MDT Reflections on Working with CCD and Sexually Disinhibited Behaviours

Case report by Su-lin Yii & Kim Gauld

Neuropsychologist & Speech & Language Therapist

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The Wolfson Neurorehabilitation Centre

NHS
St George's, Epsom and St Helier
University Hospitals and Health Group

Overview

Literature and Guidance

Case Study

Reflections

Definitions

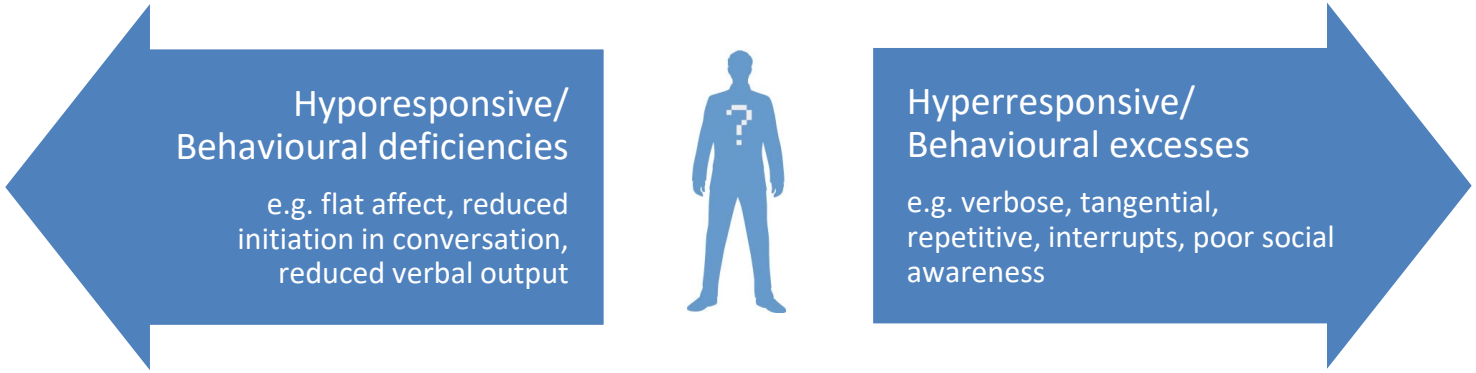
- **Cognitive Communication Disorder (CCD):** Difficulties with communication competence (listening, speaking, reading, writing, conversational interaction) that result from underlying cognitive impairments (attention, memory, organisation, information processing, problem solving & executive functions). **College of Speech-Language Pathologists & Audiologists of Ontario, 2015**

- **Inappropriate Sexual Behaviour:** "any verbal or physical act of an explicit or perceived sexual nature which is unacceptable within the social context in which it is carried out" (Knight, 2023)

- **Social cognition:** a collection of processes that allow us
  - To perceive social cues from the self and others
  - To interpret and understand both our own and others' emotions, beliefs and behaviours
  - To generate responses to these inferences to guide social behaviour
    (Cassel et al 2019)

Cognitive Communication Disorder

A communication continuum:



Psychosocial impact:

- **Families** report less satisfactory, more frustrating communication (Crewe Brown et al, 2011). Key areas of distress were changes to social cognition, insight and the "filter switch" (Grayson et al, 2020)

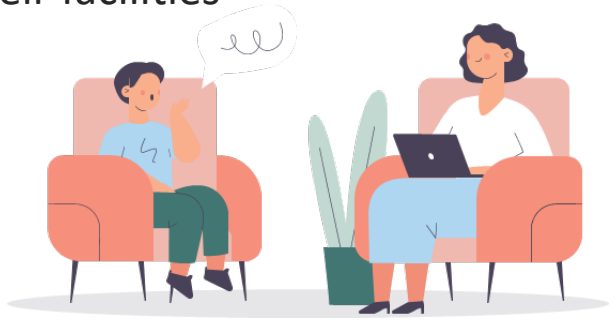
- **Social/community -** >50% difficulties – conversation/social relationships

(Togher, 2014)

- **Incidence of CCD: '**CCDs are the most prevalent group of communication disorders after ABI, with a reported incidence **as high as 80-100%'** (MacDonald & Wiseman-Hakes, 2010)
- First time stroke – **39-77% had CCD** (Hinckley, 2014)

