J Head Trauma Rehabil
Vol. 39, No. 5, pp. 395–407

OPEN

INTIMASY-TBI Guideline: Optimization of INTIMAcy, SexualitY, and Relationships Among Adults With Traumatic Brain Injury

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Introduction: Traumatic brain injury (TBI) can negatively impact intimacy, relationships, and sexual functioning through changes in physical, endocrine, cognitive, behavioral, and emotional function. Without intervention, diminished intimacy and/or sexual functioning in individuals with TBI may persist. Although most health care professionals agree that sexuality and intimacy in relationships are significant concerns and should be addressed in rehabilitation, these concerns are not typically discussed during rehabilitation and discharge planning for people with TBI. To address this gap, an expert panel of North American clinicians and researchers convened to develop evidence-informed recommendations to assist clinicians in providing a framework and guidance on how clinicians can support individuals after TBI. **Methods:** A systematic search of multiple databases was conducted to identify relevant evidence published from 2010 to 2023. The INTIMASY-TBI Expert Panel developed recommendations for optimizing discussions and interventions related to intimacy and sexuality for people with TBI in rehabilitation and community-based programs. For each recommendation, the experts evaluated the evidence by examining the study design and quality to determine the level of evidence. **Results:** A total of 12 recommendations were developed that address the following topic areas: (1) interprofessional team training, (2) early education on the effects of TBI on intimacy, relationships, and sexuality, (3) creating individualized interventions, (4) education, assessment, and management of the causes of sexual dysfunction, and (5) providing written materials and relationship coaching to persons with TBI and their partners. Two recommendations were supported by Level A evidence, 1 was supported by Level B evidence, and 9 were supported by Level C (consensus of the INTIMASY-TBI Expert Panel) evidence. A decision algorithm was developed to assist clinicians in navigating through the recommendations. **Conclusion:** The INTIMASY-TBI Guideline is one of the first comprehensive clinical practice guidelines to offer strategies to trained clinicians to discuss the physical, psychosocial, behavioral, and emotional aspects of intimacy and sexuality with persons with TBI. **Key words:** *clinical practice guideline, intimacy, romantic relationship, sexuality, traumatic brain injury*

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Supplemental digital content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal's Web site (www.headtraumarehab.com).

The authors declare no conflicts of interest. The project described in this manuscript was funded through Neurotrauma grant number 719 from the Ministry of Health and Long-Term Care of Ontario, Canada (Lead: Dr Mark Bayley). The authors declare that no competing financial interests exist. The authors further declare that the funders did not participate in the organization of the project nor the expert panel process, evidence synthesis nor formulation of the recommendations. The views expressed in the publication are the views of the authors and do not necessarily reflect those of the Province of Ontario.

We gratefully acknowledge the support of the Ministry of Health and Long-Term Care Ontario.

Disclosure*: In no event shall the INTIMASY-TBI Guideline developers, its contributors, affiliated institutions, and supporting partners be liable for any damages, claims, liabilities, costs, or obligations incurred in connection with the use, misuse, or reliance upon the recommendations and associated material including loss or damage arising from any claims made by a third party.*

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DOI: 10.1097/HTR.0000000000000981

SEXUALITY IS A COMPLEX and multidimensional phenomenon encompassing sex, pleasure, intimacy, gender identities and roles, sexual orientation, and reproduction.[1,2] Interpersonal relationships, intimacy, and sexuality are important determinants of quality of life and can be negatively affected by the physical, cognitive, behavioral, and emotional sequelae of moderate to severe traumatic brain injury (TBI).[3,4] More than half of individuals with TBI report disruption in sexual functioning.[5–9] Most individuals post-TBI report experiencing hyposexuality, defined as diminished arousal and sex drive and decreased quality/number of sexual encounters.[2] However, some may experience hypersexuality (ie, increased sexual arousal often accompanied with inappropriate sexual behavior).[2]

Sexual disturbances and dysfunction may lead to negative feelings about sexuality, diminished arousal and sex drive,[10] erectile dysfunction,[11] early ejaculation,[11] dyspareunia, difficulty achieving orgasm, dissatisfaction with sexual functioning,[11] depression, anxiety, pain, and fatigue.[12–15] Furthermore, social, cognitive, and behavioral changes post-TBI, including challenges with social communication, egocentricity, emotional recognition, and regulation, may create difficulty in forming and maintaining interpersonal relationships.[14,16] Emotional and behavioral changes may cause mood swings, verbal outbursts, impulsivity, and apathy.[17,18] As a result of these challenges, even when relationships endure, high relationship dissatisfaction is common for both the individual with TBI and their intimate partner.[19] Partners may feel emotionally disconnected as they are often required to become full-time caregivers[17,20] and adjust to a new financial situation,[20] and household responsibilities.[20] Furthermore, individuals with TBI and their partners have expressed a need for sexual and reproductive health issues to be addressed by an interdisciplinary care team[21] during subacute rehabilitation and in the community.[14,22,23]

