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Brain Impairment

Supplementary Material

Co-designing for behavioural change: understanding barriers and enablers to addressing sexuality after traumatic brain injury and mapping intervention strategies in a multi-disciplinary rehabilitation unit

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Appendix A: Design prompts for ‘Areas for Development’ co-design exercise

General prompts

1. **What** (Is it? Do we say? Does it look like? Team/person? Content is covered? Is it similar with? Is the purpose?)
2. **When** (Is it brought up, provided, implemented, reviewed)
3. **Who** (Is it for? Addresses this? Do we refer to & how?)
4. **How** (Presented? Often? Can this be implemented? Is it done?)

Specific prompts

(1) Patient informational resources, visual aids, ward poster, and handouts

- Form/presentation
- Content on them
- For whom?
- When will patient receive/see?
- Who hands out?
- Placed where?
- What needs to be there and to be done, to allow this to happen?

(2) Roles and Referrals

- Who brings it up?
- What does this process look like?
- Where is there guidance?
- Where can this be discussed?
- When is it discussed?
- How can this be integrated/done?
- Any paperwork or clinical adaptations to be made?
- What needs to be there and to be done, to allow this to happen?

(3) Training

- Modality (online/in-person/workshop/lecture)
- When and frequency of training
- Discipline specific / whole ABI unit
- Content (on what)
- Resources?
- What needs to be there and to be done, to allow this to happen?

(4) How to have conversation and confidence

- Situation-specific scripts (specify which situations)
- Where available
- For who

- Buy-in sentence starters
- Assessment tool (BIQS)
- What needs to be there and to be done, to allow this to happen?

(5) Case conference and clinical team integration

- What is the team approach
- How can it be integrated
- Staff responsibilities (who/when)
- Paperwork adaptations
- Routine adaptations
- What needs to be there and to be done, to allow this to happen?

Appendix B: Coding guidelines

TDF Coding Guideline		
TDF domain	**Subconstructs**	**General principles**
(1) Knowledge *An awareness of the existence of something*	Knowledge (including knowledge of condition/scientific rationale)	• Do they know about guidelines? • What do they know of best practice? • What do they know about sexuality changes after TBI? • Do they know why they should be addressing sexuality?
	Procedural knowledge	
	Knowledge of task environment	
(2) Skills *An ability or proficiency acquired through practice*	Skills	• Do they know how to address sexuality? • How easy or difficult to they find it to address sexuality? • Have they been trained in addressing sexuality?
	Skills development	
	Competence	
	Ability	
	Interpersonal skills	
	Practice	
	Skill assessment	
(3) Social/professional role and identity (self-standards) *A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting*	Professional identity	• Is addressing sexuality compatible or in conflict with professional standards / identity? (e.g., moral / ethical issues, limits to autonomy) • Do they think it is their job / responsibility to address sexuality? • Is it clear what is expected of them in addressing sexuality? • Are the objectives of addressing sexuality and their role in doing so are clearly defined for them?
	Professional role	
	Social identity	
	Identity	
	Professional boundaries	
	Professional confidence	
	Group identity	
	Leadership	
	Organisational commitment	

(4) Beliefs about capabilities (self-efficacy)
 	
Acceptance of the truth, reality, or validity about an ability, talent, or facility that a person can put to constructive use
	Self-confidence	• How confident are they in addressing sexuality in the following scenarios?
		  ○ General confidence
		  ○ Even when other professionals do not do it
		  ○ Even when there is little time
		  ○ Even when patients/clients are not motivated

	Perceived competence	
	Self-efficacy	
	Perceived behavioural control	
	Beliefs	
	Self-esteem	
	Empowerment	
	Professional confidence	
(5) Optimism *The confidence that things will happen for the best or that desired goals will be attained)*	Optimism	• How confident are they that the problem of addressing sexuality routinely will be solved?
	Pessimism	
	Unrealistic optimism	
	Identity	

