Research to Integrate Services for Individuals with Traumatic Brain Injury, Mental Health, and Addictions: Proceedings of a MultiDisciplinary Workshop

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ABSTRACT

We present the findings from a one-day, multidisciplinary meeting to gather feedback for an integrated knowledge translation research project addressing the integration of health services and supports for individuals with traumatic brain injury, mental health, and/or addictions; especially those who experience homelessness/vulnerably housed, intersect with the criminal justice system, and are survivors of intimate partner violence. This meeting brought together persons with lived experience, service providers, decision makers, and researchers, who provided feedback that further refined the research methodology and highlighted existing gaps. This event was successful in inviting collaboration, knowledge exchange and dissemination, and advancing an important knowledge-to-action cycle for this research.

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Keywords: traumatic brain injury, participatory action research, health systems, housing instability, vulnerable populations, mental health.

RÉSUMÉ

Cet article présente les résultats d'une réunion multidisciplinaire visant à recueillir des commentaires sur un projet de recherche portant sur l'intégration des services de santé et de soutien aux personnes souffrant de traumatisme crânien et de problèmes de santé mentale et/ou de dépendances; particulièrement les itinérants suivis par le système de justice pénale et victimes des violences de leur partenaire. Cette réunion rassemblait des personnes avec une expérience vécue, fournisseurs de services, décideurs et chercheurs susceptibles d'offrir une rétroaction constructive sur la méthodologie de recherche et de mettre en évidence les lacunes éventuelles. Cet événement a donné lieu à des échanges fructueux et nécessaires à la mise en route de ce projet de recherche.

Mots clés : traumatisme crânien, recherche-action participative, systèmes de santé, itinérance, populations vulnérables, santé mentale.

TRAUMATIC BRAIN INJURY, MENTAL HEALTH, AND ADDICTIONS

Traumatic brain injury (TBI) can lead to impairments in cognition, communication, new learning, behavioural self-regulation, and mood, which negatively impact functioning, educational and vocational success, relationships, and activities of daily living (MacDonald & Wiseman-Hakes, 2010; Ponsford, Kelly, & Couchman, 2014; Rabinowitz & Levin, 2014). Additionally, more than one in five people who access mental health and/or addictions services (MHA) have a history of traumatic brain injury (TBI; Graham & Cardon, 2008; Hwang et al., 2008). The prevalence of brain injury in this population is even higher; that is, three in five for individuals who also have other concurrent disorders, experience homelessness, or legal involvement (Graham & Cardon, 2008; Hwang et al., 2008; McIsaac et al., 2016; Topolovec-Vranic et al., 2012). There is also growing empirical recognition of the high prevalence of TBI among women survivors of intimate partner violence (IPV); these individuals may also access MHA services, as well as services related to shelter, housing, and the criminal justice sectors (Campbell et al., 2018; Valera & Berenbaum, 2003).

Challenges related to securing stable housing, experiences of homelessness, IPV, and incarceration may also contribute to or exacerbate mental health problems and are often associated with systemic poverty. While TBI occurs among people from across all sociodemographic backgrounds, evidence suggests a strong socioeconomic gradient with disadvantaged individuals being at greater risk (Colantonio et al., 2014; Hwang et al., 2008; Williams, Hughes, et al., 2015). There is additional evidence of differential early life experiences among marginalized populations who experience social and health inequities (Colantonio et al., 2014), and the cycle of poverty significantly complicates neurorehabilitation and undermines the well-being of people with TBI and their families (North American Brain Injury Society, 2014, June).

Furthermore, as many as 80% of incarcerated adults have a history of TBI compared to 8.7% in the general population (McIsaac et al., 2016; Silver, Kramer, Greenwald, & Weissman, 2001; Williams et al.,

2018). For youth, the prevalence ranges from 16.5% to 72% (Williams, Hughes, et al., 2015; Williams, Wszalek, & Turkstra, 2015). The combination of TBI-related impairments such as difficulties with memory, new learning, communication, problem-solving and emotional and behavioural dysregulation, (Anderson, Hawes, & Snow, 2016; Hughes, Williams, Chitsabesan, Davies, & Mounce, 2012; Snow & Powell, 2011), are often superimposed on comorbidities such as pre-existing communication disorders (prevalent in 60–90%; Anderson et al., 2016; Snow & Powell, 2011) and learning disabilities (prevalent in 23–32%; Hughes et al., 2012). These add an additional layer of complexity to MHA treatment (Graham & Cardon, 2008) as well as for individuals in the criminal justice system (Anderson et al., 2016; Hughes et al., 2012; Snow & Powell, 2011; Yuhasz, 2013). However, there is evidence that communication-partner training of criminal justice staff (police) and other community-based professionals in communication strategies, can support individuals with TBI as they navigate the justice system and community reintegration (Wiseman-Hakes et al., 2020).

