

Research Priorities for Optimizing Long-term Community Integration after Brain Injury

Emily J. Nalder, Karl Zabjek, Deirdre R. Dawson, Carolina L. Bottari, Isabelle Gagnon, Bradford J. McFadyen, Anne W. Hunt, Suzanne McKenna, Marie-Christine Ouellet, Sylvain Giroux, Nora Cullen, Ewa Niechwiej-Szwedo, ONF-REPAR ABI Team

ABSTRACT: *Objective:* This paper reports on a funded summit, which convened a multidisciplinary group of experts to provide consensus on the research priorities necessary for improving long-term community integration of individuals with traumatic brain injury (TBI) and their caregivers. *Methods:* The 2-day summit was directed using the World Café Methodology, to engage stakeholders and collaboratively arrive at a consensus on the problems to be targeted in research. Participants ($n = 54$), drawn from two Canadian provinces, included an interdisciplinary group of researchers, clinicians, representatives from brain injury associations, individuals with TBI, and caregivers. In small groups, participants discussed challenges to long-term community integration and potential initiatives that would address these barriers. Field notes from the discussions were analyzed using qualitative content analysis. *Results:* The consensus on prioritized research directions included developing interventions to optimize the functioning and participation of individuals with TBI, reducing caregiver burden, and evaluating how emerging technology can facilitate delivery of care. *Conclusions:* The World Café Methodology was an effective method for developing research priorities. The breadth of expertise of participants and the collegial environment allowed for the identification of a broad perspective on important future research directions with potential to enhance the long-term community integration of individuals with brain injury.

RÉSUMÉ: *Établir des priorités de recherche visant à améliorer l'intégration à long terme d'individus victimes de lésions cérébrales.* *Objectif:* Cet article vise à rendre compte d'une rencontre à laquelle a été convié un groupe multidisciplinaire d'experts. Son objectif était de parvenir à un consensus quant aux priorités de recherche nécessaires pour améliorer l'intégration communautaire à long terme d'individus ayant été victimes de lésions cérébrales traumatiques ainsi que celle de leurs aidants naturels. *Méthodes:* Cette rencontre de deux jours a été organisée en utilisant la *World Café Methodology*. Cette méthode a permis aux parties prenantes invitées de participer activement et d'atteindre ensemble un consensus en ce qui regarde les aspects problématiques devant être abordés par la recherche. Au nombre de 54, issus de deux provinces canadiennes, les participants venaient de tous les horizons: groupe interdisciplinaire de chercheurs, cliniciens, représentants d'associations de victimes de lésions cérébrales, individus ayant été eux-mêmes victimes de lésions cérébrales traumatiques et leurs aidants naturels. En petits groupes, ces participants ont examiné les obstacles qui rendent difficiles une intégration communautaire à long terme et les initiatives potentielles qui pourraient permettre de les surmonter. Les notes prises dans le cadre de cette rencontre ont été ensuite analysées au moyen de la méthode d'analyse qualitative de contenu. *Résultats:* Selon les participants, voici les avenues de recherche qui devraient être privilégiées: développer des interventions visant à maximiser le fonctionnement et la participation des individus victimes de lésions cérébrales traumatiques; réduire le fardeau imposé aux aidants naturels; enfin, évaluer dans quelle mesure les nouvelles technologies peuvent faciliter la prestation de soins. *Conclusions:* La *World Café Methodology* s'est avérée une méthode permettant de définir des priorités de recherche de façon efficace. L'étendue de l'expertise présente associée à l'approche collégiale privilégiée a rendu possible l'établissement d'une vaste perspective en matière d'avenues de recherche futures. Ces dernières ont le potentiel d'améliorer l'intégration à long terme des individus victimes de lésions cérébrales traumatiques.

Key words: Traumatic brain injury, Stakeholder engagement, Rehabilitation, World Café Method

doi:10.1017/cjn.2018.334

Can J Neurol Sci. 2018; 45: 643-651

From the Department of Occupational Science and Occupational Therapy & Rehabilitation Sciences Institute, University of Toronto, Toronto, Ontario, Canada (EJN, DRD, AWH); March of Dimes Canada, Toronto, Ontario, Canada (EJN); Department of Physical Therapy & Rehabilitation Sciences Institute, University of Toronto, Toronto, Ontario, Canada (KZ); Rotman Research Institute, Baycrest, Toronto, Ontario, Canada (EJN, DRD); School of Rehabilitation & Centre for Interdisciplinary Research in Rehabilitation, Université de Montréal, Montreal, Quebec, Canada (CLB); School of Physical and Occupational Therapy & Montreal Children's Hospital, McGill University, Montreal, Quebec, Canada (IG); Centre interdisciplinaire de recherche en réadaptation et intégration sociale, Université Laval, Quebec, Quebec, Canada (BJN, MCO); Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, Toronto, Ontario, Canada (AWH); Brain Injury Canada, Ottawa, Ontario, Canada (SM); Faculté des sciences, Université de Sherbrooke, Sherbrooke, Quebec, Canada (SG); Toronto Rehabilitation Institute, University Health Network, Toronto, Ontario, Canada (EJN, KZ, DRD, NC); Department of Kinesiology, University of Waterloo, Waterloo, Ontario, Canada (ENS).

RECEIVED AUGUST 11, 2017. FINAL REVISIONS SUBMITTED JULY 3, 2018. DATE OF ACCEPTANCE AUGUST 5, 2018.