(6) Beliefs about consequences *Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation*	Beliefs	• What do they think will happen if they do/do not address sexuality? • What are the costs of addressing sexuality and the costs of the consequences of address sexuality?
	Outcome expectancies	
	Characteristics of outcome expectancies	
	Anticipated regret	
	Consequents	
(7) Reinforcement *Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus*	Rewards (proximal/distal, valued/not valued, probable/improbable)	• Are there incentives to addressing sexuality (e.g., financial, recognition in work-context, recognition from patients / clients)? • Are there consequents to not addressing sexuality (e.g., negative social response amongst teammates)
	Incentives	
	Punishment	
	Consequents	
	Reinforcement	
	Contingencies	
	Sanctions	
(8) Intentions *A conscious decision to perform a behaviour or a resolve to act in a certain way*	Stability of intentions	• Have they made the decision to address sexuality routinely? • How much do they feel they need to address sexuality? • Are there other things they want to do or achieve that might interfere? • What stage of change are they at in implementing routine discussions or initiating discussions about sexuality?
	Stages of change model	
	Transtheoretical model and stages of change	
(9) Goals *Mental representations of outcomes or end states that an individual wants to achieve*	Goals (distal/proximal)	• How much do they want to address sexuality routinely? • How often is working on something else on their agenda more urgent than addressing sexuality routinely?
	Goal priority	
	Goal/target setting	
	Goals (autonomous/controlled)	
	Action planning	
	Implementation intention	
(10) Memory, attention and decision processes *The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives*	Memory	• Do they usually address sexuality? • Is it something they often forget to do? • How much attention will they have to pay to address sexuality? • Might they decide not to do it due to competing tasks, time constraints, etc.?
	Attention	
	Attention control	
	Decision making	
	Cognitive overload/tiredness	
(11) Environmental context and resources	Environmental stressors	• To what extent do physical or resource factors facilitate or hinder the practice of
	Resources/material resources	

Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence and adaptive behaviour	Organisational culture/climate Salient events/critical incidents Person × environment interaction Barriers and facilitators	addressing sexuality? • Do they have beliefs about how certain characteristics of their patients that would influence their responses to a discussion on sexuality?
(12) Social influences *Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours*	Social pressure Social norms Group conformity Social comparisons Group norms Social support Power Intergroup conflict Alienation Group identity Modelling	• To what extent do social influences facilitate or hinder the practice of addressing sexuality? • Do they think their colleagues/management will be helpful in addressing sexuality? • Can they count on their colleagues / management to support each other in addressing sexuality routinely even when things get tough?
(13) Emotion *A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event*	Fear Anxiety Affect Stress Depression Positive/negative affect Burn-out	• Does the idea of addressing sexuality evoke an emotional response?
(14) Behavioural regulation *Anything aimed at managing or changing objectively observed or measured actions*	Self-monitoring Breaking habit Action planning Self-monitoring	• Do they have a clear plan on how the team will address sexuality routinely? • Do they have systems they could use for monitoring whether or not the team has addressed sexuality?

BCW intervention functions coding guideline	
Intervention function	**Principles**
1. Education	Increasing knowledge or understanding • promoting understanding of the benefits of the behaviours and on how and when to enact them effectively • address concerns about the potential costs • provide specific guidance on how to minimise adverse spill-over effects • consider varying levels of educational level and varying circumstances.
2. Persuasion	Using communication to induce positive or negative feelings or stimulate action • generating a feeling of responsibility and a sense that the behaviours are valued by groups with which the target group identifies. • promote concern and active engagement rather than anxiety and defensive avoidance
3. Incentivization	Creating an expectation of reward • e.g., social reward, including thanking people and praising them, to make people feel positive about having engaged in the behaviour
4. Coercion	Creating an expectation of punishment or cost • where threat of punishment is used, this must be accepted as appropriate by the community and applied in a way that is seen as equitable and proportionate. • Contingencies should be clearly set out and explained. As far as possible any sanctions applied should be immediate (for example, on-the-spot fines). • Use of social coercion should focus on the behaviour, not the person, and be delivered in a way that is perceived as supportive and just.
5. Training	Imparting skills • May involve demonstrating the behaviour in full and component-by-component (including what to do and what not to do), provide a schedule for practice, and show common mistakes and how to rectify them.
6. Restriction	Using rules to reduce the opportunity to engage in the undesired behaviour (or to increase the desired behaviour by reducing the opportunity to engage in competing behaviours) • should involve setting clear and specific social rules around behaviours, with boundaries that are readily understood, explaining the rationale and providing specific examples of what is and is not acceptable.
7. Environmental restructuring	Changing the physical or social context • could involve redesigning indoor and outdoor spaces, include environmental cues that promote the behaviour, • ensure that people have the material resources they need to enact the behaviours whenever required, • create or provide access to physical spaces that support the behaviour, • and ensure that social and organisational rules and norms are supportive of the behaviour.
8. Modelling	Providing an example for people to aspire to or imitate • showing people with whom the target group identifies enacting the behaviour in ways that are culturally appropriate and realistic to achieve.
9. Enablement	Increasing means/reducing barriers to increase capability (beyond education and training) or opportunity (beyond environmental restructuring) • could include a range of interventions for improving capability, such as promoting collective action across unit to overcome barriers to improving care

Appendix C. Barrier themes and quotes mapped against TDF domains.