Currently, approaches to serving this population of individuals with TBI and MHA are fragmented, even though TBI and MHA are deemed important healthcare priorities. Disparities in awareness and knowledge persist, as do misconceptions about the sequelae of TBI and “mild” TBI in particular, among non-expert professionals and laypersons (Graham & Cardon, 2008; Yuhasz, 2013). Innovations in practice are required to enhance knowledge and simultaneously integrate services among and between TBI and MHA programs.

Finally, there are gaps in existing literature regarding the experiences and needs of women with TBI and MHA, which is concerning as research suggests that women may experience differences in care and recovery following TBI (Choleris, Galea, Sohrabji, & Frick, 2018; Colantonio, Harris, Ratcliff, Chase, & Ellis, 2010; Haag et al., 2016; Harris et al., 2012; Wiseman-Hakes et al., 2019). There is a critical need for an informed, collaborative, inter-disciplinary and inter-sectoral approach to research to develop integrated services, funding, policies, and the provision of appropriate supports and treatment. Therefore, it is appropriate that persons with lived experience of TBI and MHA and the organizations who serve them, be directly involved in research on this topic. Integrated knowledge translation (IKT) is a research approach that emphasize the importance of creating partnerships between researchers and the people for whom the research is ultimately meant to be of use; i.e., the “knowledge users/stakeholders” (Jull & Graham, 2017).

TBI and the comorbidities of TBI and MHA are a pressing public health issue. To better address these gaps for individuals with TBI and MHA, our team, in consultation with community partners and stakeholders who participated in the development and review of the research proposal, received a two-year research grant, entitled Integrating Brain Injury, Mental Health, and Addictions. This grant has an overarching aim to integrate explicit consideration of sex and gender (Johnson, Greaves, & Repta, 2009) to inform the development of *gender and sex-sensitive* (WHO, 2009) approaches to services for individuals with TBI and MHA who intersect with the criminal justice system, for women who have been exposed to intimate partner violence, and for individuals who require housing support and services.

Under the umbrella of this program, four specific studies were proposed: see Figure 1 and Table 1 for a description.

Figure 1**Overview of Research Program: Integrating Brain Injury, Mental Health, and Addictions** **Multidisciplinary Stakeholder Workshop-Meeting**

The underlying approach to this research program is one which emphasizes collaboration between individuals with lived experience, researchers, stakeholders and knowledge users; i.e., an IKT approach. Thus, we began with a one-day workshop held in Toronto, Ontario, Canada, on March 22, 2018. Stakeholders were defined as any organization or individuals with (1) either experience of TBI and MHA, or (2) who provide services or policy for, or (3) who conduct studies with these individuals using systematic rigorous research methods, and who can affect, or who can be affected by the research project. Please see Table 2 for participants by sector and organization.

Objectives

The overarching aim of this event was to provide a face-to-face participatory action forum where relevant stakeholders, individuals with lived experience, and researchers could meet as equal partners and begin the process of project implementation, knowledge dissemination, and service integration for individuals with concurrent TBI and MHA. Approval was granted by the Research Ethics Board at the University of Toronto.

Table 1**Descriptive Overview of Research Program: Integrating Brain Injury, Mental Health, and Addictions**

Study 1: An examination of the impact of concurrent TBI and MHA on system level outcomes	This retrospective cohort study utilizes population-based health administrative datasets in the province of Ontario to identify patients with TBI and/or MHA. Data will be analyzed to identify sex-specific and broader determinants of negative system level outcomes (e.g., Alternate Level of Care days, re-hospitalization within 30 days, and repeat non-urgent emergency department visits).
Study 2: Access and use of health services	This cross-sectional study is using province-wide survey data to identify perceived barriers and facilitators regarding accessing services and support for individuals with a self-reported history of TBI. The sample is drawn from respondents of the CAMH Monitor, the longest ongoing epidemiological survey of MHA in adults living in Ontario. Additionally, data from this sample will be linked to health administrative data to determine health service use of individuals with TBI. Sex-specific analyses will be conducted to explore differences and similarities between males and females.
Study 3: Critical characteristics of housing support services	This qualitative study is examining the critical characteristics of housing and support services for individuals with TBI and MHA and, exploring their perspectives and those of service providers in these fields. In-depth semi-structured interviews are focused on (a) support needs in securing and maintaining housing; (b) characteristics of housing that are valued and/or helpful; (c) models of housing and their impact; and (d) challenges that need to be overcome in the system to ensure access to stable housing, from the perspective of individuals with lived experiences of TBI and MHA and service providers. An intersectional gender-based analysis will explore critical characteristics of housing support for diverse groups of women, men, and gender-diverse people with TBI and MHA.
Study 4: Knowledge and practice gaps regarding men, women, and gender-diverse people in the criminal justice system, and women exposed to IPV	<p>Study 4a: This qualitative study is examining education and training needs of staff in the forensic and criminal justice system who support/supervise individuals with TBI and MHA. We are recruiting previously incarcerated individuals living in the community with TBI and/or MHA for in-depth qualitative interviews and staff for four focus groups.</p> <p>Study 4b: This qualitative study is examining TBI education and training needs of first responders offering support to women exposed to IPV. The sample for the study of women survivors of IPV will include individuals (staff and women survivors of IPV with TBI and/or MHA).</p> <p>The in-depth semi-structured interviews from Studies 4a/4b will inform development of KT materials, best practice guidelines for recognizing and understanding the cognitive-communication impairments associated with TBI, policy/legislation recommendations for practice and, provide guidelines for communicating effectively with criminalized individuals and women survivors of IPV with TBI and MHA. An intersectional gender-based analysis will be used to explore the experiences and needs of diverse groups of women, men, and gender-diverse people with respect to communication and the criminal justice system, and communication with women exposed to IPV. Participants will provide feedback on recommendations and KT material, with training and education occurring concurrently. KT material will be evaluated using surveys post-dissemination.</p>