Inappropriate Sexual Behaviour
(Knight, C, 2023)

- 37-54% people report sexual difficulties after stroke (Yeates, 2023)
- 50-60% for people post-TBI (Knight, 2023)
- Inappropriate Sexual Behaviour (ISB) is one of the most significant and pervasive neurobehavioural contributors to social handicap
- Possible outcomes:
  - Social isolation
  - Relationship breakdown
  - Loss of employment
  - Loss of independence
  - Criminal proceedings
- Up to 70% of brain injury rehab professionals have reported sexual touching as a problem of working in their facilities



Inappropriate Sexual Behaviour
(Knight, C, 2023)

- The rehab environment can be a factor; increasing sexual frustration while minimising the opportunity for sexual expression
- Tends to happen when the demands of the rehabilitation programme are lower
- May reflect a means of expressive sexual needs through seeking social engagement, as opposed to aggressive behaviours which may serve as avoidance or escape functions

Guidance

- **NICE guidelines (2023)** of stroke rehabilitation in adults - no mention of CCD or ISB
- **Incog 2.0 guidelines for cognitive rehabilitation** following TBI, part IV cognitive communication and social cognition disorders (Togher, 2023) - not specific to stroke
- **(PBS) Positive Behaviour Support** – person-centred framework for managing behaviours that challenge. PBS is based on psychological principles and aims to understand why behaviours happen and enhance the individual's quality of life. This aims to reduce the likelihood the behaviour will happen again.
- **NICE & BPS guidance for managing behaviours that challenge** in learning disabilities and dementia - not specific to stroke rehab.

Stroke Association:

- Stroke can have an impact on sex life and intimate relationships because of emotional changes, physical difficulties, relationship and communication problems.
- Advice: access specialist support (ie. Healthcare professionals) – SA information leaflet

Case Study: Michael*
Background

- Michael* was a 68-year-old man admitted for neurorehabilitation following a bilateral thalamic and right paramedian midbrain stroke (seen around 3-4 months post-stroke)
- Following the stroke, Michael experienced difficulties with motor functioning, swallowing, sensation, cognition and communication
- During his admission, Michael participated in an intensive neurorehabilitation programme seen by physiotherapy, occupational therapy, speech and language therapy and neuropsychology.

Case Study
Background

- Michael worked part-time as a consultant petroleum engineer whilst also completing a Masters Degree in Artificial Intelligence and lecturing at the university at the time of his stroke.
- Michael described himself as very social and takes pride in being a skilled communicator.
- He lived with his current partner and wife (with whom he was separated but not divorced). They were in the process of trying to sell the house.

Case Study
Assessment

Assessments carried out: La Trobe Communication questionnaires, Montreal Evaluation of Communication (MEC), the TASIT & communication observations

Communication features:

- Dysarthria and dysphonia
- Features of CCD including, verbose and tangential speech, poor topic maintenance, topic perseveration, variable eye contact – sometimes difficult to maintain (?due to vision or head control) and sometimes overly-intense with reduced blinking, flat affect (less facial expressions) and monotonous voice
- Social cognition difficulties, i.e. difficulties interpreting nonverbal expression of emotions, and difficulties with social inference (i.e. identifying sarcasm)
- A 'lack of filter' - disinhibited comments, including overly-familiar questions and comments towards women
- Other: visual difficulties (blurred & double vision)- closing R eye to compensate
- Reduced insight into cognitive and communication changes.

Case Study
Assessment

Assessments carried out: Full neuropsychological assessment

Findings:

- Slowed processing speed
- Remembering things he has heard, specifically if they have no context
- Remembering things he has seen
- Being able to “stop” automatic responding; acting without thinking

Case Study
Assessment

Recorded note: ‘Inappropriate touch during session (stroking SLT's arm, pt then verbally described what he was doing including saying it was inappropriate), pt responded immediately to request to let go.’

Recorded note: ‘Pt initiated hand shaking during review and stated he would do something inappropriate if he could’

Inappropriate sexual behaviours (ISB)

During his admission, Michael made inappropriate comments towards staff (telling female staff he finds them attractive, asking about their relationships, talking about sex), he touched female staff (reaching out to hold hands, touching/stroking staff on the arm or back) and on one occasion touched himself sexually in the presence of a staff member.