Most health care professionals agree that intimacy should be addressed in rehabilitation.[13,23,24] Unfortunately, it is not proactively addressed during TBI rehabilitation.[7,21,23,25,26] Arango-Lasprilla et al conducted an international survey exploring how health care providers address the assessment of the treatment of sexuality following TBI. Ninety-seven percent of health care professionals believed that sexuality should be discussed within rehabilitation. However, only 36% reported discussing sexuality with their patients and their partners.[27] Some TBI health care professionals indicate they do not feel they are "sufficiently qualified" to discuss sexuality post-TBI and require additional training and resources.[23,28,29] Only 53% of health care providers reported feeling comfortable addressing sexuality-related issues with their patients, with 14.9% unsure of how to approach this topic with them.[27] Thus, sexuality is often only addressed when the individual with TBI or their partner raises it and many individuals may "suffer from undetected but treatable sexual problems."[5,13,30]

Recognizing these gaps, we sought to form an interprofessional panel of experts to develop the *Intima*cy and *Sexuality* after Moderate to Severe *T*raumatic *B*rain *I*njury (INTIMASY-TBI) Guideline. The INTIMASY-TBI Guideline provides expert-level recommendations for integrating intimacy and sexuality within TBI rehabilitation and community-based programs. The Guideline aims to provide strategies for appropriately trained clinicians to discuss the physical, psychosocial, behavioral, and emotional aspects of intimacy and sexuality post-TBI. The intended primary users of the INTIMASY-TBI Guideline are clinicians, allied health care professionals, and rehabilitation support workers who treat adults (≥18) who have sustained a moderate to severe TBI.[31] While the expert panel recognizes the importance of developing recommendations and resources for adolescents who have sustained a TBI, the recommendations below have been tailored to adults based on the literature search strategy taken. The Guideline may also be used by stakeholders (ie, policymakers and administrators) who make decisions about or provide rehabilitation care for individuals with TBI and their partners.

METHODS

The INTIMASY-TBI Guideline followed a rigorous development process:

(1) **Establish an expert panel**: The INTIMASY-TBI Guideline process was initiated by the development of an interprofessional steering committee comprised of clinicians, program leaders, researchers, and administrators. The expert panel members were invited by the steering committee based on their established clinical and research expertise. The expert panel consisted of occupational therapists, sex educators, psychologists, neuropsychologists, individuals with lived experience, individuals with guideline development expertise, established TBI researchers specializing in intimacy, and sexuality post-TBI and TBI program administrators.

(2) **Literature review**: A systematic search of several databases (Medline, EMBASE, Cochrane, CINAHL, and PsycINFO) was conducted with medical subject headings and keywords related to brain injury, rehabilitation, therapy, psychotherapy, intervention, interpersonal relationships, romantic relationships, intimacy, sexual partners, sexual behavior, sexual dysfunction, and couples therapy (Supplemental Digital Content, available at: http://links.lww.com/JHTR/A825). All references were exported and refined using Endnote X9 (Clarivate Analytics, 2018).

Duplicates were removed, and 2 reviewers independently performed title and abstract screening. Final inclusion was determined following a full-text review. The original search was conducted from January 1, 2010 to June 30, 2020. The search was subsequently updated to include articles published from July 1, 2020 to December 31, 2023. Articles were extracted and provided to the working groups if they met the following criteria: (1) interventional or single-case design, (2) more than 3 participants, (3) human participants, (4) at least 50% of the participants had a TBI, and (5) mean age of participants was 18 years and older. An evidence matrix with a synopsis of the newly identified evidence was provided to the expert panel for their consideration (Table 1).

(3) **Expert panel meetings develop recommendations**: The INTIMASY-TBI expert panel held 12 one-hour meetings via an online videoconference platform (Zoom Technologies Inc.™). Email communication was also used to provide materials to be discussed at the following panel meeting and to address any meeting discussion points. The expert panel developed all recommendations based on the most current evidence and their clinical expertise. Once each recommendation was drafted, the panel reviewed supporting evidence to assign 1 of the 3 levels of evidence using a standardized grading system (Table 2), used within the Canadian Best Practice Recommendations for Stroke Care[37] and numerous clinical practice guidelines for traumatic brain injury, and spinal cord injury.[37–45] Consensus was reached when all INTIMASY-TBI group members agreed to the wording and evidence grade of all recommendations. An algorithm to guide clinicians in the implementation of the recommendations was also developed (Figure 1).

Expert panel voting and final modifications: The expert panel voted on all recommendations using an online survey tool (Survey Monkey®). The panel was asked to select whether the recommendation should be included within the Guideline, whether further modifications were required, or whether it should be rejected. Recommendations that received at least 80% agreement by the expert panel were included within the Guideline. Recommendations that required minor modifications were revised by the expert panel.