The following specific objectives guided the meeting:

- (i) provide consultation and advice among stakeholders, partners, and the research team on the studies described above;
- (ii) provide an opportunity for networking and knowledge exchange among stakeholders and the research team;
- (iii) disseminate knowledge on the cognitive-communication challenges experienced by individuals with TBI and evidence-based best practices for communication with individuals with TBI; and
- (iv) gather evaluative feedback on the participatory workshop process.

METHODS

Participants

Eighty-nine participants were invited; they included individuals with lived experience and individuals and organizations across the province of Ontario, Canada who interact with or provide services to this vulnerable population. The meeting was attended by 70 of these stakeholders, which represents 79% of those invited. Participants included front-line workers, non-governmental organizations (NGOs), non-profit advocacy associations, individuals with lived experience of TBI and MHA, government/regulatory and professional/industry associations, researchers, trainees, and volunteers (see Table 2). All 89 participants expressed an interest in attending and those who did not attend had scheduling conflicts. Participants signed an informed consent to share specific and collective feedback.

The activities included keynote addresses on the current state of these vulnerable populations. To provide further context, four individuals with lived experience of TBI and MHA described their experiences, both negative and positive. Two instructive presentations were also included in the agenda: an overview of the cognitive-communication and social communication impairments associated with TBI and evidence for communication partner training; and an introduction to the use of animated film as an innovative knowledge-dissemination approach.

Table 2
Participants by Sector and Organization

Sector	Number of Attendees & Percentage of Participants
Individuals with lived experience	9 (12.8%)
Professional/industry/service providers	15 (21.4%)
Government and regulatory bodies (provincial)	12 (17.1%)
Advocacy/non-governmental/non-profit organizations	15 (21.4%)
Education/academia (including trainees and student volunteers)	25 (35.8%)

Note. see Table 3 for details of stakeholder participant organizations.

Two sets of break-out working groups were held to engage participants in consultation and feedback on the research program and on the current state of services in Ontario. Anonymized discussion points and comments were documented by trainees, research staff, and volunteers to ensure that all relevant feedback was captured. Documented discussions were later reviewed and summarized by the research team for each research aim. At the end of the meeting, participants were given the opportunity to complete a confidential survey about the day, with the majority of questions answered by means of a 4-point Likert rating scale and some by open-ended responses.

Meeting Results

Objective 1: Provide consultation and advice among stakeholders, partners, and the research team on four proposed research studies

In advance of the workshop, a summary of each of the four proposed research studies was distributed. During the first break-out sessions, project leads for each study provided an overview of background literature and the rationale and objectives. Stakeholders and partners engaged with the research teams in a series of small group presentations and discussions to provide consultation and advice. Each study was presented twice during two consecutive breakout sessions. Participants chose in advance the sessions they deemed most relevant to their organization or interests. In total, 22 participants provided feedback on Study 1 (system level outcomes), 26 provided feedback on Study 2 (barriers and facilitators to services and support), 24 on Study 3 (critical characteristics of housing), and 21 each respectively for Study 4a (TBI, MHA and the criminal justice system) and 4b (TBI, MHA and IPV). Wherever possible, feedback from participants was later incorporated as additions or modifications into each research aim.

For Study 1, an examination of the impact of concurrent TBI, MHA, and/or addictions on system level outcomes using health administrative data, participants emphasized a number of points. First, TBIs are often diagnosed retrospectively and thus, may not be captured in health datasets. It was suggested that the limitations of identifying TBI from administrative databases be considered. Second, a number of persons with intellectual disability experience TBI and this is also a population of interest. The research team reported that this is being simultaneously investigated by a master's thesis project external to the grant. Third, participants discussed that there are significant direct and indirect economic costs to persons with TBI and MHA as well as caregivers, and that administrative health data can only be used to investigate health service-related costs. Finally, data that would enable better understanding of the impact of a concurrent TBI and MHA on health system outcomes is needed to inform policy and further discussion.