Whole team recording behaviours using **ABC charts**

Disinhibited behaviours include:

- **Inappropriate comments towards staff**
- **Inappropriate touching of female staff**
- **Sexual touching of himself**

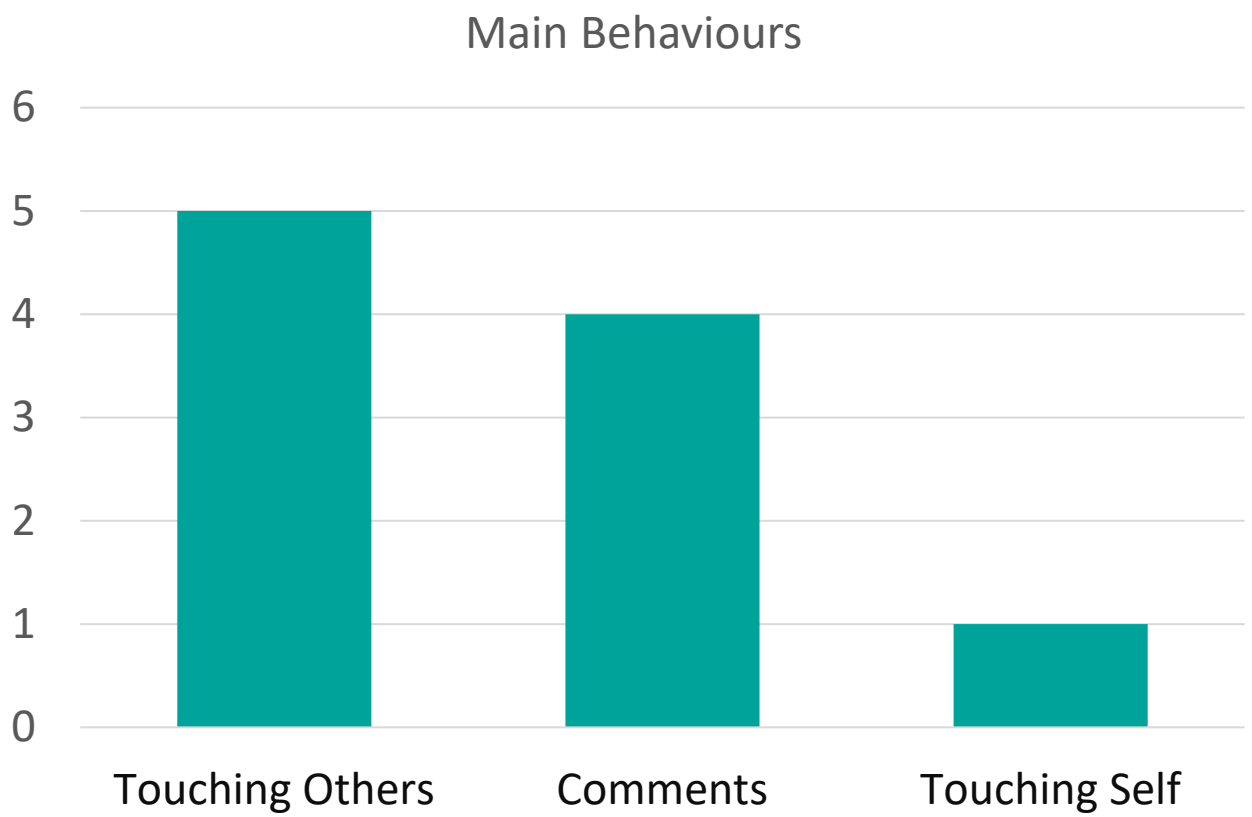
Case Study
Assessment

Discussion with partner:

- Partner Joy* shared that Michael's inappropriate behaviours were not entirely inconsistent with his premorbid personality explaining that he was very sexual; had 9 children to 7 different women and has had multiple sexual partners at once. She disclosed that his "sexual personal life is a mess" and detailed the difficult living situation she is in, living with his wife (with whom he is separated but not yet divorced).
- Prior to the stroke, Michael would not repeatedly comment on someone's appearance and seek frequent physical contact. This was very different to his baseline social communication style. He enjoyed studying and working and could maintain professional relationships.