RESULTS

Recommendations and literature review

Twelve recommendations were developed addressing the following 5 topics: (1) interprofessional team training, (2) early education on TBI effects on intimacy, relationships, and sexuality, (3) creating individualized interventions, (4) education, assessment, and management of causes of sexual dysfunction, and (5) providing written materials and relationship coaching to persons with a TBI and their partners, if applicable. Two recommendations were supported by Level A evidence, 1 was supported by Level B evidence, and 9 were supported by Level C (consensus of the INTIMASY-TBI Expert Panel) evidence.

INTIMASY-TBI #1: *All multidisciplinary team members should have a basic understanding and training on how TBI can affect intimacy and sexuality. Clinicians should be provided with key phrases they can use to respond to individuals with TBI and partners, and guidance on how clinicians can safely approach this topic. Level C evidence.*

It is important to recognize the shared responsibility of the health care team in addressing intimacy and sexuality. In an integrative review of the literature, Marier-Deschênes et al found that 52.9% of sources were in support of using the PLISSIT (Permission, Limited Information, Specific Suggestions, Intensive Therapy) model to assist health care professionals in discussing sexuality with individuals with TBI.[5,13,14,21,46–48] The PLISSIT model was developed in 1967 by Annon in the field of sexology and was later extended by Taylor and Davis (2007) to create the Ex-PLISSIT model to address the sexual well-being of individuals with an acquired disability or chronic illness.[49–51] The model utilizes a phased approach for initiating conversations about sexuality that can be applied by clinicians caring for individuals with TBI. Simpson noted that TBI rehabilitation teams, at minimum, can consider providing interventions at the Permission, Limited Information, and Specific Suggestion stage.[5] Fraser and colleagues reported that their findings support the PLISSIT/Ex-PLISSIT in a study testing a CBT intervention to help couples and singles improve their sexual well-being following TBI.[52]

In the review by Marier-Deschênes et al, 58% of sources highlighted the importance of training health care providers on sexuality issues.[53] Sources recommended training on all levels of the PLISSIT model for improving comfort in discussing sexuality, sexuality as a health outcome, sexuality through the life span, personal dimensions of sexuality and sexual identity, and cultural differences in sexuality.[53] Training programs should include providers exploring their own thoughts, beliefs, and feelings about discussing intimacy and sexuality and how this impacts their ability to discuss sexual health issues with their patient.[21,53,54]

INTIMASY-TBI #2: *Multidisciplinary teams should identify 1 or 2 key appropriately trained team members who will consistently seek permission to initiate a discussion about intimacy and sexuality with the individual with TBI and/or their partner taking into consideration potential cultural factors. Level C evidence.*

According to Heinemann and colleagues, there are aspects of sexuality that are influenced by culture (ie, values, decisions regarding appropriate sexual behaviors,

TABLE 1 *Intervention characteristics*

Study	Methods	Aim	Intervention	Main Outcome Measures	Outcomes
Backhaus et al. (2019)[32]	Design: Randomized waitlist-controlled trial Setting: Midwestern outpatient brain injury rehabilitation center Country: United States Participants: Persons with TBI and their intimate partners (n = 22)	(1) Examine the efficacy of a treatment to enhance a couple's relationship after brain injury particularly in relationship satisfaction and communication; and (2) Determine couples' satisfaction with this type of intervention.	Couples caring and relating with empathy (CARE) intervention 16-week, 2-hour, manualized small group treatment Uses psychoeducation, affect recognition, empathy training, cognitive-behavioral and dialectical-behavioral strategies, communication skills training, and Gottman's theoretical framework for couples adjusted for persons with TBI. Participants were randomly allocated to the treatment or waitlist-controlled group.	Dyadic adjustment scale Quality of marriage index 4 horsemen of the apocalypse communication questionnaire Completed by both partners at baseline, immediate postintervention, and 3-month follow-up.	Significant improvement at post-test and follow-up on the dyadic adjustment Scale and the horsemen questionnaire compared to baseline. Waitlist-controlled group which showed no significant changes on the outcome measures. No significant effects were observed on the quality of marriage index for either group. 95% reported satisfaction with the quality of the service, 90% would recommend the group to a friend in similar need, 79% were satisfied with CARE workbook.
Kreutzer et al. (2020)[33]	Design: Two-arm parallel, randomized, controlled trial with wait-listed control Setting: Outpatient brain injury rehabilitation center Country: United States Participants: Persons with TBI and their intimate partners (n = 75)	Examine the effectiveness of the therapeutic couples intervention, designed to improve relationship quality for couples after TBI.	Therapeutic Couples Intervention 5 to 6 2-hour sessions Structured treatment program to improve relationship quality and stability after TBI using education, skill-building, and psychological support. Participants were randomly allocated to the treatment or waitlist-controlled group.	Revised dyadic adjustment scale (RDAS) Marital status inventory Neurobehavioral functioning inventory Completed by both partners at baseline, posttreatment and 3-month follow-up.	Persons with TBI and partners in the therapeutic couples intervention group showed increased RDAS scores after completing the intervention. Waitlist control participants did not. 62% of individuals within the intervention group did not meet the cut-off for relationship distress. At post-treatment and 3-month follow-up, RDAS scores in the intervention group showed the treatment effects were lasting.