For Study 2, an examination of the barriers and facilitators to access and use of health services, participants emphasized a number of points and questions for consideration. First, the screening question for TBI should be revised to include individuals who do not lose consciousness, and the caregiver perspective should be included. Second, data collection by phone may limit participants to a select population and thus, marginalized and vulnerable individuals (i.e., those most likely to "fall through the cracks" and experience barriers to accessing health services) may not be represented. Stakeholders suggested that, ideally, the survey should be administered in person or left at community partner organizations. This was acknowledged by the research team as a limitation. While the study did not have the resources to permit this mode of questionnaire administration, future studies will be explored to address this.

Table 3
Detailed List of Stakeholder Participant Organizations

Sector	Organization	Number of Attendees
Individuals with lived experience	NA	9
Professional/industry/service providers	Centre for Addiction and Mental Health Community Head Injury Resource Services Cota (Community Mental Health and Cognitive Disability Services) Eaton Kent Criminal Defence Law Health Sciences North North Bay Regional Health Centre Ontario Shores Centre for Mental Health Sciences Pauktuutit Inuit Women of Canada Waypoint Centre for Mental Health Women's Shelters Canada Women's Habitat WomenatthecentreE	15
Government and regulatory bodies (provincial)	Local Health Integration Networks (LHINS)* Mental Health Navigators and Brain Injury Navigators Probation Officers Association of Ontario	12
Advocacy/non-governmental/non-profit organizations	Brain Injury Canada Brain Injury Services of Durham Brain Injury Services of Northern Ontario Brain Injury Society of Toronto Canadian Association of Elizabeth Fry Societies Human Services Justice Coordinating Committee-Downtown Toronto John Howard Society of Canada March of Dimes Ontario Brain Injury Association Ontario Neurotrauma Foundation Peterborough Brain Injury Society Prisoners HIV/AIDS Support Action Network	15
Education/academia (including trainees and student volunteers)	Centre for Addiction and Mental Health Centre for Urban Health Solutions-St. Michael's Hospital, Li Ka Shing Knowledge Institute Toronto Rehabilitation Institute-University Health Network University of Ontario Institute of Technology University of Toronto	25

* Local Health Integration Networks (LHINS) were the health authorities responsible for regional administration of public healthcare services in the province of Ontario, Canada.

For Study 3, an examination of the critical characteristics of housing and support services for individuals with TBI and MHA, participants identified the need for a multi-level systems approach to understanding needs, experiences and barriers. Participants expressed their concern regarding current issues of stigma experienced by individuals with TBI and MHA. The high costs and lack of available housing, particularly in urban areas, were identified as priority issues as well as the additional complications that exist for individuals who receive disability support; for example, the high costs of housing leave limited funds for food and daily living. For individuals who are able to work part-time, disability support is thus reduced, which perpetuates the cycle of poverty. Participants stressed the importance of considering the supports needed by individuals with TBI and MHA to access and maintain a home and enhance well-being. Participants also shared their experiences with what they identified as a “flawed and overly complicated” system. It was recognized that numerous organizations deal with housing yet work “in silos” with limited interagency communication. Participants further reinforced the need to consider system level barriers to accessing housing.

Participants with lived experience and front-line staff also shared their personal experiences of badly maintained and unsafe housing, lack of accessibility to transportation, difficult landlords and immense frustration with, and feelings of being punished by, the system. Participants acknowledged that in order to address these issues, there is the need for a systematic and rigorous means of documenting issues and experiences related to housing so that data are available to impact policy. Consistent with Study 2, participants expressed the need to ensure that individuals who are homeless or transient are represented in data collection.

Study 4 was subdivided (4a and 4b) to address two specific populations with TBI and MHA.

Study 4a addresses individuals in the forensic and criminal justice systems. Participants discussed the lack of understanding of the terms ABI (acquired brain injury) and TBI (traumatic brain injury) among community partner and referral organizations, and how different agencies may use different definitions of ABI. Participants suggested that education is needed to clarify the terms ABI and TBI as well as to provide information regarding TBI. Participants also recognized that some individuals may experience TBIs during incarceration and these injuries should be acknowledged and considered in the data collection. A query was raised as to whether or not screening/diagnoses, medical supports, and interventions are available to those in the prison system and suggested this should be identified within the context of the research. Segregation of people with TBI and MHA was also deemed an important issue and the research should consider including individuals who either are currently or have been segregated during incarceration. Participants suggested that the term *offender* should not be used in any materials related to the research or subsequent education and policy materials given its negative connotation. Judges and justices-of-the-peace should be included in training initiatives.

Some participants were concerned that the topics of communication and communication best practices were either too narrow, as there are many important systemic issues within the criminal justice system that impact those with TBI, or too broad, as the communication needs may vary between organizations. Despite the fact that there is research evidence of benefits for both incarcerated individuals and staff (Snow, Bagley, & White, 2018; Snow, Woodward, Mathis, & Powell, 2016), participants identified a lack of awareness and understanding regarding the potential utility of speech-language-pathology (SLP) assessments and interventions for individuals with TBI and MHA in the criminal justice system. In Ontario, referrals for individuals in the criminal justice system to SLP are rare.