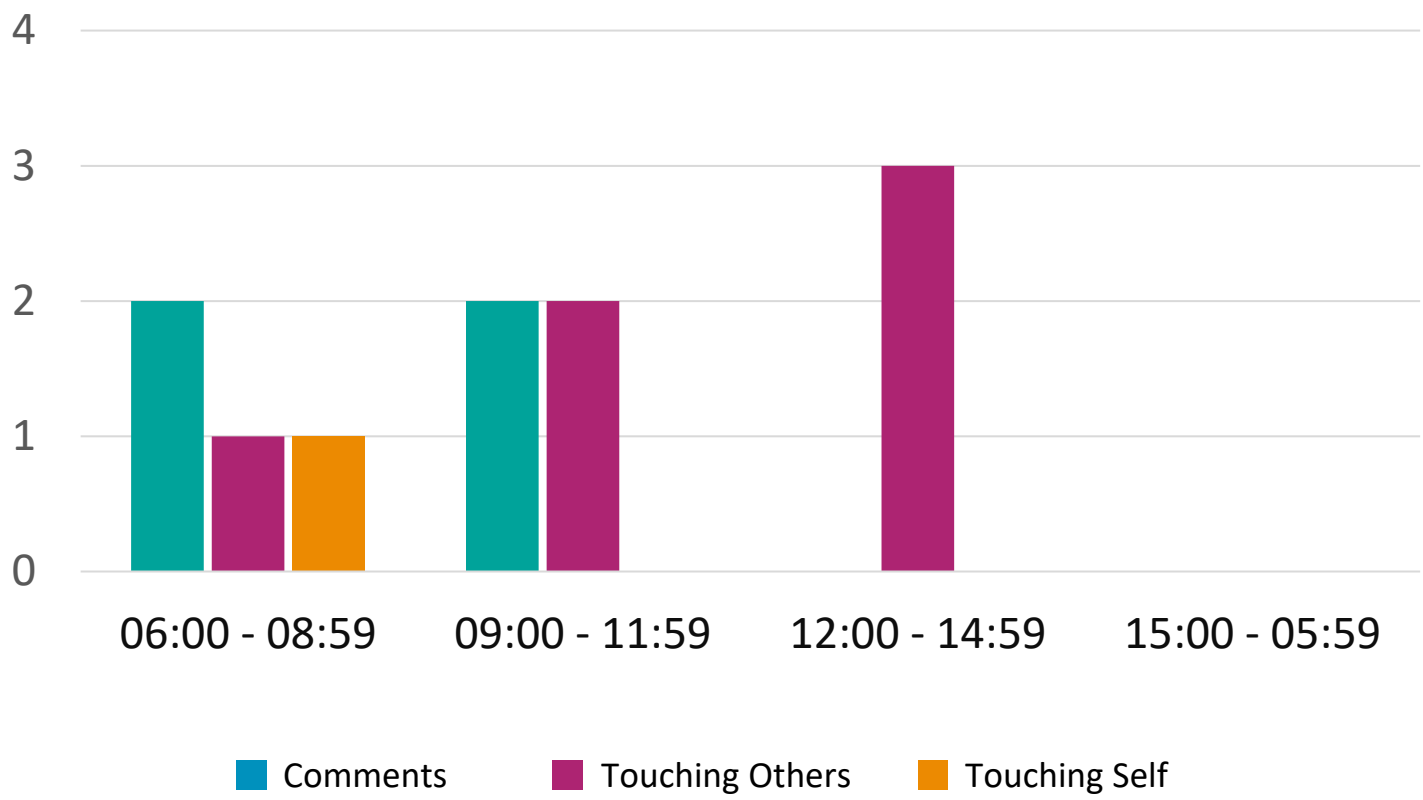
Case Study
Assessment

- ABC charts allowed us to work out which behaviours occurred most frequently



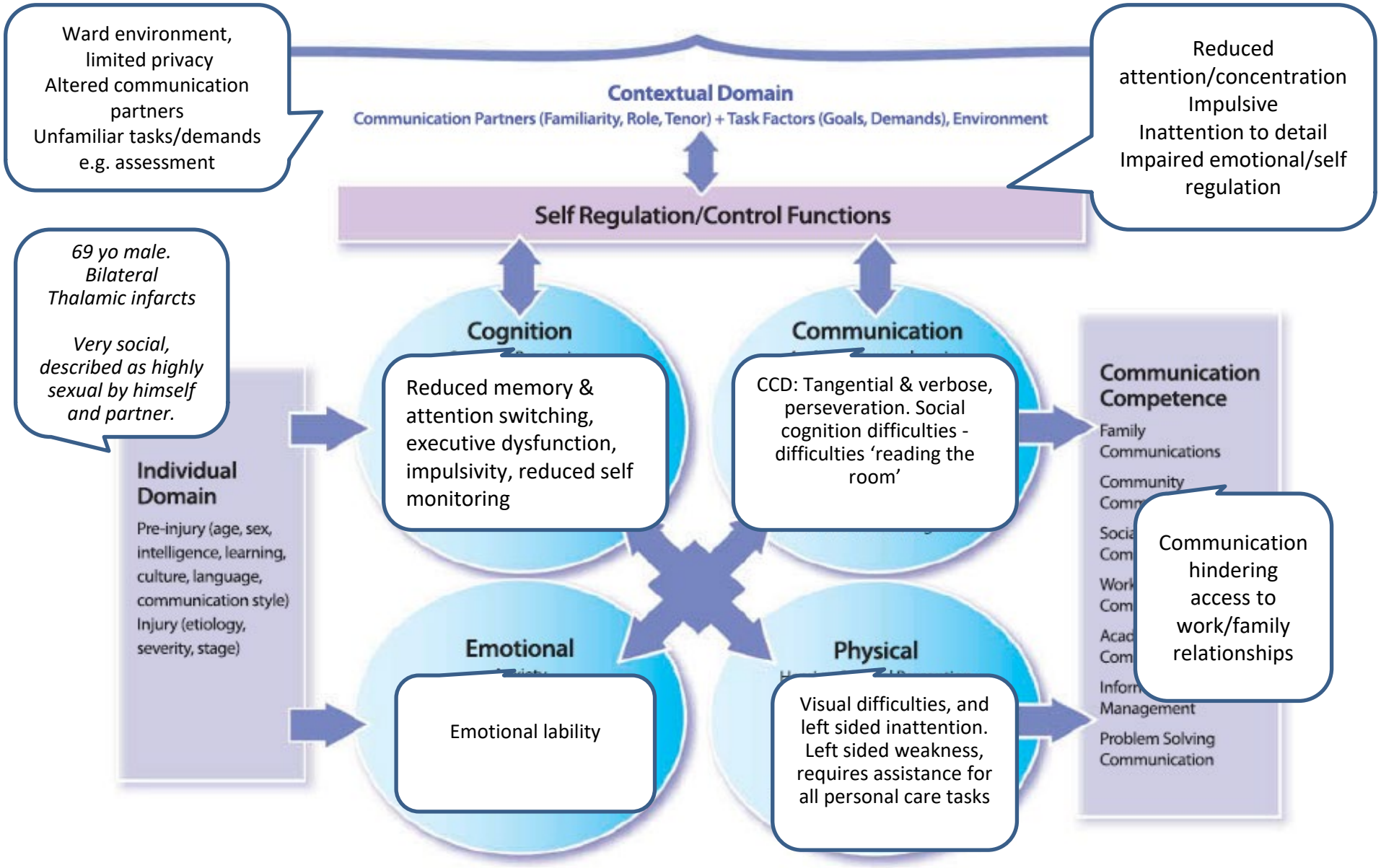
Case Study
Assessment

- This also allowed us to work out which behaviours were more likely to happen at different times of the day:



Formulation of ISB using the Model of cognitive-communication competence

MacDonald (2017), Brain Injury



Case Study
Formulation

- Michael was previously a highly sexually active person, and this played an important role in his life.
- Thalamic strokes may lead to ISB because the thalamus plays a role in cognitive processing and regulation of behaviours (Mukku et al., 2022).
- Since admission to hospital, Michael had not been given opportunities for privacy or intimate time with his partner.
- Ongoing CCD and social cognition changes resulted in difficulties monitoring his behaviours and stopping before acting
- Michael was eager not to offend others and greatly valued his rehabilitation. He did not want his behaviours to impact on this input.