(*continues*)

TABLE 1 *Intervention characteristics* (Continued)

Study	Methods	Aim	Intervention	Main Outcome Measures	Outcomes
Graham et al. (2020)[34]	Design: Two-arm, parallel, randomized trial with a waitlist control Setting: Outpatient brain injury rehabilitation center Country: United States Participants: Persons with TBI and their intimate partners/caregivers (n = 75)	Examine the effectiveness of the therapeutic couples intervention on caregiver needs and burden after brain injury.	Therapeutic Couples Intervention Five 2-hr sessions, with a sixth optional session on parenting after brain injury. Structured treatment program to improve relationship quality and stability after TBI using education, skill-building, and psychological support. Participants were randomly allocated to the treatment or waitlist-controlled group.	Family needs questionnaire (FNQ-R) Zarit burden interview (ZBI) Marital status inventory (MSI) Neurobehavioral functioning inventory (NFI) Completed by both partners at baseline, post-treatment and 3-month follow-up.	Caregivers in the TCI group demonstrated reduction in unmet needs for 5 of the 6 FNQ-R subscales; individuals on the waitlisted group did not demonstrate the same reduction. ZBI scores improved significantly for only TCI caregivers. At the 3-month follow-up, benefits were maintained on the ZBI. Benefits were maintained for 4 of the 6 FNQ-R subscales (health information, emotional support, Professional support, and community support network).
Boakye et al. (2022)[35]	Design: Single case methodology with bi-phasic A-B design Setting: Specialist neuro-rehabilitation outpatient service Country: United Kingdom Participants: Persons with TBI and their partners (n = 8)	Explore the outcomes of behavioral couples therapy (BCT) for couples with TBI.	Behavioral Couples Therapy (BCT) Fourteen weekly 1-hour sessions The treatment consisted of: (i) behavioral interventions (ie, skill-based interventions); (ii) guided behavior change (eg, couples were encouraged to schedule a routine date night) and (iii) psychoeducation on the emotional and behavioral changes following TBI.	Couples satisfaction index scale-8 (CSI-8) Patient health Questionnaire-9 items (PHQ-9) Generalized anxiety Disorder Assessment-7 items (GAD-7) Completed by both partners at baseline, posttreatment, and 6-month follow-up.	Significant improvement in relationship anxiety and satisfaction by both the individual with TBI and their partner. Significant reduction in overall depression scores in partners of the individual with TBI.

(*continues*)

TABLE 1 *Intervention characteristics* (Continued)

Study	Methods	Aim	Intervention	Main Outcome Measures	Outcomes
Fraser et al. (2022)[36]	Design: Nonconcurrent, multiple baselines, AB single-case experimental design (SCED) with follow-up (ie, baseline; treatment; follow-up) Setting: Not provided Country: Australia Participants: Persons with TBI (n = 9)	Evaluate the preliminary efficacy of an individualized intervention using a cognitive behavior therapy framework to treat sexuality problems after TBI.	Cognitive behavior therapy framework Eight 60-min sessions delivered weekly and 1 booster session completed approximately 2 months later. Treatment guide was organized into 12 modules with accompanying handouts. The goals of the cognitive behavior therapy framework were to: (i) shift cognition and behavior to let couples/individuals feel more in control of their sexuality; (ii) improve satisfaction with sexuality; and (iii) aid persons with TBI in accepting and managing sexuality changes. Medical review was also incorporate into the treatment design to help to understand the organic and psychogenic causes.	Author-developed rating scale to measure participants' subjective satisfaction with their sexuality. Brain injury questionnaire of sexuality (BIQS) Hospital anxiety and depression scale (HADS) Participation assessment with Recombined Tools-Objective (PART-O) goal attainment scaling (GAS) Subjective satisfaction with sexuality was measured 3 times weekly. Other outcome measures completed pretreatment, posttreatment, and 8-week follow-up.	All participants reported an improvement in a minimum of 1 goal area after the treatment. Improvements in sexuality satisfaction were maintained for 2 months following treatment completion. Five participants demonstrated treatment response in the therapeutic direction. Only 3 participants recorded being "satisfied" with their sexuality. One participant minimal maintenance on treatment gains on the author-developed rating scale. This may have been due to a participant's expectations that all physical sexual issues would be resolved at treatment completion. Treatment intervention demonstrated treatment adherence and feasibility.