Table 4
Potential First Responders for Women Exposed to Intimate Partner Violence

Suggested First Responder Category	Members
Non-professional	Family: mother, sister, aunt, cousin Non-family supports: friend, trusted co-worker, cultural/ethnic/religious healer, elder, “person of cloth”
Medical community	Paramedic, emergency room nurse, doctor, X-ray technician, others in emergency room
Legal/justice system	Parole officer, healthcare system within a jail, mental health workers, mental health court workers, police
911 emergency	Police, paramedic, firemen/women
Children’s aid	Social workers, intake worker
Northern communities	RCMP
Suicide or mental health crisis support phone lines	Women’s shelters with collect or toll-free access, crisis line, women’s help line
Sexual/reproductive health clinic	i.e., a “hassle-free” and safe clinic that women can access even without healthcare coverage
Women’s shelters	Front line intake worker
Workplace	Ontario Law on Workplace Violence and Harassment: Bill 168 states that it is required by law to report to the employer when a co-worker is experiencing violence (including domestic violence) in the workplace

For Study 4b, an examination of knowledge and practice gaps regarding women exposed to IPV, there was acknowledgement by both participants and the research team that “first responders” are an important service population to include in the recruitment process. A lively discussion ensued about who constituted a first responder, and it was recognized that in the context of IPV, that many different individuals and organizations may fit this term. Table 4 provides a summary of the first responders identified.

Participants also provided the following feedback and advice to the research team as a whole:

Consideration of issues relating to stigma, judgement and fear of disclosure are of paramount importance during the development of research questions, training and educational materials. Participants further raised the issue of distrust among groups who have historically been marginalized, including Indigenous women, immigrant women, women of colour and those who identify as LGBTQI2S. It was recognized that there are current organizational and societal barriers to disclosure of both IPV and TBI that may deter women from seeking support.

Furthermore, staff and service users may lack knowledge/experience/understanding of the prevalence and consequences of TBI among those with IPV as well as the possible need for accommodations (such as giving the person extra time to think and respond) to support communication and sensitive communication practices.

There were a number of points and themes addressed that were common to all of the research studies:

1. There is a need to accurately identify and diagnose TBI and ensure consistency of definitions of TBI and ABI within and between agencies and stakeholders.
2. Stakeholder organizations need training and education about TBI, how to screen, document precisely, and access supports.
3. Given that the research program involves individuals with addictions, consider screening for ABI as a result of drug overdose (i.e., non-traumatic brain injury). This issue is timely given the recent opioid crisis in Ontario. This point was recognized as a limitation of the current research program which is specific to TBI. This should be considered in future studies.
4. Ensure that KT materials are trauma-informed and incorporate respectful, cultural, gender-neutral and gender-sensitive language.
5. Ensure measurement of training uptake.

Knowledge Translation

The long-term knowledge translation (KT) plans for Studies 3 and 4 (a and b) include the development of two research-based animated films that will be used for staff training. Following presentation of examples of animation created in the context of other TBI-related research (Colantonio, 2016), participants were invited to offer feedback regarding the use of animation as a dissemination strategy, as well as different animation styles. The following feedback was provided:

- The benefits of animation (e.g., its accessibility across literacy levels, creativity) suggest it is an effective method of KT.
- Participants expressed concern regarding the potential for oversimplification of complex experiences when using a medium with duration limits (animations typically last ~2 minutes).

Following the meeting, participants were asked to complete an evaluation form and to provide additional comments/suggestions not raised in discussion. Sixty-four percent of non-research participants completed the survey. These data informed the research teams' evaluation of the relative success of each of the remaining three meeting objectives.

Objectives 2, 3, and 4

There was a diverse representation of individuals, organizations, and institutions in attendance that allowed for rich networking and knowledge exchange. The meeting provided a unique opportunity for discussion and exchange of ideas between a multi-disciplinary group of participants and increased opportunities for research capacity through the inclusion of individuals with lived experience.

The meeting also included an educational presentation on a multi-dimensional framework of communication, the types of challenges experienced in the domains of communication, cognitive-communication and social communication by individuals with TBI (and individuals with TBI and MHA) and information regarding current evidence for the efficacy of communication partner training to enhance communication

success. The educational elements of the meeting were well received by participants and most (not all) reported it as being applicable to their practice.

The structure of the meeting itself was an important component of the day and participants reported overall that the balance between didactic presentations and participant engagement in the break-out working sessions was excellent. The presentations by four individuals with lived experience of TBI and MHA, including one with TBI and MHA due to intimate partner violence, were regarded as a highlight of the day. Participants acknowledged the importance of these presentations as underscoring equal partnership of individuals with lived experience with the research team. Participants also reported that the information exchange, learning opportunities and networking were positive features of the day, and some participants particularly mentioned appreciation for the diverse representation of sectors. However, a number of participants indicated that some relevant stakeholders were missing or underrepresented at the meeting, which was important information for the research team. Table 5 identifies groups and stakeholders recommended for inclusion in future meetings.

Finally, a number of participants correctly highlighted the lack of diversity among the research team who are predominantly white, urban, and female.