Case Study
Intervention

Client centred goals

Used Wolfson Values-based goal setting process.

Goals were to live with his partner and explore returning to a teaching role.

Fortnightly Goal planning meetings, to track progress of goals and support Michael / family management of expectations

Formulation – whole MDT involvement

Keyworker process; regular contact with family to maintain communication and coordinate admission & discharge

Communication partner training - Education to caregivers / family members

Michael and his partner benefitted from psychoeducation re: CCD and how disinhibition can affect behaviour following a stroke.

The aim was to reduce apprehension, stigma and improve communication

Terminology was carefully used to avoid putting guilt on Michael (e.g., “YOUR brain finds it hard to stop and think” instead of “YOU find it had to stop and think”)

Collaborative Communication & behaviour guidelines

My Brain Book – regular supported self-reflections and insight raising

Psychology led family sessions - psychoeducation

Case Study
Intervention

Communication strategy & metacognitive awareness
Behaviour guidelines
Insight-raising and supported self-reflections
All therapy / care interactions were an exercise of maintaining ‘professional relationship’

Reintegration into daily function / social roles
Goals were geared towards maintaining relationship with partner and social network
Socially appropriate communication tasks / activities, for example based on client interests in academia and AI
Assist with adjustment to impairments

Group-based therapy
Weekly brain injury education group, with family members welcome
Conversation goal to be worked on in group

Social cog testing and therapy
The Awareness of Social Inference Test (TASIT)

Monitoring & feedback
Behaviour management plan - next slide
Consistent approach to feedback from all communication partners

Case Study
Intervention

Background:

is a 69-year-old man who suffered a stroke in the middle of his brain in August 2022. He has been described by his partner as a highly sexual person who had several partners.

Behaviours of Concern:

- **Inappropriate comments towards staff** (telling female staff he finds them attractive, asking about their relationships, talking about sex)
- **Inappropriate touching of female staff** (reaching out to hold hands, touching/stroking staff on the arm)
- **Sexual touching of himself**

Contributing Factors:

- **Disinhibition-** It is hard for to stop himself from saying his thoughts.
- **Difficulty Shifting Attention-** can become "stuck" on a topic and have trouble thinking of something else.
- **Likely Memory Problems-** may forget previous conversations about appropriate/inappropriate behaviour
- **Cognitive Communication Difficulties-** struggles to judge what might be appropriate or inappropriate. He may have difficulties reading social situations.
- **Eyesight difficulties-** poor eyesight may impact on his ability to see facial expressions clearly and know someone feels uncomfortable
- **Long hospital admission** has not had the opportunity to spend private time with his partner since the stroke.

General Strategies:

- is very eager not to offend people and has asked that **clear feedback is given immediately if he says or does something inappropriate.**
  - **He responds very well to feedback that you feel uncomfortable**
  - *His suggestions of what to say includes:*
    - don't say/do that"
    - that's inappropriate"
  - *Other helpful feedback may include:*
    - "I'm starting to feel a bit uncomfortable talking about this, could be talk about X instead?"
    - that is an inappropriate comment, so let's move on from that"
- **It is important that we do not shame or make feel he is being punished for his behaviours, and that it is the result of his stroke.**
- **Redirect** back to the task or another activity following feedback.
- If the behaviours continue, use the following steps:

1) Provide immediate feedback the behaviour is inappropriate.
2) Let know the session will be terminated early if it continues (I've asked you not to do that. If it happens again we might have to stop the session.")
3) Provide with a 5-10 minute break and leave the room (I did give you a warning that I would leave because of these comments/behaviour. I'll give you a break now and come back in x minutes" or ' that makes me feel uncomfortable. I'm going to give us a 5 minute break and see if you can concentrate better when I come back")
4) Discontinue the session, with explanation (that behaviour is inappropriate. I have asked you to stop and given you a break. I'm going to finish this session now")

Michael's Behaviour Guidelines

Background:

Michael is a 68-year-old man who suffered a stroke in the middle of his brain in August 2022. He has been described by his partner as a highly sexual person who had several partners.