Correspondence to: Emily J. Nalder, Department of Occupational Science and Occupational Therapy and Rehabilitation Sciences Institute, University of Toronto, Toronto, ON, Canada; Rehabilitation Sciences Building, University of Toronto, 160-500 University Avenue, Toronto, Ontario, Canada M5G 1V7. Email: emily.nalder@utoronto.ca

INTRODUCTION

The prevalence of disablement following traumatic brain injury (TBI) is well known,^{1–3} and of increasing concern as we now recognize that several sequelae can persist and worsen in the chronic stages.^{3–5} One longitudinal study found that in the first 5 years following injury 39% of individuals had deteriorated in global functioning, 55% were unemployed, and about 30% were not independent in performing activities of daily living.³ Indeed, TBI has been described as a chronic condition, with a potential for lifelong activity limitations and participation restrictions. Moreover, level of function is not static and can deteriorate with time post injury.⁵ Decline in functioning has been attributed to psychosocial factors, co-morbidities, aging, or to neurodegenerative processes.^{6,7} For example, atrophy in at least one brain region in the first 2 years post injury was observed in 95% of participants in one study.⁶ Because TBI is now recognized as a chronic condition,⁷ and in the context of limited research dollars, researchers and funding agencies agree that setting priorities with the aim of maximizing well-being for survivors and their families is critical.⁵ The purpose of this paper is to describe the process and results of a summit held in 2016 with Canadian experts in TBI to formulate research priorities. The aim of reporting these data is to highlight the priority research areas needed to optimize the long-term community integration for individuals with TBI, and to illustrate a methodology to identify research directions.

Traumatic brain injury may affect all aspects of a person's functioning, including the physical, cognitive, emotional, and social spheres. Developing research priorities is thus essential because of the breadth of support needs and multiplicity of important research directions. For instance, current research in TBI addresses epidemiology,⁸ health service needs and usage,⁹ consequences of TBI in terms of functioning, community integration³ and individuals' views of self,¹⁰ and the nature and efficacy of specific healthcare and/or rehabilitation service models and interventions.¹¹ The latter category can be further divided according to interventions that aim to remediate or compensate for impairments in emotional, physical, cognitive, communication and/or behavioral functioning,¹² medical management of TBI,¹¹ and interventions designed to enhance participation in everyday life (e.g., meta-cognitive strategy training,¹³ vocational rehabilitation,¹⁴ and social services such as affordable and supportive housing, income supports, and accessible transport).⁹ It is also essential to consider the needs of family caregivers who play a vital role in facilitating long-term community integration.¹⁵

Given the limits in terms of funding and resources for research, it is critical to prioritize the many potential research directions that could be pursued to optimize the long-term community integration of individuals with TBI and their caregivers, as they both age. A recent review paper synthesizing evidence on long-term outcomes and chronic neurological changes following TBI called for more research to examine how neurological functioning and participation change over time. Such information is essential to identify potential targets for intervention, and guide researchers to develop and evaluate interventions that may improve community integration.⁵ We were given an opportunity by two Canadian provincial organizations to identify research priorities that could ultimately be pursued by an interdisciplinary TBI research team on the theme optimizing long-term community integration. This team consisted of clinicians, decision-makers, TBI survivors and

caregivers, and over 40 top Canadian researchers in the field of TBI, and the funders' vision was to promote collaboration and innovation by allowing the team to work on a common research agenda.

The first step toward identifying research priorities for our team was to engage stakeholders in discussions around the theme to identify potential research directions. Stakeholder meetings are specifically effective at engaging members of the community and identifying research questions that reflect their priorities,¹⁶ and are an important component in efforts to develop research agendas designed to influence policy and practice.¹⁷ In addition, using stakeholder meetings to set research priorities is viewed as a method for reducing research waste and fostering innovation by promoting collaboration and knowledge exchange across researchers in different disciplines or fields.¹⁸

There are a few examples of research agendas published in relation to TBI, but to our knowledge none explicitly focus on long-term community integration. Some address specific topics, such as homelessness¹⁹ or the needs of women with TBI,²⁰ whereas others are more global looking at all aspects of TBI.¹¹ One of the first published examples of a consensus activity to identify research priorities specific to TBI occurred in 2005.¹¹ The Conemaugh International Brain Injury Symposium brought together over 100 neuroscientists, and other associations and professionals, involved in the rehabilitation and treatment of individuals with TBI¹¹ to review progress made in research over the preceding decade, and to make recommendations to government on the priority areas for TBI research moving forward. The committees formulated research priorities in four areas: basic science, acute care, post-acute rehabilitation, and improving quality of life. The basic science group identified mechanisms of progressive brain injury and therapeutic discovery and development as two priorities for further study, and the acute care and post-acute teams called for more clinical trials to determine the efficacy of interventions, noting the paucity of level I evidence. Participants at this meeting also identified a need for more precise assessment tools to measure outcomes, and for studies looking at comparative effectiveness and cost-effectiveness of different models of interventions.¹¹ As over 10 years has passed since this symposium, and more is now known regarding the chronic nature of TBI, it is timely to review and update research priorities for TBI.

In sum, our broad objective was to formulate research priorities with the most potential for improving the long-term community integration of individuals with TBI and their family caregivers. Our specific objectives were (1) to identify the primary challenges to optimal long-term community integration that are encountered by survivors, their families, and caregivers; (2) to identify potential short-term (2 years) and longer-term initiatives (5 years) that will address these barriers to community integration; and (3) to synthesize and prioritize these initiatives into specific research priorities.

METHODS

Design

A 2-day stakeholder meeting was arranged, using the World Café Methodology—a conversational method designed to engage large groups in conversation around important issues to catalyze

Table 1: Participants involved in formulating the research priorities*

	Academic/Institute researchers			Trainees	Health service delivery	Community-based organization representative	Persons with lived experience	Caregivers
	Applied research	Fundamental research	Knowledge translation research					
Ontario (n)	20	3	5	4	14	4	1	1
Quebec (n)	26	3	1	1	2	3	0	0

*Some participants had more than one role; hence, the totals do not add up to $n = 54$, which was the total number of participants engaged in the process.

change,²¹ and used, in other contexts, to generate research priorities.¹⁷ This type of conversational method is effective in promoting interdisciplinary collaboration, fostering innovation and creative thought, and enhancing the relevance of research, by asking end-users about their priorities.^{21,22} A team grant in TBI research provided by two provincial organizations was used to fund the 2-day meeting.