DISCUSSION

The overarching aim of this meeting was to provide a face-to-face forum where relevant stakeholders, individuals with lived experience, and researchers could meet as equal partners and begin the process of project implementation, knowledge dissemination, and service integration for individuals with concurrent TBI and MHA.

The findings from this meeting are consistent with research, which suggests that greater than 20% of individuals with TBI exhibits a mental health illness that persists over time if left untreated (Santopietro, Yeomans, Niemeier, White, & Coughlin, 2015). While a specific percentage was not specified by participants, the commonality and challenges of these comorbidities was clearly acknowledged. Moreover, even with clear evidence of these comorbidities, evidence suggests that only 33% of TBI survivors who need psychiatric care at 12-months post-injury actually receive this care (Bryant, Creamer, McFarlane, Clark, & Silove, 2010; Koponen et al., 2002). Participants also endorsed emerging literature regarding substance abuse and TBI. TBI and substance abuse are bidirectionally related for both risks and treatment. It was further acknowledged that particularly for those with mild TBI, subtle impairments in cognitive, executive, and decision-making functions are often poorly recognized, and when these impairments are combined with subsequent difficulties in psychosocial adjustment and coping skills, as well as a lack of personal and system support, these individuals are at increased risk for chronic substance abuse and mental health challenges (Graham & Cardon, 2008; Hwang et al., 2008).

Participants also endorsed previous literature that suggests coordinated provincial and local efforts are needed to integrate and strengthen the care delivery system for individuals with TBI. Evidence also suggests that moving forward, TBI programs and stakeholders must continue to emphasize rehabilitative care as a core value even for those who are in the chronic stages of this lifelong injury (Santopietro et al., 2015). An emphasis on rehabilitation rather than recidivism was also touched on by participants who attended the

sessions for Study 4a as a future direction for those with TBI and MHA who intersect with the criminal justice system. Greater attention to screening efforts is critical to ensure early access to services and appropriate delivery of care. Due to the multitude of stakeholders involved, strengthening collaborations among these groups will help to streamline care and narrow the gaps. Attention should also be placed on the introduction of innovative care strategies to increase access and to engage individuals with TBI. Lastly, sustainable sources of financing are needed to support this population over the long term which will ultimately require advocacy, public education, and political will (Santopietro et al., 2015).

Implications and Relevant Future Directions: Modifications to the Research Protocol Based on Feedback from the Meeting

As one of the primary aims was to gather feedback on the research protocol, the following modifications were made based on participant responses during the breakout working groups.

- An additional research question was added to examine the direct economic costs of TBI and MHA.
- The TBI screening question was revised and questions on caregiving were added to the follow-up survey.
- Based on feedback regarding the need for a systematic and rigorous means of documenting issues related to housing, the research methodology was modified to include interview questions investigating how agencies communicate with one another regarding housing, and how housing is accessed.
- It was recognized that the ability to address individuals who have been placed in segregation while incarcerated is outside the scope and budget of the current grant. However, there was unanimous agreement that this is an important topic and should be addressed in future research.
- Based on the above feedback, individuals who may have been injured while institutionalized will now be included.
- First responders now include emergency room physicians and nurses, paramedics arriving on scene, and x-ray technicians.
- Efforts will be made to include persons with lived experience of IPV in the development of the interview question guides to find ways to reduce the impact of stigma concerning disclosure.
- The inclusion of researchers and collaborators who belong to traditionally marginalized groups has added diversity.
- Interview questions will seek to reveal and understand existing organizational and societal barriers to women survivors seeking help.
- The concern regarding the potential for oversimplification of complex experiences when using animation will be addressed when KT materials are developed.
- The lack of diversity amongst the research team was respectfully acknowledged and efforts are being made to address this critical gap to include a more racially, gender, and geographically diverse representation.

Table 5
Additional Organizations for Future Meetings and Research Initiatives

Category	Suggested Additions
Advocacy/non-governmental organizations	Indigenous support services LGBTQ Advisory Group Ontario Alliance for Healthier Communities Sheltering programs YMCA
Governmental (provincial and municipal)	Elder Abuse Ontario Ministry of the Attorney General Ministry of Colleges and Universities Ministry of Municipal Affairs and Housing Public Health Ontario Politicians
Lived experience	Caregivers Individuals who are homeless or without access to computers and or phones Prisoners Racialized communities Rural and remote communities
Justice/legal	Legal Aid Judges Lawyers and law clerks
Mental health and addictions	Canadian Mental Health Association Mental Health Ontario Ontario HIV and Substance Use Training Program Addictions counselling centres

CONCLUSIONS

The organization and effort required to conduct such a meeting was extensive; however, it was of immense value in building collaborative networks and learning through critical consumer consultation. Involving individuals with lived experience as participatory partners in the research process is equally important for furthering a meaningful and ecologically valid research program. This meeting was the first of its kind to utilize an integrated consumer/stakeholder consultation among and between organizations that serve these vulnerable populations. Feedback from participants indicated that this unique event was successful in supporting collaboration, knowledge dissemination and advancing an important knowledge-to-action cycle though the research agenda.

