered Indigenous Women and Girls*. Vol 1a. National Inquiry into Missing and Murdered Indigenous Women and Girls; 2019.
16. Cimino AN, Yi G, Patch M, et al. The effect of intimate partner violence and probable traumatic brain injury on mental health outcomes for Black women. *J Aggress Maltreat Trauma*. 2019;28(6):714–731. doi:10.1080/10926771.2019.1587657
17. Stockman JK, Hayashi H, Campbell JC. Intimate partner violence and its health impact on ethnic minority women. *J Womens Health (Larchmt)*. 2015;24(1):62–79. doi:10.1089/jwh.2014.4879
18. Iverson KM, Pogoda TK. Traumatic brain injury among women veterans: an invisible wound of intimate partner violence. *Med Care*. 2015;53(4)(suppl 1):S112–S119. doi:10.1097/MLR.0000000000000263
19. Iverson KM, Dardis CM, Pogoda TK. Traumatic brain injury and PTSD symptoms as a consequence of intimate partner violence. *Compr Psychiatry*. 2017;74:80–87. doi:10.1016/j.comppsy.2017.01.007
20. Valera EM, Berenbaum H. Brain injury in battered women. *J Consult Clin Psychol*. 2003;71(4):797–804. doi:10.1037/0022-006x.71.4.797
21. Gutman SA, Diamond H, Holness-Parchment SE, et al. Enhancing independence in women experiencing domestic violence and possible brain injury: an assessment of an occupational therapy intervention. *Occup Ther Ment Health*. 2004;20(1):49–79. doi:10.1300/J004v20n01_03
22. Andelic N, Arango-Lasprilla J, Røe C. The complexity of traumatic brain injury. *J Rehabil Med*. 2013;45(8):708–709.
23. Beydoun HA, Williams M, Beydoun MA, Eid SM, Zonderman AB. Relationship of physical intimate partner violence with mental health diagnoses in the nationwide emergency department sample. *J Womens Health (Larchmt)*. 2017;26(2):141–151. doi:10.1089/jwh.2016.5840
24. St Ivany A, Kools S, Sharps P, Bullock L. Extreme control and instability: insight into head injury from intimate partner violence. *J Forensic Nurs*. 2018;14(4):198–205. doi:10.1097/JFN.0000000000000220
25. Whitenack GG, Cuthbert JP, Corrigan JD, Bogner JA. Risk of negative outcomes after traumatic brain injury: a statewide population-based survey. *J Head Trauma Rehabil*. 2016;31(1):E43–E54. doi:10.1097/HTR.0000000000000141
26. St Ivany A, Bullock L, Schminkey D, Wells K, Sharps P, Kools S. Living in fear and prioritizing safety: exploring women's lives after traumatic brain injury from intimate partner violence. *Qual Health Res*. 2018;28(11):1708–1718. doi:10.1177/1049732318786705
27. Hofgren C, Esbjornsson E, Sunnerhagen KS. Return to work after acquired brain injury: facilitators and hindrances observed in a sub-acute rehabilitation setting. *Work*. 2010;36(4):431–439. doi:10.3233/WOR-2010-1039
28. Ponsford JL, Downing MG, Olver J, et al. Longitudinal follow-up of patients with traumatic brain injury: outcome at two, five, and ten years post-injury. *J Neurotrauma*. 2014;31(1):64–77. doi:10.1089/neu.2013.2997
29. Ahman S, Saveman BI, Styrke J, Bjornstig U, Stalnacke BM. Long-term follow-up of patients with mild traumatic brain injury: a mixed-method study. *J Rehabil Med*. 2013;45(8):758–764. doi:10.2340/16501977-1182
30. Harris JE, Colantonio A, Bushnik T, et al. Advancing the health and quality-of-life of girls and women after traumatic brain injury:

- workshop summary and recommendations. *Brain Inj.* 2012;26(2):177–182. doi:10.3109/02699052.2011.635361
31. Haag HL, Caringal M, Sokoloff S, Kontos P, Yoshida K, Colantonio A. Being a woman with acquired brain injury: challenges and implications for practice. *Arch Phys Med Rehabil.* 2016; 97(2)(suppl):S64–S70. doi:10.1016/j.apmr.2014.12.018
 32. Colantonio A, Mar W, Escobar M, et al. Women's health outcomes after traumatic brain injury. *J Womens Health (Larchmt).* 2010;19(6):1109–1116. doi:10.1089/jwh.2009.1740
 33. Corrigan JD, Wolfe M, Mysiw WJ, Jackson RD, Bogner JA. Early identification of mild traumatic brain injury in female victims of domestic violence. *Am J Obstet Gynecol.* 2003;188(5)(suppl):S71–S76. doi:10.1067/mob.2003.404
 34. Valera EM, Cao A, Pasternak O, et al. White matter correlates of mild traumatic brain injuries in women subjected to intimate-partner violence: a preliminary study. *J Neurotrauma.* 2019;36(5):661–668. doi:10.1089/neu.2018.5734
 35. Haag HL, Sokoloff S, MacGregor N, Broekstra S, Cullen N, Colantonio A. Battered and brain injured: assessing knowledge of traumatic brain injury among intimate partner violence service providers. *J Womens Health (Larchmt).* 2019;28(7):990–996. doi:10.1089/jwh.2018.7299
 36. Kumar RG, Gao S, Juengst SB, Wagner AK, Fabio A. The effects of posttraumatic depression on cognition, pain, fatigue, and headache after moderate-to-severe traumatic brain injury: a thematic review. *Brain Inj.* 2018;32(4):383–394. doi:10.1080/02699052.2018.1427888
 37. Nemeth JM, Mengo C, Kulow E, Brown A, Ramirez R. Provider perceptions and domestic violence (DV) survivor experiences of traumatic and anoxic-hypoxic brain injury: implications for DV advocacy service provision. *J Aggress Maltreat Trauma.* 2019;28(6):744–763.
 38. Minkler M, Wallerstein N. *Community-Based Participatory Research for Health: From Process to Outcomes.* John Wiley & Sons; 2011.
 39. Wallerstein NB, Duran B. Using community-based participatory research to address health disparities. *Health Promot Pract.* 2006; 7(3):312–323. doi:10.1177/1524839906289376
 40. Denzin NK, Lincoln YS. *Collecting and Interpreting Qualitative Materials.* Sage; 1998.
 41. Denzin NK, Lincoln YS. *Handbook of Qualitative Research.* Sage; 2000.
 42. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3(2):77–101. doi:10.1191/1478088706qp063oa
 43. Birt L, Scott S, Cavers D, Campbell C, Walter F. Member checking: a tool to enhance trustworthiness or merely a nod to validation? *Qual Health Res.* 2016;26(13):1802–1811. doi:10.1177/1049732316654870
 44. Cullen P, Mackean T, Walker N, et al. Integrating trauma and violence informed care in primary health care settings for First Nations women experiencing violence: a systematic review. *Trauma Violence Abuse.* Published online February 12, 2021. doi:10.1177/1524838020985571
 45. Ravi KE, Robinson SR, Schrag RV. Facilitators of formal help-seeking for adult survivors of IPV in the United States: a systematic review. *Trauma Violence Abuse.* Published online March 9, 2021. doi:10.1177/1524838021995954
 46. Robinson SR, Ravi K, Voth Schrag RJ. A systematic review of barriers to formal help seeking for adult survivors of IPV in the United States, 2005-2019. *Trauma Violence Abuse.* Published online April 8, 2020. doi:10.1177/1524838020916254