The World Café method involves groups of people discussing a topic of importance to them. Participants change groups, so that they discuss the issue with different people. The method is based on a social constructivist paradigm, whereby knowledge is viewed as socially constructed through interactions with others.²¹ Key principles for hosting a World Café discussion are as follows: (1) create a hospitable space; (2) explore questions that matter; (3) encourage everyone's contribution; (4) connect diverse people and ideas; (5) listen together for insights, patterns, and deeper questions; and (6) make collective knowledge visible.²³ The specifics of how we implemented this method to develop research priorities follows.

Participants

We used purposeful snowball sampling to identify a diverse group of participants ($n = 54$) with broad expertise for the 2-day summit. Researchers who were part of existing inter-provincial TBI research teams in Ontario and Quebec were first invited, and they invited others from their networks including researchers, persons living with TBI, and persons working for community-based TBI organizations, specifically Brain Injury Canada, the Ontario Brain Injury Association, the Quebec Association for Individuals Living with Traumatic Brain Injury, and the Quebec Rehabilitation Research Network. Graduate students and post-doctoral fellows working with researchers were also invited. The resulting team (see Table 1 for details of participants, $n = 54$) comprised a broad range of professionals, stakeholders, and individuals with lived experience with expertise in occupational therapy ($n = 15$), psychology ($n = 13$), physical medicine and rehabilitation ($n = 3$), medicine ($n = 4$), service delivery/administration ($n = 3$), computer science ($n = 3$), speech and language pathology ($n = 3$), biomechanics ($n = 2$), case management ($n = 2$), epidemiology ($n = 2$), neuroscience ($n = 2$), nursing ($n = 2$), physical therapy ($n = 2$), and social work ($n = 1$). In addition, there were two representatives from Brain Injury Associations: one individual with lived experience and one caregiver. Further, several participants held leadership roles on TBI advisory boards and professional associations that influence policy and service delivery, and several of the researchers were engaged in work to synthesize current best evidence and produce clinical

practice guidelines for the management of mild TBI,²⁴ and rehabilitation in moderate-to-severe TBI.²⁵ Each team member attended either one ($n = 24$) or both meetings ($n = 15$), or, if unable to attend in person, provided input via email ($n = 15$, all researchers).

Procedure

The stakeholder meeting was held over 2 days in February and April 2016 in Canada. The first day involved multiple group conversations to identify a broad range of challenges pertaining to long-term community integration and potential solutions to these issues. The second day was used to refine this list, reach consensus on priorities, and develop a research agenda. The 2 days were not held consecutively so that participants had time to further reflect on the discussions before formulating research priorities.

Day 1

The meeting began with a series of presentations illustrating ongoing research on TBI in Canada. Of note was a presentation of key findings from a recent national survey in Canada, designed to identify research gaps in relation to TBI and spinal cord injury rehabilitation and recovery from the perspective of individuals living with these conditions. Priority research topics identified in this survey were improving mood and cognitive function, understanding the functioning of the brain, housing, and enhancing community living skills. After these initial presentations, small groups of ~9 individuals per group discussed the barriers to community integration and short- and longer-term initiatives that could address these barriers. Group discussions were based around a key question (see Table 2). Questions were developed before the meeting by the meeting chairpersons (DD, IG) and adapted from questions used in published stakeholder meetings using the World Café Methodology.¹⁷

Three 35-minute group conversations occurred simultaneously, each led by a facilitator and addressing one of the three questions. The facilitators were team members and received instruction before the summit regarding how to structure the conversations. Following each conversation, participants moved to another room, to discuss a different question, with a different group of people. After the three small-group conversations, the facilitators presented a summary of the major ideas that had emerged to the reassembled, whole group. The summit chair then facilitated a town-hall-style discussion in which emerging ideas were grouped together into broad themes. Themes were recorded on flip chart paper, and then placed on the walls around the room forming a visual gallery of the key themes derived through the conversations.

Table 2: Key questions guiding the small-group discussion

If we were writing a letter to someone in government about the current realities facing individuals living with TBI, what should go in that letter?
In the next 2 years, what steps should be taken so that individuals with TBI could have more optimal community integration?
Five years from now, you reflect back and think that _____ has really improved the lives of those living with TBI?

TBI = traumatic brain injury.

To reach consensus, we used a voting procedure²⁶ to prioritize these themes. Each participant was given six stickers and asked to place them on the theme or themes they perceived were most important to improving the community integration of individuals with TBI. Each sticker represented one vote and participants could assign multiple votes to a theme as they wished. After the meeting a list of the identified themes was sent to those participants who were not able to attend in person and they allocated their six votes to a theme (or themes) via email. Because there were fewer participants from community-based organizations, or with lived experience of TBI, these individuals ($n = 4$) each received 12 votes to give them more influence.

A small group of researchers with experience in qualitative methods and/or who were involved in the overall planning and organization of the meeting (DD, CB, IG, EN, and KZ) met to tabulate the votes and develop definitions of each theme using a qualitative content analysis.²⁷ This involved re-reading all the flip chart notes to increase familiarity with the data, coding the data, and theorizing the relationships between codes and the themes identified during the meeting on day 1. Codes were thus used to define the themes, ensuring internal validity (content all related to a core idea) and external validity (delineating conceptual boundaries between the themes identified). The thematic summary and tabulated votes were sent to all participants via email and discussed on day 2 of the meeting.