While it is common to identify the importance of engaging knowledge-users/stakeholders in the design and implementation of research, we have documented here the value that results in terms of improved

methodology and increased utility of the research to the stakeholder community. As we continue this research, additional stakeholders will be invited to participate to inform all stages of the research process and the development and exchange of knowledge translation materials.

Further efforts are required to increase awareness and understanding of TBI, as well as routine screening among stakeholder agencies that work in the context of mental health and addictions, the criminal justice system and with women survivors of IPV. Coordinated provincial and national efforts are needed to integrate and strengthen the care delivery system for individuals with TBI of all severities. Moving forward, TBI programs, stakeholders, and policymakers must emphasize rehabilitation and mental health supports as core values even for individuals who are in the chronic stages of this lifelong injury, in order to mitigate the risks for MHA, unstable housing and intersection with the criminal justice system.

REFERENCES

- Anderson, S. A., Hawes, D. J., & Snow, P. C. (2016). Language impairments among youth offenders: A systematic review. *Children and Youth Services Review*, 65, 195–203.
- Bryant, R., O'Donnel, M. L., Creamer, M., McFarlane, A. C., Clark, C. R., & Silove, D. (2010). The psychiatric sequelae of traumatic injury. *American Journal of Psychiatry*, 167(3), 312–320.
- Campbell, J. C., Anderson, J. C., McFadgion, A., Gill, J., Zink, E., Patch, M., ... Campbell, D. (2018). The effects of intimate partner violence and probable traumatic brain injury on central nervous system symptoms. *Journal of Women's Health*, 27(6), 761–767.
- Choleris, E., Galea, L. A. M., Sohrabji, F., & Frick, K. M. (2018). Sex differences in the brain: Implications for behavioral and biomedical research. *Neuroscience & Biobehavioral Reviews*, 85, 126–145. doi:10.1016/j.neubiorev.2017.07.00510.1016/j.neubiorev.2017.07.005.
- Colantonio, A. (2016). Educational resources about concussion in the workplace. Retrieved from <http://abiresearch.utoronto.ca/research/workrelatedtbi/resources/>
- Colantonio, A., Harris, J. E., Ratcliff, G., Chase, S., & Ellis, K. (2010). Gender differences in self reported long term outcomes following moderate to severe traumatic brain injury. *BMC Neurology*, 10(1), 102. doi:10.1186/1471-2377-10-102
- Colantonio, A., Kim, H., Allen, S., Asbridge, M., Petgrave, J., & Brochu, S. (2014). Traumatic brain injury and early life experiences among men and women in a prison population. *Journal of Correctional Health Care*, 20(4), 271–279.
- Graham, D. P., & Cardon, A. L. (2008). An update on substance use and treatment following traumatic brain injury. *Annals of the New York Academy of Sciences*, 1141(1), 148–162.
- Haag, H. L., Caringal, M., Sokoloff, S., Kontos, P., Yoshida, K., & Colantonio, A. (2016). Being a woman with acquired brain injury: Challenges and implications for practice. *Archives of Physical Medicine and Rehabilitation*, 97(2), S64–S70.
- Harris, J. E., Colantonio, A., Bushnik, T., Constantinidou, F., Dawson, D., Goldin-Lauretta, Y., ... Warren, J. (2012). Advancing the health and quality-of-life of girls and women after traumatic brain injury: Workshop summary and recommendations. *Brain Injury*, 26(2), 177–182.
- Hughes, N., Williams, H., Chitsabesan, P., Davies, R., & Mounce, L. (2012). *Nobody made the connection: The prevalence of neurodisability in young people who offend*. Retrieved from http://dera.ioe.ac.uk/16045/1/Neurodisability_Report_FINAL_UPDATED_01_11_12.pdf
- Hwang, S. W., Colantonio, A., Chiu, S., Tolomiczenko, G., Kiss, A., Cowan, L., ... Levinson, W. (2008). The effect of traumatic brain injury on the health of homeless people. *Canadian Medical Association Journal*, 179(8), 779–784. doi:10.1503/cmaj.080341
- Jull, J., Giles, A., & Graham, I. D. (2017). Community-based participatory research and integrated knowledge translation: advancing the co-creation of knowledge. *Implementation Science* 12(150), 1–9.
- Johnson, J. L., Greaves, L., & Repta, R. (2009). Better science with sex and gender: Facilitating the use of a sex and gender-based analysis in health research. *International Journal for Equity in Health*, 8(1), 14.