TABLE 2 *INTIMASY-TBI level of evidence grading system*

A: Recommendation supported by at least 1 meta-analysis, systematic review, or randomized controlled trial of appropriate size (>60) with relevant control group.
B: Recommendation supported by cohort studies that at minimum have a comparison group (includes small randomized controlled trials).
C: Recommendation supported primarily by expert opinion based on their experience though uncontrolled case studies or series may also be included here.

suitable partner or partners, appropriate age of consent, as well as who is to decide what is appropriate).[55] Consequently, the symptoms of sexual dysfunction and the treatment expectation can differ according to cultural beliefs that can be different from the clinician's views. An appropriate culturally based approach requires exploring awareness of differences, knowledge of the patient's culture, being able to distinguish pathology and culture, and the use of culturally appropriate interventions.

Intimacy and sexuality should be consistently addressed within the TBI inpatient rehabilitation setting.[54,56] To ensure this happens proactively, 1 or 2 rehabilitation professionals who are comfortable with and trained in discussing sexuality should be formally selected to provide resources and education to all individuals with TBI and their partners, if applicable.[21] As there is often limited time for intimacy and sexuality-related discussion, a focused number of topics should be covered, such as physical aspects (eg, sensory deficits, cervical screening, disruption to the menstrual cycle, and erectile dysfunction) and psychosocial aspects (eg, communication and altered roles).[53] If an individual with TBI is in a relationship, both individuals should have the opportunity to discuss intimacy and sexuality with a health care professional and receive relevant educational materials.[48,57]

Sander and colleagues conducted a focus group at the TIRR Brain Injury Research Centre where individuals with TBI and their caregivers were asked when they wanted to receive information regarding sexuality.[54] Some study participants reported they would have liked to receive this information prior to discharge; however, other participants noted that they were not prepared to process the information on sexuality until after discharge from rehabilitation. The researchers highlighted that it may be challenging for some participants postdischarge to access a clinician to discuss their questions about sexuality which supports the recommended early approach.[54]

An open, person-centered approach, which considers the individual's unique traits and values, should be used.[58] The rehabilitation team member appointed to provide information about sexuality should offer individuals with TBI detailed education and resources on sexuality and may consider using the following introduction[57]:

> "I know that you are dealing with a lot right now, and sex may be the last thing on your mind. However, I want to tell you that brain injury can affect sexual functioning. If you would like some information on this, I can provide it to you. If you are not ready to talk about it now, that's O.K. I can give you some reading material to take home. You can also ask your doctor or another rehabilitation professional about it when you do have questions or want more information."

Clinicians can also consider integrating 1 to 2 questions related to intimacy and sexuality, such as "Are you sexually active and/or are you satisfied with your sexual functioning?" and "Do you have any questions or concerns about the impact of TBI on sex?".[8]

Marier-Deschênes and colleagues[53] suggested that an appointed team member can also reaffirm this information with the individual with TBI and their partner on various occasions (ie, before the first home visit and before discharge from inpatient rehabilitation).

INTIMASY-TBI #3: *Consider the role of each member within an individual's care team in addressing different aspects of intimacy and sexual functioning with the individual with TBI and their partner. Level C Evidence.*

Moreno and colleagues indicate that individuals with TBI are open to discussing sexuality with various health care professionals.[21] In a survey, although 79% of rehabilitation professionals thought sexuality should be addressed within rehabilitation, only 9% addressed it on a regular basis.[30] Following initial discussions on intimacy by the designated team member, sexuality should be discussed with clinicians from varying specialties depending on the patient's specific needs.[13,59] For instance, a physiotherapist or occupational therapist may be able to assist with functional and mobility issues by providing specific recommendations around adaptive equipment and positioning.[21] A speech-language pathologist can assist with changes related to social communication. Neuropsychologists can offer "strategies to accommodate for neurocognitive impairments".[21]

INTIMASY-TBI #4: *Individuals with TBI and their partners (if applicable) should at a minimum, be provided with written and other supporting educational materials regarding sexuality, relationships, and intimacy early during inpatient and/or outpatient rehabilitation. Provide individuals with TBI with the opportunity to discuss the*