Day 2

The second full-day meeting was facilitated by the summit chairpersons (DD and CB). The day began with three small groups of ~9 participants, each with a facilitator, reviewing the thematic summary developed from the discussions on day 1, to decide whether they agreed with the identified themes, and to group similar themes together. Everyone then reconvened to listen to and discuss each group's ideas for grouping themes, and to collectively decide on the two or three most important research priorities for our team.

RESULTS

Research themes—initiatives to improve long-term community integration after TBI

The themes that emerged using the World Café Methodology (day 1) and the number of votes they each received are listed in Table 3. On day 2, consensus was achieved for combining the 12 themes into three priority areas for research (all focused on moderate-to-severe TBI): (1) optimizing functioning through individualized intervention; (2) supporting caregiver needs; and (3) using technology as a driver of care (see Figure 1). Two cross-

cutting themes also emerged that were viewed as important for our team's work in all three of these research areas, namely knowledge translation (KT) and enhancing the lens of TBI as a chronic condition. An explanation of each of these research priorities follows.

Optimizing functioning through individualized intervention

The first research priority reflected the need for work to develop, evaluate, and implement interventions that would optimize the functioning and participation of individuals with TBI, and prevent relapse or deterioration in function over time. Some key discussion points related to this research priority included the need for (1) developing and evaluating the psychometric properties of ecologically valid assessments that can be used to evaluate intervention efficacy and monitor functional changes arising in the context of individuals' daily life; (2) identifying and evaluating self-management interventions to maintain physical, psychological, and cognitive functioning; (3) understanding the critical characteristics of supported housing for individuals with TBI who may need to transition from the family home into alternative accommodation as caregivers age; and (4) producing evidence of real-world effectiveness of interventions, through information on how specific interventions influence participation in unstructured and changing environments more like real life, and by evidence that the skills acquired in therapy can be transferred to other tasks and contexts. Themes from day 1 of the World Café discussion initially separated interventions targeting the individual from those targeting aspects of the environment. However, the group felt that intervention research should consider the complex relationships between individuals and environments and how each influences the other over time.

Supporting caregiver needs

The second research priority was supporting caregiver needs. Key discussion points related to this research priority included the following: (1) the need to better understand the experiences of aging caregivers providing support to someone with TBI in the home, and how their needs change over time and across contexts (e.g., during residential transitions, or as individuals go into respite care); (2) the importance of developing and evaluating individualized interventions that would reduce caregiver burden, in particular case management, respite services, social support, strategy training, and education; (3) the need to evaluate the cost-effectiveness of interventions that would improve caregiver well-being and family functioning; and (4) the importance of recognizing that families have complex needs including observing improvements in the functioning of their relative or friend with TBI. Thus, in addition to examining interventions targeting the caregiver, it will also be important to explore how interventions targeting the functioning and participation of individuals with TBI influence caregiver burden.

Technology as a driver of care

The third research priority was to explore how emerging technology platforms could be used to complete assessments, deliver interventions, or support the everyday functioning of individuals with TBI and/or their caregivers in the home and community. Key discussion points related to this research priority included the need

Table 3: List of themes describing challenges and strategies to optimal long-term community integration following TBI

Theme	Example of the issue	Number of votes received
Optimize functioning	Developing and evaluating individualized interventions to optimize function and participation and prevent relapse (e.g., self-management intervention; customized care plans, cognitive rehabilitation)	40
Advancing platforms for technology	Developing, evaluating, and implementing technology platforms to optimize care (e.g., telehealth and monitoring technology)	27
Integration to the community	Understanding and modifying environmental factors that influence community integration (e.g., housing support, caregiver supports)	22
Widening access to care	Developing, evaluating, and implementing interventions targeting system-level and policy challenges (e.g., models of integrated care, or interventions targeting health system transitions)	19
Information access	Developing infrastructure to provide individuals with TBI, families, and professionals/service providers with access to the right information at the right time (e.g., wiki platforms, websites)	18
Addressing caregiver needs	Developing, evaluating, and implementing interventions to support informal caregivers and families and to accommodate changing needs of aging carers (e.g., reducing caregiver burden, provision of respite care, financial planning)	15
Integration-KT	Employing models of funding and practice that integrate research with service delivery and education (e.g., collecting data for research as part of service delivery involving trainees and students in the process)	12
Managing TBI across the life span	Understanding how experiences of community integration and support needs change across the life span (e.g., life-long issues of individuals who sustain a TBI in childhood)	12
Enhancing the lens of TBI as a chronic/degenerative condition	Knowledge translation interventions to shift the understanding of TBI as an acute injury to a chronic condition (e.g., advocacy or application of chronic disease models of care to TBI)	11
Integration across service sectors	Interventions targeting the service delivery system to optimize receipt of the right care at the right time (e.g., partnering across sectors of care, education to enhance the ability of other sectors for instance mental health or criminal justice systems to manage TBI)	11
Restoration	Interventions that would focus on cure, promoting neuroplasticity, and understanding mechanisms of recovery (e.g., research to identify biomarkers, understand neural mechanisms of recovery)	10
Establishing prevalence of TBI	Epidemiological research to establish prevalence, the scale, and costs of TBI to society	3

KT = knowledge translation; TBI = traumatic brain injury.

to (1) develop and evaluate telehealth platforms and/or centers for intervention delivery, and examine whether they improve access to health and rehabilitation services for individuals with TBI; (2) understand the utility of technology to monitor body functions and/or participation patterns of individuals with TBI and provide this information to individuals or health professionals in a manner that can support self-management; (3) investigate the role of technology in supporting individuals with TBI and their caregivers to navigate the healthcare system, and more easily identify services to meet their needs, and coordinate different services and providers;

(4) develop apps or websites to facilitate KT and inform end-users (e.g., professionals, individuals, and families) about the quality of evidence related to specific interventions or assessments; and (5) identify ethical aspects of technology use (e.g., choice, risk, and autonomy) and barriers to implementation of technology-mediated interventions with individuals with TBI so that those who need technology for community integration can access and use it. It was noted that not all individuals with TBI have access to technology platforms, or perhaps more importantly to the Internet, and thus the need to develop partnerships between industry, research, and service providers that could begin to address barriers to uptake of technology-mediated interventions.