- Koponen, S. T., T., Portin, R., Himanen, L., Isoniemi, H., Heinonen, H., Hinkka, S., & Tenovu, O. (2002). Axis I and II psychiatric disorders after traumatic brain injury: A 30 year follow-up study. *American Journal of Psychiatry*, 159(8), 1315–1321.
- Macaulay, A. C., Commanda, L. E., Freeman, W. L., McCabe, M. L., Robbins, C. M., & Twohig, P. L. (1993). Participatory research maximizes community and lay involvement. *BMJ*, 319(7212), 774–778.
- MacDonald, S., & Wiseman-Hakes, C. (2010). Knowledge translation in ABI rehabilitation: A model for consolidating and applying the evidence for cognitive-communication interventions. *Brain Injury*, 24(3), 486–508.
- McIsaac, K. E., Moser, A., Moineddin, R., Keown, L. A., Wilton, G., Stewart, L. A., ... Matheson, F. I. (2016). Association between traumatic brain injury and incarceration: A population-based cohort study. *CMAJ Open*, 4(4), E746–e753. doi:10.9778/cmajo.2016007210.9778/cmajo.20160072. eCollection 2016 Oct-Dec.
- North American Brain Injury Society. (2014, June). Special issue on poverty, education, employment, policy reform and advocacy. *Brain Injury Professional*, 11(1), 1–35. Retrieved from <https://issuu.com/bipmagazine/docs/bip38www>
- Ponsford, J., Kelly, A., & Couchman, G. (2014). Self-concept and self-esteem after acquired brain injury: A control group comparison. *Brain Injury*, 28(2), 146–154.
- Rabinowitz, A. R., & Levin, H. S. (2014). Cognitive sequelae of traumatic brain injury. *The Psychiatric Clinics of North America*, 37(1), 1–11. doi:10.1016/j.psc.2013.11.004
- Santopietro, J., Yeomans, J. A., Niemeier, J. P., White, J. K., & Coughlin, C. M. (2015). Traumatic brain injury and behavioral health: The state of treatment and policy. *North Carolina Medical Journal*, 76(2), 96–100.
- Silver, J. M., Kramer, R., Greenwald, S., & Weissman, M. (2001). The association between head injuries and psychiatric disorders: Findings from the New Haven NIMH Epidemiologic Catchment Area Study. *Brain Injury*, 15(11), 935–945.
- Snow, P. C., Bagley, K., & White, D. (2018). Speech-language pathology intervention in a youth justice setting: Benefits perceived by staff extend beyond communication. *International Journal of Speech-Language Pathology*, 20(4), 458–467.
- Snow, P. C., & Powell, M. B. (2011). Oral language competence in incarcerated young offenders: Links with offending severity. *International Journal of Speech-Language Pathology*, 13(6), 480–489.
- Snow, P. C., Woodward, M., Mathis, M., & Powell, M. B. (2016). Language functioning, mental health and alexithymia in incarcerated young offenders. *International Journal of Speech-Language Pathology*, 18(1), 20–31.
- Topolovec-Vranic, J., Ennis, N., Colantonio, A., Cusimano, M. D., Hwang, S. W., Kontos, P., ... Stergiopoulos, V. (2012). Traumatic brain injury among people who are homeless: A systematic review. *BMC Public Health*, 12(1), 1059. doi:10.1186/1471-2458-12-1059
- Valera, E. M., & Berenbaum, H. (2003). Brain injury in battered women. *Journal of Consulting and Clinical Psychology*, 71(4), 797–804.
- WHO. (2009). BOX 1.4, Gender-sensitive and gender-responsive programming. In *Integrating gender into HIV/AIDS programmes in the health sector: Tool to improve responsiveness to women's needs*. Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK143050/box/section1.box4>
- Williams, H., Chitsabesan, P., Fazel, S., McMillan, T., Hughes, N., Parsonage, M., & Tonks, J. (2018). Traumatic brain injury: A potential cause of violent crime? *The Lancet Psychiatry*, 5(10), 836–844. doi:10.1016/S2215-0366(18)30062-2
- Williams, H., Hughes, N., Williams, W., Chitsabesan, P., Walesby, R. C., Mounce, L. T., & Clasby, B. (2015). The prevalence of traumatic brain injury among young offenders in custody: A systematic review. *Journal of Head Trauma Rehabilitation*, 30(2), 94–105.
- Williams, H., Wszalek, J. A., & Turkstra, L. S. (2015). Language impairments in youths with traumatic brain injury: Implications for participation in criminal proceedings. *Journal of Head Trauma Rehabilitation*, 30(2), 86–93.
- Wiseman-Hakes, C., Ryu, H., Lightfoot, D., Kukreja, G., Colantonio, A., & Matheson, F. I. (2020). Examining the efficacy of communication partner training for improving communication interactions and outcomes for individuals with traumatic brain injury: A systematic review. *Archives of Rehabilitation Research and Clinical Translation*, 2, 10036.
- Wiseman-Hakes, C., Saleem, M., Poulin, V., Nalder, E., Balachandran, P., Gan, C., & Colantonio, A. (2019). The development of intimate relationships in adolescent girls and young women with Traumatic Brain Injury: A framework to guide Gender Specific Rehabilitation and enhance positive social outcomes. *Disability and Rehabilitation*, April 1–7.

Yuhasz, J. E. (2013). Misconceptions about traumatic brain injury among correctional health care professionals. *Journal of Correctional Health Care*, 19(2), 135–143.