TDF Domain	Barrier	Sample quotes
Knowledge	Limited knowledge about post-TBI sexuality and options for assessment and interventions	**"…**if it is brought up by the patient then you know, I felt limited in my knowledge and advice that I could give to the patient." (P21, IP)
	Unsure what sexuality may entail	"Often when you say sexuality everyone thinks sex and that's not necessarily what you're after. And that's a difficulty." (P18, CIT)
Skills	Belief that sexuality is too large and complex to tackle	**"…**it's such a big topic, isn't it? that you actually need quite a consumed amount of time to even start the topic and then to continue on." (P2, both)
	Low confidence and skill level	"Lack of confidence due to inexperience of talking about sexuality" (Anonymous exercise)
	Unsure how to discuss	"But also, how do we initially bring up this conversation?" (P9, IP)
Professional role and identity	Not seen part of job scope	"…basically it's not within my train tracks. Uhm I prefer to refer out." (P14, IP)
	Unsure whose role it is or what is expected of them	"Bringing it up vs waiting for client to bring it up; Who will have the conversation?" (Anonymous exercise)
Self-efficacy	Low self-efficacy in addressing sexuality well	"So I don't actually naturally bring it up as is this something that concerns you or is there a change, because I don't have anything to offer" (P21, IP)
Pessimism	Belief that making it mandatory might result in tick-box exercise	"…if we made it practice that everyone has to talk about it then it becomes a tick box exercise, but it doesn't necessarily mean that we're going to do it effectively." (P17, IP)
Beliefs about consequences	Belief that it will create extra workload	"I'm just concerned about with doing this, what sort of extra work is going to open up to the nurses" (P9, IP)
	Concerns about nocebo effect	"They might think … 'I have these symptoms, this is my identity' and then they take on these symptoms." (P5, CIT)
	Belief that discussions will be embarrassing or uncomfortable for both staff and patients	"There is always that embarrassment from both sides. Most of our patients are young males and they don't want to be talking about this with someone older." (P9, IP)
Intentions	Some staff in precontemplation stage	"… until the facilitation of this workshop I suppose I haven't really thought about it… it's not on the forefront of my mind sexuality in TBI" (P14, IP)
	Uncertain if routine discussions are relevant	"Not making this a topic just for the sake of it" (Anonymous exercise)

TDF Domain	Barrier	Sample quotes
Memory, attention, and decision processes	Staff forgetting to ask	"…we just forget to ask about all these other things. We do mood a lot better now, but just don't ask that [sexuality] question." (P9, IP)
	Not something that is routinely or usually done	"It's always things that I think about but often don't get to it." (P10, CIT)
Environmental context and resources	Belief that culture, age, gender, and religion are barriers	"We don't know enough about different cultures, you know? What offends whom? …are there certain things we need to know that we don't, where we step on a trap or a landmine and we don't realise?" (P6, TLC)
	Belief that it is not part of Epworth's culture	"Also the therapists' assumptions of the [organisational] culture" (P12, CIT)
	Competing priorities and time constraints	"Other more acute issues requiring attention first" (Anonymous exercise)
	Concerns around TBI-related inappropriate behaviours	"…there are patients who are inappropriate already before you even started to talk about anything intimate." (P16, IP)
	Difficulties ensuring privacy and confidentiality	"↓ privacy on ward [due to] shared rooms" (Anonymous exercise)
	Lack of educational or training resources	"[lack of] informational materials to provide; Lack of training" (Anonymous exercise)
	Lack of good referral options	"How do we find clinicians to refer to for them to know about in the community who won't brush them off or won't say: 'oh I really don't know about that'." (P6, TLC)
	Losing skills with staff turnover	"when there is a high turnover, how do we then make sure that people aren't slipping through the cracks with education in this area." (P7, IP)
	Negative salient events	"…but a very bad experience with a previous patient when you brought up sexuality can put you off for a while when addressing it again." (P3, both)
	TBI-related cognitive impairments	"Patient's cognition / PTA" (Anonymous exercise)
	Unsure when to discuss and when patient will be ready	"…the other thing is about our timing as well… looking at inpatient versus outpatient." (P9, IP)
Social influences	It is the norm to refer out	"…we use that referral service. So not to say that we're conservative but this is the way we do things" (P14, IP)
	Discussing topic is not yet normalised across healthcare	"Discomfort at possibly being the first person to address topic" (Anonymous exercise)
Emotions evoked	Anxiety, nervousness, and apprehension	"Apprehension about how the patient would respond / react; Feelings of anxiety and awkwardness" (Anonymous exercise)