Cross-cutting themes: KT and enhancing the lens of TBI as a chronic condition

A cross-cutting theme of KT emerged reflecting the need to identify and address evidence to practice gaps, and to develop, evaluate, and implement knowledge-translation interventions to ensure that interventions with best evidence are used in practice. Key discussion points related to this cross-cutting theme included the following: (1) the potential value of developing community–research partnerships, as this is suggested to increase the likelihood that research evidence can be applied in practice.²⁸ The impact of these partnerships on evidence-informed decision-making should also be studied; (2) the need for targeted exchange of knowledge across sectors to promote integrated care for individuals with TBI (e.g., between brain injury and mental health

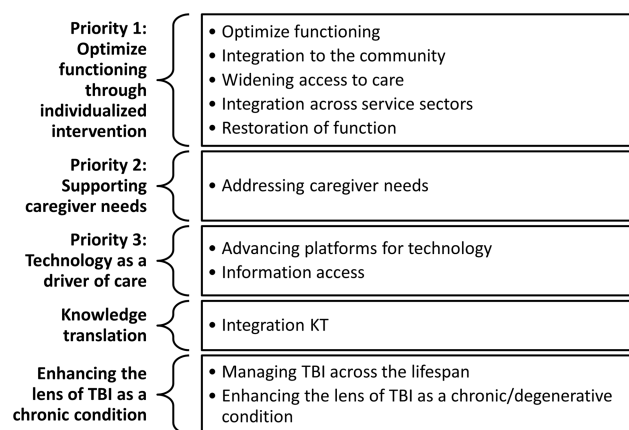


Figure 1: Prioritized research directions and their relationship to the themes emerging from the World Café discussions.

services); (3) the need for high-quality knowledge syntheses in each of our prioritized research areas (interventions to optimize functioning and participation, supporting caregivers, and the use of technology to drive care) was viewed as a vital step to facilitating KT.

Another cross-cutting theme that emerged was the need to advance the understanding of TBI as a chronic and long-term condition in order to address some of the systemic challenges of limited access to long-term care and support to enable community integration. Key discussion points related to this cross-cutting theme included the following: (1) when developing interventions, it may be beneficial to review existing evidence generated in other populations with chronic illness (e.g., in relation to self-management and caregiver needs); (2) there is a need to advocate and apply consistent language so that TBI is understood as a chronic condition rather than an acute condition; and (3) understanding and evaluating funding and service models that provide care across the life span.

DISCUSSION

The broad objective of this study was to formulate research priorities with the potential for improving the long-term community integration of individuals with TBI and their family caregivers. To achieve this broad goal, we used the World Café Methodology in a 2-day stakeholder meeting. The primary questions that were addressed in the first day revolved around the identification of current realities that individuals with TBI and their families are confronted with, and which strategies have a higher probability of improving the lives of individuals with TBI and their families in the long term, according to experts' own experiences or research programs, and their knowledge of existing evidence related to TBI. The second day of stakeholder discussion revolved around the identification and prioritization of strategic research directions. Many potential directions for research emerged through the process, and as per the request from our funder to develop a collaborative research network working on a common research agenda, we synthesized these into three priority areas: optimizing functioning through individualized intervention, supporting caregiver needs, and using technology as a driver of care. It was interesting to note that although we began this process with experts working in mild and moderate-to-severe TBI, the consensus-building process narrowed the focus to research addressing the needs of those with moderate-to-severe injuries and their caregivers.

The World Café Methodology engaged experts in TBI rehabilitation including individuals from different disciplines engaged in research, service management/design, and frontline delivery of rehabilitation for individuals with TBI, as well as caregivers and individuals living with TBI. The team included participants from two provinces in Canada, which allowed for more nuanced considerations of how potential research projects could be carried out and ultimately influence two different healthcare systems. The varied expertise of participants ranged from basic science to clinical rehabilitation and enabled a breadth of issues that individuals who are living with TBI experience, to emerge through the process. In addition, the stakeholder meeting allowed for the identification of links between different research areas and opportunities for collaboration, and provided a voice to individuals working in TBI associations whose role is to advocate for

individuals and families living with TBI.²² The breadth of expertise among participants in this 2-day meeting allowed for the identification of strategic priorities that cannot be addressed only by researchers in one discipline, and can potentially lead to new innovations as participants with very different backgrounds learn and problem-solve during their conversations.

Optimizing function and the need for evidence-based real-world interventions

The theme of optimizing functioning through individualized intervention was a very broad theme reflecting the need for intervention in many areas, such as enhancing physical/psychological/cognitive and behavioral functioning, optimizing inclusion and participation, and preventing decline with aging, as well as systems-level interventions that would widen access to care. The need for intervention research aligns with the literature, as recent systematic reviews and clinical practice guidelines in brain injury rehabilitation consistently note the lack of evidence demonstrating the efficacy and cost-effectiveness of rehabilitation interventions.^{25,29} Moreover, other published research agendas for individuals with TBI, including the Conemaugh symposium, have called for a focus on research to develop and evaluate interventions.¹¹ Taken together, these findings suggest that producing evidence of intervention effectiveness is a continuing priority.