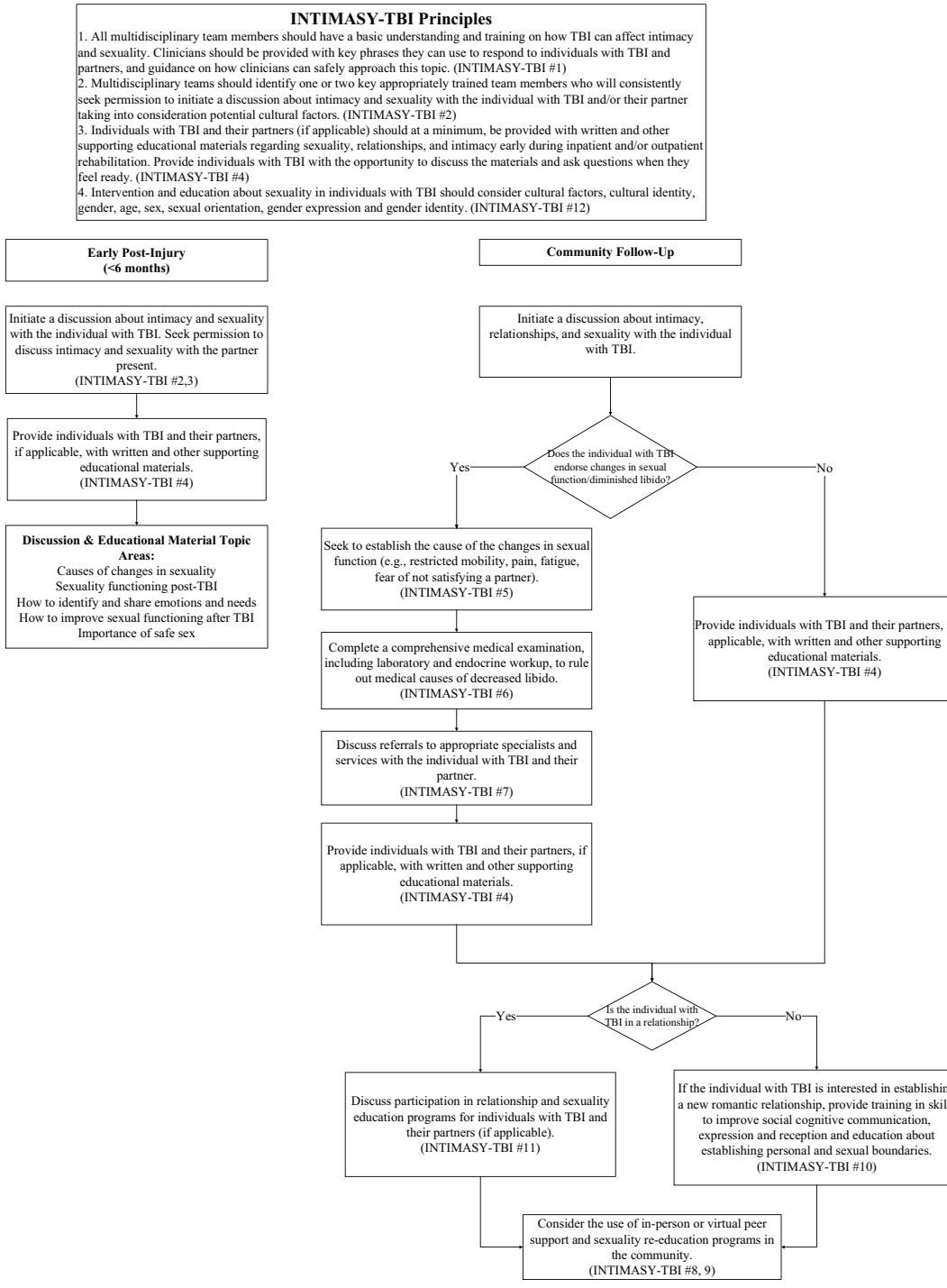

Figure 1. Algorithm to facilitate implementation of the recommendations.

materials and ask questions when they feel ready. Level C evidence.

In a systematic review by Moreno and colleagues (2019), 52.9% of studies supported the use of written and other supporting educational materials, such as videos and online sources.[5,13,46,54,57,60,61] Written materials should be provided in lay terms,[53,57] at a 6th-grade reading level and adapted for individuals with TBI.[57,62] These written materials would facilitate the appointed rehabilitation professional in providing education.[53]

Educational materials should cover the following topics: causes of changes in sexuality, sexual functioning post-TBI, how to improve sexual functioning after TBI, the importance of safe sex, and how to discuss intimacy

and sexuality with a health care professional.[57] Written materials should be provided directly to the individual with TBI prior to discharge.[63] However, in cases where an individual with TBI has impairments in memory, processing speed, or cognitive communication, written materials can be provided to the partner or parent (if applicable) to be transferred to the person with TBI when appropriate.

INTIMASY-TBI #5: *During outpatient follow-up visits, clinicians should explore if there has been a change in intimacy or sexual function and specifically inquire about changes in libido with an individual with TBI and their partner (if applicable). Level C evidence.*

Clinicians should address intimacy and sexuality issues during outpatient visits.[53,64] Given the personal nature of intimacy and sexuality, it often takes time for health care providers to develop trust and build rapport with individuals who have TBI.[53] Readiness should be determined on an individualized basis and should inform the: timing of the discussion(s), topic areas to be discussed, amount of information provided, and educational tools and materials used.[47] These sessions may include practical knowledge, role-playing and interpersonal skills training.[13,53] Clinicians should also discuss reproductive and sexual safety topics, including contraception, HIV/STD prevention, safer sex practices, and the desire to start a family.[1,21]

INTIMASY-TBI #6: *During outpatient follow-up visits, if an individual with TBI endorses changes in libido, clinicians should complete a comprehensive medical examination, including laboratory and endocrine workup, to rule out a medical cause of decreased libido and provide advice regarding other causes of sexual dysfunction. Level C evidence.*