TDF Domain	Barrier	Sample quotes
	Concerns about being inappropriate	**"**How the conversation would be perceived; Worry about cultural / age differences – stepping over the line" (Anonymous exercise)
	Embarrassment or discomfort	"…it is not an area that I would naturally feel comfortable with." (P16, IP)
Behavioural regulation	No structure to sustain behavioural change	"I think we had sexuality training about 5 years ago. But once we do one big workshop then it drops off for the next cohort of people to come through." (P7, IP)
	No clear protocol on how to or who should address sexuality within the unit	"What do we do [with an] inpatient? How do we do [it] with an outpatient?" (P9, IP)
	Reliance on external pressure to make team wide changes	"The case conference form got reviewed because of the fund requirements... there's always an external pressure to change your forms." (P7, IP). "And where has our internal pressure gone?" (P18, CIT)

Note. Participant quotes are followed by (participant number, setting). CIT = Community integration team. IP = Inpatient. TLC = Transitional living centre. Both = inpatient and outpatient settings.

Appendix D: Summary of co-designed intervention options mapped against BCW intervention functions

Co-designed intervention options	Specifications	BCW intervention functions
Staff training	**Content:** • Training might not necessarily be about fixing sexuality problems but how to ask the question. • Training to elucidate and remind staff about their existing transferrable skills. • More in-depth training for community staff and specific inpatient team members (e.g., occupational therapy and social work). • Include patient interviews / case studies sharing lived experiences. • Training on how to deal with inappropriate sexual behaviours or advances. • Provide Team-wide and discipline-specific content (e.g., how each discipline can contribute in different contexts such as inpatient ward, community settings, follow up appointments, etc.) **Mode:** • Establish it as part of the core mandatory online onboarding training for new staff induction and kept under 30 minutes. • To be treated like other essential skills training such as CPR training **Delivery:** • Built into existing educations plans such as annual ABI / Neurology team in-service sessions. • Have annual refreshers.	Training; Environmental restructuring; Enablement
Staff educational resources	**Content:** • Broad information on definitions, influence of TBI on sexuality, how to recognise indications for further discussions, and intervention options. • Educate team on how to overcome assumptions on age, gender and culture. • Provide team with buy-in sentence starters that cater for different confidence levels. • Provide flowcharts with prompts to aid with conversational / assessment flow (e.g., suicide risk assessment flowchart). • Provide tips and tricks for stickier conversations (e.g., someone younger or older, concussion, etc.) • Resources to be reviewed annually to ensure relevance and utility. **Mode:** • Both soft and hard copy versions. • Laminated sheets to put up in workspaces. **Delivery:** • To be accessed online and have in the offices.	Education

Patient information resources	**Content**: • Encourage patient to talk to team and let them know it is ok to ask questions. • Provide statistics to normalise (e.g., 50% have decreased libido) • List of common problems • Information on resuming sex after brain injury • Information on where to get help (e.g., hotlines, websites, organisations) • Have separate resources for patient and partners. • Translated into relevant languages. • Ensure that language is accessible with visual aids with multimodal options such as video resources to cater for TBI-related cognitive impairments. **Mode:** • Multimodal options – e.g., pamphlet, short video clip • To increase amount of information that is currently provided within the family guide to align with high frequency of symptom report. **Delivery:** • Given with discharge pack to every patient as routine. • To be placed on the ward and clearly visible.	Enablement; Environmental restructuring
Visual cues for normalisation	**Content:** • Encourage people to be open and provide permission to discuss sexuality. • Let patients know that staff may raise the topic with them. **Mode:** • Posters **Delivery:** • Placed in ward and therapy areas, notice boards, staff tearoom	Enablement; Environmental restructuring
Documentation	• To systematically document sexuality discussions conducted with patients. • Having a sexuality interview assessment form / questionnaire / document to assess patient needs. • To include a section in all allied health forms, patient discharge summaries and other handover documentation. • To amend official forms and include topic in subheadings as a prompt.	Enablement; Environmental restructuring
Patient sexuality liaison and coordinator	• Patient liaisons will be decided by the team at case conference to initiate conversation and/or deep dive with patient to assess their needs. • Liaison can then coordinate with the rest of the team to come up with strategies or therapeutic options. • Liaison will need to be trained and educated on sexuality to be able to assess and recognise how each discipline may help.	Modelling; Enablement

Case conference meetings	• To leverage on highly structured multi-disciplinary case conference meetings. • Doctors to lead the conversation and check if topic has been broached. • To be discussed in both the initial admission and discharge case conference meetings. • To amend case conference form subheadings to include prompt for documentation.	Enablement; Environmental restructuring
Establishing sexuality champion(s) within each disciplinary team	• Appointing pro-sexual individuals within each discipline team to keep topic front of mind and to guide new staff and students	Modelling
Six-week medical follow up	• To ensure that sexuality is broached at six-week follow up with Epworth medical team internally or with external medical referral using documentation of follow up recommendations to be provided on discharge summary.	Enablement; Environmental restructuring