Although our team identified a need for intervention work in many different areas, there was a commonly identified theme, specifically the need for evidence of real-world effectiveness. This is in line with increasing evidence that highlights the importance of designing contextualized interventions that involve tasks and activities representative of everyday life,^{13,25} and developing ecologically valid outcome measures.^{30,31} Developing ecologically valid assessments and evidence of their reliability, validity, and responsiveness is essential so that they can be used as outcome measures in intervention studies. This will enable researchers to draw conclusions about whether the intervention being studied and any improvements observed correspond with performance in daily life, and not just reflect performance in a controlled, clinical environment.³²

Supporting caregiver needs

Supporting caregiver needs was another priority research direction. Representatives of the community-based organizations identified aging caregivers as experiencing major stressors when considering long-term community integration. Many of the challenges for caregivers that were identified in the stakeholder meeting were consistent with existing evidence pertaining to the experiences of caregivers of individuals with TBI, in particular the high levels of caregiver burden,³³ lack of access to community services and supports, and the high levels of stress during transitions of care.^{34,35} Although some qualitative evidence exists describing the perceptions of aging caregivers regarding their support needs,^{34,35} these studies typically occur at one point in time, and lack detail regarding the contextual factors influencing caregivers' experiences and how they change over time as they and the individual with TBI age.

A recent systematic review demonstrated that there is limited high-quality evidence from randomized controlled trials regarding how to intervene to alleviate caregiver burden,³⁶ perhaps owing to the multiplicity of intervention strategies and factors contributing to caregiver burden. This supports the research direction identified

within this stakeholder meeting that was to focus on developing, evaluating, and implementing interventions to alleviate caregiver burden, and to include caregiver outcomes as a secondary measure in trials evaluating interventions targeting the functioning of individuals with chronic TBI.^{36,37}

The potential promise of new technology

The potential promise of new technology platforms within the context of optimizing long-term community integration of individuals living with a TBI was unanimously identified as a priority direction for further research. In fact, the group discussion highlighted numerous ways in which these new technologies could widen access to care, improve patient monitoring and system navigation, and support research and education. However, rigorous research is required to determine the benefits and also the limits of how technology can be applied.

Technology in the form of mobile applications, wearable sensors, and sensor networks is increasingly being explored to support the management of complex health conditions in the community.³⁸ In parallel, the emergence of generic commercial applications (e.g., smartphone apps) that promote health, and management of daily tasks, has also been widely accepted by the general public. One of the major areas in which technology is being used in general is to support self-management particularly of adults with chronic health conditions through self-monitoring of functioning, and the remote delivery of interventions (either in a self-directed or therapist-delivered manner using videoconferencing).³⁹ Within the context of TBI, however, the primary focus of technology-based interventions pertains to the use of assistive technology as a cognitive aid and to support the performance of activities of everyday living.^{40,41} Preliminary research has demonstrated the initial promise of telerehabilitation to serve as a tool to deliver rehabilitation and improve caregiver self-management.^{42,43} Smart home technologies have also shown much promise in optimizing independence and safety in the home for individuals with cognitive deficits.⁴⁴ However, there still remains a need to fully explore the potential of the different types of technology and their optimal application, as well as the limitations of this method of delivering care. This work to enhance the evidence for technology driving care for individuals with TBI requires interdisciplinary input to produce innovation, to ensure that technologies can be implemented effectively and integrated within existing practices and systems, and to address complex ethical issues that accompany the increasing application of technology in healthcare.

Cross-cutting themes

Knowledge translation emerged as a cross-cutting idea, perhaps related to the fact that all three of our identified priorities focus on intervention development and evaluation, with the long-term goal of moving knowledge outputs into clinical practice. One strategy identified through the World Café discussions for enhancing KT was having integrated models where researchers work with end-users, or as part of service organizations.²⁸ Collaborative applied research with community members has been shown to influence evidence-informed decision-making among healthcare professionals, and is increasingly being requested by research funders;¹⁶ however, to our knowledge, these models have not yet been evaluated in the context of TBI. A possible

direction for our team moving forward is to evaluate the impact of our research partnership involving academics, service providers, and persons with lived experience, on key indicators of KT (e.g., evidence-informed decision-making).

The final cross-cutting theme reflects the need to consider TBI as a chronic condition when developing and evaluating interventions and advocating for system-level changes. This aligns with accumulating evidence that demonstrates that functioning after TBI is not static, and that both deterioration in functioning and brain atrophy have been observed over time.^{3–6} Traumatic brain injury is therefore considered to be a chronic condition, and that, similar to other chronic illnesses, interventions should be focused on how to monitor functioning, developing, and evaluating lifestyle interventions that can support self-management, and at a system level provide access to supports, and the flexibility to match services to needs over the life span.^{5,9}

Limitations

As the process of forming research priorities was driven through consultation and engagement of a purposeful sample of stakeholders, in one context, there is a potential that important perspectives from stakeholders that were under-represented, or from other contexts may have been omitted. Thus, the three directions presented do not represent the only priorities for research in TBI but rather the areas prioritized by our team. In particular, there was only one caregiver and one individual with lived experience of TBI involved in the current process, so the perspectives of survivors and families may have been under-represented, and we had a large number of participants from occupational therapy and psychology, meaning the weight given to their perspective may have been stronger than other professions with less representation (e.g., social work, recreation therapy). However, TBI association members were included and they work directly with individuals and families on a daily basis as advocates for their needs.