A comprehensive medical examination should include the following: (1) Psychosexual identity, including body image, desire, and past sexual experiences.[65] (2) Screening for medical issues that could contribute to sexual dysfunction, including diabetes, heart disease, kidney disease, mental health issues, and thyroid function. (3) Identify medications that interfere with sexual function (eg, sedatives, antidepressant medications, antihypertensive medications). (4) Blood work to rule out causes of fatigue and diminished libido, including a complete blood count, electrolytes, testosterone, luteinizing hormone, follicle-stimulating hormone, and screen for pituitary dysfunction. (5) Establish the cause of the dysfunction, ie, physical changes (weakness, restricted mobility, tremors, spastic movements),[66] pain, fatigue, vaginal dryness, anxiety, and fear of not satisfying a partner.

Following this examination, specific suggestions to improve sexual functioning should be provided including: (1) Information on safe sex practices (ie, birth control, prevention of sexually transmitted diseases). (2) Strategies to increase social networks (eg, TBI support groups, and other social organizations). A list of available organizations can be available in your clinic. (3) Changing current medications, as appropriate.[65] (4) Positioning changes during sexual activity to reduce the impact of balance, physical changes, and pain. (5) Use of lubricants, dilators, prosthetic devices, and medications as appropriate.

INTIMASY-TBI #7: *During outpatient follow-up visits, discuss referrals to appropriate specialists and counseling services as necessary. Level C evidence.*

Referrals for urology, obstetrics, and/or gynecology examinations should be completed as appropriate. If applicable, primary health care providers should encourage and refer individuals with TBI and their partners to meet with a licensed sexual therapist, couples or marital counselor, psychologist, or peer mentor.[67]

INTIMASY-TBI #8: *Consider the development of a community-based relationship and sexuality re-education program for individuals with TBI. Level C evidence.*

Building on the recommendations provided by Khajeei and colleagues,[66] a sexuality re-education program can include the following topic areas: biological and anatomical information using person-first language and inclusive terminology, sexuality after disability, tools and techniques to manage changes in sexuality post-TBI, sexual safety (sexually transmitted infection, contraception, boundaries, sexual abuse), and strategies to improve arousal, pleasure, and relaxation confidence (resiliency and rejection, social skills training and communication, and sexual self-identity). These programs should be developed in consultation with individuals with TBI.[58,68,69]

INTIMASY-TBI #9: *During outpatient follow-up visits, consider the use of in-person or virtual peer support programs in the community. Level B evidence.*

In a systematic review conducted by O'Shea and colleagues in 2020,[58] 8 studies were identified that investigated the efficacy of peer support programs specifically focused on relationships and sexuality for individuals with TBI. These studies strongly recommended community-based, peer-to-peer programs.[58] Peer-to-peer programs were found to improve self-efficacy, self-confidence, and self-reported quality of life satisfaction and increase knowledge and service engagement.[58] Peer program developers should consider the limitations of in-person and virtual peer support programs and ensure that programs monitor and track distress.[70]

INTIMASY-TBI #10: *During outpatient follow-up visits, provide training in skills that are likely to enhance their personal safety and chances for success to individuals with TBI who are not currently in a romantic relationship but would like to be. Level A evidence.*

Individuals who have sustained a TBI frequently have difficulty with social cognition and behaviors that are fundamental to building emotional and intimate

connections with others.[63,71] These issues include, but are not limited to, impaired recognition of emotions in self and others, blunted affect, diminished empathy, and poor social communication skills.[63,71] While these problems can have a negative impact on all types of relationships (eg, family and friends), they are important barriers that can make it particularly difficult for the individual to develop new romantic relationships with others.[36] To increase the likelihood of establishing successful romantic relationships, these social cognition skills and behaviors should be evaluated and addressed during rehabilitation. Therapists should teach their clients how to use perspective-taking to consider other peoples' points of view, how to demonstrate care, concern, and emotional support for others' needs and feelings, as well as how to identify and share their own emotions and needs.[33,72] Further, individuals with TBI should be taught components of cognitive communication and social cognition including expression (eg, communicating their thoughts and feelings with kindness; displays of affection and following social pragmatics) and reception (eg, respectful listening; inferring others' thoughts and emotions and interpretation of social cues).[72] If an individual with TBI exhibits challenges related to emotional or behavioral dysregulation, or issues with poor hygiene, judgment, disinhibition, or impulsiveness that could impact one's success and/ or safety when establishing new relationships and, therefore, should be addressed as part of treatment.

