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1. Project Title and Purpose

1. Project Title: Asking the Question:

Addressing Intimacy & Sexuality in Acquired Brain Injury

Project Purpose (clearly indicate the Recommendation number and wording from the Clinical Practice Guideline):

ONF Clinical Practice Guideline Recommendation	Project Purpose
<p>Q1.3. A discussion about sexuality should be carried out with individuals following TBI. The discussion should be initiated by an appropriately trained clinician and should cover the following aspects of sexuality:</p> <ul style="list-style-type: none"> - Physical aspects (e.g., positioning, sensory deficits, erectile dysfunction, drugs, disruption to menstrual cycle) - Psychological aspects (e.g., communication, fears, altered roles, disinhibition, threats to safety, and sense of attractiveness) <p>Level of evidence: C</p>	<ul style="list-style-type: none"> • <u>Primary objective:</u> to ensure the topic of intimacy & sexuality is initiated with patients and/or caregivers within the inpatient and outpatient ABI services at Toronto Rehab, UHN • <u>Secondary objective:</u> to support our inpatient and outpatient ABI clinical teams in being able to initiate and to engage in conversations with patients on the topic of intimacy and sexuality.

2. Project Description:

A. Methods:

Stakeholder Engagement:

- An interprofessional working group was formed, comprised of ABI team members from both inpatient and outpatient neuro-physical and neuro-cognitive ABI programs and two Patient Partners recruited from UHN Patient Experience
 - The interprofessional working group included members from neuropsychology, medicine, occupational therapy, physiotherapy, speech therapy, social work, managers, advanced practice lead, and service coordinator

Literature Review & Resource Gathering:

- Conduction of literature review
- Liaised with leading organizations and clinicians involved with intimacy and sexuality initiatives across the GTA

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Data Collection & Evaluation:

- Pre-implementation data collected to identify facilitators and barriers to the completion and sustainability of the initiative. Post-implementation data collection will be completed to evaluate the effectiveness of the developed process.
- Pre- and post-implementation data will be collected using:
 - Staff survey
 - Patient and caregiver interviews
 - Chart review

B. Data collection Tools:

i. Tools to measure Clinical process

Staff online survey locally developed
Patient/caregiver interviews

ii. Tools to measure Clinical outcome

Staff online survey locally developed
Patient/caregiver interviews

iii. Tools to measure Implementation process

Tracking completion of key process steps that aimed to foster team communication, accountability, and sustainability

iv. Tools to measure Implementation outcome

Tracking the number of patients in which designated clinicians initiated intimacy and sexuality discussions during their inpatient and/or outpatient program

C. Findings (process and outcome):

Pre-implementation Evaluation Data & Learnings

Patient & Caregiver Data collected to date demonstrated that:

- 92% of patients did not have the conversation with a team member on the topic of intimacy and sexuality
- 92% of patients would like to have the conversation

*Note: 26 patients and 3 caregivers (partners) were interviewed from inpatient and outpatient ABI services

Staff Data collected to date demonstrated that:

- 35% of clinicians surveyed felt comfortable or very comfortable initiating the conversation about intimacy and sexuality with their patients/caregivers
- 93% of clinicians report having a discussion regarding intimacy and sexuality has never negatively impacted therapeutic rapport with their patient and/or caregiver

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Staff also identified the most common barriers to initiating intimacy and sexuality discussions in their current practice as follows:

1. “Cognitive challenges and/or aphasia”
2. “I don’t have the knowledge/resources to initiate the conversation”
3. “Language barrier/need for translator”
4. “My own comfort level”
5. “Not enough time”
6. “Not in my scope of practice or my role”
7. “Forget to ask”

This data demonstrates patients’ and caregivers’ interest and desire to address intimacy and sexuality post-ABI in both the inpatient and outpatient setting. This data outlines the need for consistent initiation of these discussions and common barriers currently preventing clinicians from doing so. These findings also highlight that additional support and resources are required to implement and sustain this change in clinical practice.

Post-implementation Evaluation Data & Learnings

Post-implementation data to be collected and analyzed once this initiative is re-started (on hold during COVID pandemic).

D. Summary:

- Intimacy and sexuality are not consistently addressed during a patient’s rehab/care journey during current practice standards due to a plethora of reasons, which can negatively impact patients’ and caregivers’ health and quality of life.
- This initiative provides a safe and comfortable setting for patients and caregivers to address any questions or concerns they may have in areas of intimacy and sexuality post-ABI.
- As an outcome of this initiative, patients and/or caregivers in the ABI Inpatient and Outpatient Services will consistently be provided the opportunity to address the topic of intimacy & sexuality during their rehab programming.
- The ABI Inpatient and Outpatient teams will be better supported to initiate and to engage in conversations with patients and/or caregivers on the topic of intimacy and sexuality.
- Process and educational resources will be stored in electronic format in a shared folder, allowing current and future staff to access the materials easily for orientation, teaching, and clinical use.
- The hope is that this project will continue to empower patients and caregivers to discuss the topic of intimacy and sexuality with community healthcare providers to promote increased and open dialogue on this rather taboo aspect of life

E. Lessons Learned:

- Intimacy and sexuality are identified as an important topic to address during ABI recovery and rehabilitation.
- Establishing a diverse working group with varied representation of clinicians and Patient Partners across inpatient and outpatient ABI programs was instrumental to drive process change.
- Staff engagement early on in the initiative maximized participation in data collection.

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- Collaborative partnerships made with organizations and programs with established intimacy and sexuality resources has promoted resource sharing.

3. Recommendations for next steps to support full sustainable implementation: (for your organization, for future implementation projects, for policy, for system organization)

- Ongoing support and recognition that initiation of intimacy and sexuality discussions with patients and/or caregivers is a practice standard and expectation by the leadership and clinical care teams, patients and caregivers.
- Ongoing informal feedback and biannual check-ins with defined clinicians and working group will be held to review and update standard process if required.
- Broader dissemination and resource sharing.

4. What has been done to ensure Sustainability:

Sustainability has been built into the design of this initiative as follows:

- Clinicians with the defined role (i.e., social workers and hospitalists in inpatient programs; social workers and goal coordinators in outpatient programs) will build initiation of intimacy and sexuality discussion into their standard patient care and documentation
 - Standard process will be developed to support consistency for designated clinicians to initiate intimacy and sexuality discussion with patients and/or caregivers
- Education resources and standard process guidelines will be accessible to support the clinicians with the defined role to gain the comfort, skills, and knowledge to initiate intimacy and sexuality discussions consistently as well as to orient new hires/covering staff
 - Support and resources will also be made available to the broader interprofessional teams, which can in turn improve their comfort level, and ability to address and discuss intimacy and sexuality with patients/caregivers
- Incorporate intimacy and sexuality education into standard orientation checklists for new hires of clinicians with the defined role
- Initiation of intimacy and sexuality discussions is recognized as best practice, an important part of patient care, and has the support of the ABI managers and leadership team

If you want more information about this Project, please contact:

Michelle DiLauro (Michelle.DiLauro@uhn.ca)

Edith Ng (Edith.Ng@uhn.ca)