We were requested by our funding body to identify two or three research priorities related to a broad theme (optimizing long-term community integration). We approached this using the World Café method, which draws out experts' perspectives of strengths and gaps in the literature. This approach has been recommended to enhance the relevance of the research to end-users, and to promote collaboration and reduce duplication.^{18,22} Stakeholder consultation focuses on expert opinion, and reviews of the existing literature should also be part of developing research priorities. To ensure that current literature was considered throughout the 2-day summit, we began the stakeholder meeting with a series of presentations summarizing current research related to the theme (health services and systems, mild TBI, community integration in moderate-to-severe TBI). In addition, subsequent to this stakeholder meeting, members of our group have initiated systematic reviews of the literature related to the priority areas that were identified in this meeting—specifically, reviewing evidence for interventions to alleviate caregiver burden, and describing how technology is used in TBI rehabilitation.

CONCLUSION

In a 2-day summit, involving researchers, clinicians, individuals with TBI and their caregivers, and representatives from Brain Injury Associations, research priorities were developed with

the goal of optimizing the long-term community integration of individuals with TBI. Prioritized directions for research were developing interventions to optimize functioning and evaluating their effectiveness in real-world contexts, supporting caregivers, and using technology to drive care. The results of this summit provide a guide for stakeholders in research and government on target areas for research funding, and may foster interdisciplinary study, by bringing together a diverse group of stakeholders to collaboratively form research priorities.

ACKNOWLEDGMENTS

The authors thank all members of the ONF-REPAR research team who participated in this process of formulating research priorities, as well as Yarden Levy, Denise Dubois, and Lisa Engel who helped to compile data from the 2-day meeting for analysis.

FINANCIAL SUPPORT

This work was supported by a team grant in acquired brain injury (awarded to DRD and CLB) funded by the Ontario Neurotrauma Foundation and the Réseau Provincial de Recherche en adaptation-réadaptation in Quebec, Canada. All other authors have no conflicts to disclose.

STATEMENT OF AUTHORSHIP

EJN and KZ drafted the paper with input from all authors. DRD, CLB, and IG conceptualized the summit, and developed the agenda and questions guiding the discussions using the World Café Methodology. EJN, KZ, BJM, SM, and AWH facilitated group conversations within the summit. All authors participated in the summit meeting, and in subsequent discussions to analyze the data, helped to edit the manuscript, and read and approved the final paper, before its submission.

DISCLOSURES

EJN, KZ, IG, BJM, AWH, SM, MCO, SG, NC, and ENS have nothing to disclose. DD reports grants from ONF-REPAR during the conduct of the study. CLB reports grants from Ontario Neurotrauma Foundation and the Réseau Provincial de Recherche en adaptation-réadaptation.

REFERENCES

- Dawson DR, Chipman M. The disablement experienced by traumatically brain-injured adults living in the community. *Brain Inj.* 1995;9(4):339-53.
- O'Connor C, Colantonio A, Polatajko H. Long term symptoms and limitations of activity of people with traumatic brain injury: a ten-year follow-up. *Psychol Rep.* 2005;97(1):169-79.
- Corrigan JD, Cuthbert JP, Harrison-Felix C, et al. US population estimates of health and social outcomes 5 years after rehabilitation for traumatic brain injury. *J Head Trauma Rehabil.* 2014;29(6):E1-9.
- Till C, Colella B, Verwegen J, Green RE. Postrecovery cognitive decline in adults with traumatic brain injury. *Arch Phys Med Rehabil.* 2008;89(12):S25-34.
- Wilson L, Stewart W, Dams-O'Connor K, et al. The chronic and evolving neurological consequences of traumatic brain injury. *Lancet Neurol.* 2017;16(10):813-25.
- Green RE, Colella BM, Maller JJ, Bayley M, Glazer JM, Mikulis DR. Scale and pattern of atrophy in the chronic stages of moderate-severe TBI. *Front Hum Neurosci.* 2014;8:67.
- Corrigan JD, Hammond FM. Traumatic brain injury as a chronic health condition. *Arch Phys Med Rehabil.* 2013;94(6):1199-201.
- Roozenbeek B, Maas AI, Menon DK. Changing patterns in the epidemiology of traumatic brain injury. *Nat Rev Neurol.* 2013;9(4):231-6.
- Jaglal SB, Guilcher SJ, Bereket T, et al. Development of a chronic care model for neurological conditions (CCM-NC). *BMC Health Serv Res.* 2014;14(1):409.
- Levack WM, Kayes NM, Fadyl JK. Experience of recovery and outcome following traumatic brain injury: a metasynthesis of qualitative research. *Disabil Rehabil.* 2010;32(12):986-99.
- Zitnay GA, Zitnay KM, Povlishock JT, et al. Traumatic brain injury research priorities: the Conemaugh International Brain Injury Symposium. *J Neurotrauma.* 2008;25(10):1135-52.
- Cicerone KD, Langenbahn DM, Braden C, et al. Evidence-based cognitive rehabilitation: updated review of the literature from 2003 through 2008. *Arch Phys Med Rehabil.* 2011;92(4):519-30.
- Dawson DR, Binns MA, Hunt A, Lemsky C, Polatajko HJ. Occupation-based strategy training for adults with traumatic brain injury: a pilot study. *Arch Phys Med Rehabil.* 2013;94(10):1959-63.
- Wehman P, Kregel J, Keyser-Marcus L, et al. Supported employment for persons with traumatic brain injury: a preliminary investigation of long-term follow-up costs and program efficiency. *Arch Phys Med Rehabil.* 2003;84(2):192-6.
- Nalder E, Fleming J, Cornwell P, Foster M. Linked lives: the experiences of family caregivers during the transition from hospital to home following traumatic brain injury. *Brain Impairment.* 2012;13(1):108.
- Graham ID, Kothari A, McCutcheon C. Moving knowledge into action for more effective practice, programmes and policy: protocol for a research program on integrated knowledge translation. *Implement Sci.* 2018;13(1):22.
- Restall GJ, Carnochan TN, Roger KS, Sullivan TM, Etcheverry EJ, Roddy P. Collaborative priority setting for human immunodeficiency virus rehabilitation research: a case report: Établissement en collaboration des priorités dans le domaine de la recherche sur la réadaptation des personnes atteintes du virus de l'immunodéficience humaine: Étude de cas. *Can J Occ Ther.* 2016;83(1):7-13.
- Chalmers I, Bracken MB, Djulbegovic B, et al. How to increase value and reduce waste when research priorities are set. *Lancet.* 2014;383(9912):156-65.
- Topolovec-Vranic J, Ennis N, Ouchterlony D, et al. Clarifying the link between traumatic brain injury and homelessness: Workshop proceedings. *Brain Inj.* 2013;27(13-14):1600-5.
- 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):177-82.
- Sheridan K, Adams-Eaton F, Trimble A, Renton A, Bertotti M. Community engagement using World Café: The Well London Experience. *Groupwork.* 2010;20(3):32.
- MacFarlane A, Galvin R, O'Sullivan M, et al. Participatory methods for research prioritization in primary care: an analysis of the World Café approach in Ireland and the USA. *Fam Pract.* 2017;34(3):278-84.
- Brown J, Isaacs NM. Hosting conversations that matter at the World Cafe. *Whole Syst Assoc.* 2002;1:1-20.
- Marshall S, Bayley M, McCullagh S, et al. Updated clinical practice guidelines for concussion/mild traumatic brain injury and persistent symptoms. *Brain Inj.* 2015;29(6):688-700.
- Bayley MT, Tate R, Douglas JM, et al. INCOG guidelines for cognitive rehabilitation following traumatic brain injury: methods and overview. *J Head Trauma Rehabil.* 2014;29(4):290-306.
- Rankin NM, McGregor D, Butow PN, et al. Adapting the nominal group technique for priority setting of evidence-practice gaps in implementation science. *BMC Med Res Methodol.* 2016;16(1):110.
- Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res.* 2005;15(9):1277-88.
- Kothari A, Wathen C N. A critical second look at integrated knowledge translation. *Health Policy.* 2013;109(2):187-91.
- Kumar KS, Samuelkamaleshkumar S, Viswanathan A, Macaden AS. Cognitive rehabilitation for adults with traumatic brain injury to improve occupational outcomes. *Cochrane Database Syst Rev.* 2017;6:CD007935.