INTIMASY-TBI #11. *During outpatient follow-up visits, if the individual with TBI does not endorse changes in libido but does endorse strains in their existing relationship with their partner, they should be considered for programs aimed at addressing sexuality issues and enhancing intimate relationships after TBI. Level A evidence.*

Individuals with TBI who do not report changes in libido can still experience problems with their sexuality and relationships. Relationship education programs provide information on several topic areas, including psychoeducation, positive communication, emotional regulation, coping strategies, and establishing appropriate and respectful relationships.[33–36,72] Furthermore, these programs have been shown to improve communication, coping skills, and overall relationship satisfaction and quality for individuals with TBI and their partners.[17,23,73] In the review conducted by O'Shea and colleagues,[58] 4 relationship and sexuality programs have been evaluated: Couple CARE (Caring and Relating with Empathy after Brain Injury),[17,72] You and Me Sexuality Education Program,[60] Families4Families,[74] and Brain Injury Family Intervention.[75] These programs were well-received by individuals with TBI, their partners, and health care providers. However, to date, there are no programs identified that provide support specifically for individuals who identify as 2SLGBTQ+ or Indigenous.[58]

INTIMASY-TBI #12: *Intervention and education about sexuality in individuals with TBI should consider cultural factors, cultural identity, gender, age, sex, sexual orientation, gender expression, and gender identity. Level C evidence.*

Within clinical practice, cultural factors should be discussed using a person-centered approach, such as mirroring patient terminology and language when discussing anatomy, partners and preferences, respecting native cultural preferences of when, how, and with whom to discuss sex and intimacy, and approaching care with more generalized education materials suitable to all sexual identities and genders. Clinicians are encouraged to use cultural humility when engaging with patients and their caregivers by asking open-ended questions to develop rapport and trust. There is a need for more culturally sensitive intimacy and sexuality resources that focus on 2SLGBTQ+ experiences.[58] Furthermore, 2SLGBTQ+ awareness training for clinicians is important to provide an "inclusive approach to gender and sexual identities".[76] There is limited research on the intersection between sexual diversity, gender identity, and TBI from the perspective of individuals with TBI or health care providers.[77] Providers must use inclusive language that is gender-neutral and non-heteronormative to create a safe space for all individuals with TBI (eg, "partner" or "significant other" instead of "husband or wife"; "parents" instead of "mother" and "father"; and "person" instead of "male" and "female").[77,78]

Clinicians are encouraged to follow the algorithm that outlines how clinicians can approach intimacy early post-injury (<6 months) and in the community. The algorithm also demonstrates how recommendations fit together and the timing of the interventions proposed.

DISCUSSION

The INTIMASY-TBI Guideline is one of the first comprehensive clinical practice guidelines to assist clinicians with promoting the maintenance of healthy relationships, intimacy, and sexuality for persons with TBI and their partners. Twelve recommendations were made; 2 recommendations were supported by Level A evidence, 1 was supported by level B evidence, and 9 were supported by Level C (consensus of the INTIMASY-TBI Expert Panel) evidence. Adoption of these recommendations could facilitate the standardization of practice protocols and form the basis for future evaluations of the outcomes of the approach.

The PLISSIT model has been used as a framework within both spinal cord injury and TBI to improve clinician knowledge, attitudes, and comfort related to sexuality.[21,79] A randomized controlled trial conducted by Fronek and colleagues[80] on the long-term effectiveness

of sexuality training programs for rehabilitation practitioners found long-lasting effects on clinician knowledge.

The recommendations are primarily supported by Level C evidence (ie, the consensus of the INTIMASY-TBI Expert Panel). This reflects the limited amount of empirical evidence within this area.[53] Empirical studies with a rigorous study design are needed to address the timing and format of intimacy and sexuality-related discussions within inpatient and outpatient services. Additional research in this area is required as the majority of the literature has focused on sexuality in males who have sustained a TBI. Moreover, future relationship and sexual education programs should address the cultural, emotional, and social aspects of sexuality.[58]

One of the advantages of systematically searching literature prior to developing guidelines is the identification of gaps in research. Some of the key unanswered research questions include: What is the ideal method to provide education about sexuality after TBI? What is the ideal timing to commence intervention for intimacy after TBI? Does early counseling and intervention reduce long-term relationship breakdown?

The recommendations within this paper are informed by current evidence and expert opinion at the time of publication. Evidence published after publication may influence the recommendations within future versions of the INTIMASY-TBI Guideline. Clinicians should also consider patient preferences, their clinical judgment, and context-dependent factors (ie, availability of resources) in their clinical decision-making process. Future directions for the INTIMASY-TBI Guideline involve convening a diverse group of individuals with lived experience, along with their caregivers, from across Canada to review the Guideline.

CONCLUSIONS

The INTIMASY-TBI Guideline provides expert-level recommendations with a clinical decision-making algorithm to offer concrete strategies to trained clinicians to discuss the physical, psychosocial, behavioral, and emotional aspects of intimacy and sexuality with persons with TBI.

The recommendations in this paper are informed by current evidence at the time of publication. Evidence published after publication may influence the recommendations in future versions of the INTIMASY-TBI Guideline. Clinicians must also consider patient preferences, clinical judgment, and context-dependent factors (eg, availability of resources) in their clinical decision-making process.

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