30. Dawson DR, Anderson ND, Burgess PW, Cooper E, Krpan KM, Stuss DT. Further development of the Multiple Errands Test: standardized scoring, reliability, and ecological validity for the Baycrest Version. *Arch Phys Med Rehabil.* 2009;90(Suppl 1):s41-51.
31. Bottari C, Dassa C, Rainville C, Dutil E. The criterion-related validity of the IADL profile with measures of executive functions, indices of trauma severity and sociodemographic characteristics. *Brain Inj.* 2009;23(4):322-35.
32. Burgess PW, Alderman N, Forbes C, et al. The case for the development and use of “ecologically valid” measures of executive function in experimental and clinical neuropsychology. *J Int Neuropsychol Soc.* 2006;12(2):194-209.
33. Ponsford J, Olver J, Ponsford M, Nelms R. Long-term adjustment of families following traumatic brain injury where comprehensive rehabilitation has been provided. *Brain Inj.* 2003;17(6):453-68.
34. Kitter B, Sharman R. Caregivers’ support needs and factors promoting resiliency after brain injury. *Brain Inj.* 2015;29(9):1082-93.
35. Minnes P, Woodford L, Carlson P, Johnston J, McColl MA. The needs of aging parents caring for an adult with acquired brain injury. *Can J Aging.* 2010;29(02):185-92.
36. Baker A, Barker S, Sampson A, Martin C. Caregiver outcomes and interventions: a systematic scoping review of the traumatic brain injury and spinal cord injury literature. *Clin Rehabil.* 2017;31(1):45-60.
37. Fisher A, Lennon S, Bellon M, Lawn S. Family involvement in behaviour management following acquired brain injury (ABI) in community settings: a systematic review. *Brain Inj.* 2015;29(6):661-75.
38. Wilson LS, Maeder AJ. Recent directions in telemedicine: review of trends in research and practice. *Healthc Inform Res.* 2015;21(4):213-22.
39. Aalbers T, Baars MA, Rikkert MG. Characteristics of effective Internet-mediated interventions to change lifestyle in people aged 50 and older: a systematic review. *Ageing Res Rev.* 2011;10(4):487-97.
40. DuBois D, Di Giovanni S, Chui A, Nalder E. Capitalizing on lived experience to design a smartphone app for everyday life. *OT Now,* 19(1):16-8.
41. Teasdale TW, Emslie H, Quirk K, Evans J, Fish J, Wilson BA. Alleviation of carer strain during the use of the NeuroPage device by people with acquired brain injury. *J Neurol Neurosurg Psychiatry.* 2009;80(7):781-3.
42. Damianakis T, Tough A, Marziali E, Dawson DR. Therapy online: a web-based video support group for family caregivers of survivors with traumatic brain injury. *J Head Trauma Rehabil.* 2016;31(4):E12-20.
43. Ng EM, Polatajko HJ, Marziali E, Hunt A, Dawson DR. Tele-rehabilitation for addressing executive dysfunction after traumatic brain injury. *Brain Inj.* 2013;27(5):548-64.
44. Olivares M, Giroux S, De Loo P, et al. An ontology model for a context-aware preventive assistance system: reducing exposition of individuals with traumatic brain injury to dangerous situations during meal preparation. 2016.