Behaviours of Concern:

- **Inappropriate comments towards staff** (telling female staff he finds them attractive, asking about their relationships, talking about sex
- **Inappropriate touching of female staff** (reaching out to hold hands, touching/stroking staff on the arm or back
- **Sexual touching of himself**

Contributing Factors:

- **Disinhibition-** It is hard for Michael to stop himself from saying his thoughts.
- **Difficulty Shifting Attention-** Michael can become "stuck" on a topic and have trouble thinking of something else.
- **Memory Problems-** Michael may forget some of the times he has been inappropriate
- **Cognitive Communication Difficulties**- Michael struggles to judge what might be appropriate or inappropriate. He may have difficulties reading social situations.
- **Eyesight difficulties**- Michael's poor eyesight may impact on his ability to see facial expressions clearly and know someone feels uncomfortable.
- **Long hospital admission-** Michael has not had the opportunity to spend private time with his partner since the stroke.

Michael's Behaviour Guidelines

General Strategies:

- Michael is very eager not to offend people and has asked that **clear feedback is given immediately if he says or does something inappropriate.**
- **He responds very well to feedback that you feel uncomfortable**
- His suggestions of what to say includes:
  - "Michael, don't say/do that"
  - "Michael, that's inappropriate"

- Other helpful feedback may include:
  - "I'm starting to feel a bit uncomfortable talking about this, could be talk about X instead?"
  - "Michael, that is an inappropriate comment, so let's move on from that"
  - "That is a comment about my appearance/ relationships, I don't feel comfortable discussing that.

- **It is important that we do not shame or make Michael feel he is being punished for his behaviours, as they are the result of his stroke.**
- **Redirect Michael** back to the task or another activity following feedback.

Michael's Behaviour Guidelines

If the behaviours continue, use the following steps:

1) Provide immediate feedback the behaviour is inappropriate.

2) Let Michael know the session will be terminated early if it continues ("Michael, I've asked you not to do that. If it happens again, we will have to stop the session.")

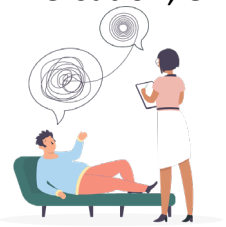
3) Provide Michael with a 5-10 minute break and leave the room ("Michael I did give you a warning that I would leave because of these comments/behaviour. I'll give you a break now and come back in x minutes" or "Michael, that makes me feel uncomfortable. I'm going to give us a 5-minute break and see if you can concentrate better when I come back")

4) Discontinue the session, with explanation ("Michael, that behaviour is inappropriate. I have asked you to stop and given you a break. I'm going to finish this session now")

Michael's Behaviour Guidelines

Strategies for Inappropriate Comments:

- After Michael makes an inappropriate comment give **immediate feedback.** You can include some of the **context** that Michael does not want to be disrespectful. This may help him remember it better.
    - e.g. "Michael, I know it's important to you not to be disrespectful, so staff agreed to let you know when you make a comment that makes us uncomfortable. That comment was not appropriate in a professional setting."
- Sometimes Michael says "I know this is inappropriate but…" before he makes a comment. In this case, interrupt Michael before he makes the comment with:
    - "Michael I'm going to stop you there, because you've told us you don't want to be disrespectful. It's not appropriate to say anything about staff's appearance or relationships." **Help Michael shift back to appropriate topics by immediately moving the conversation on to something else.**
- If comments continue use the steps above to give a **warning and terminate** the session if necessary.
- **Avoid engaging too much in Michael's compliments** (e.g., thanking him for the compliments, laughing nervously etc) which may inadvertently encourage the behaviour further.
- If Michael tries to talk about his sexual needs and you are not comfortable having this conversation, encourage him to discuss this with Psychology in the first instance.



Michael's Behaviour Guidelines

Strategies for Inappropriate Touching of Staff:

- It has been agreed that therapists should be able to shake Michael's hand at the start and/or end of a session as a social greeting if the therapist feels comfortable.
- If shaking Michael's hand:
  - **Limit the handshake to 2 shakes, then firmly remove your hand** (therapists will need to initiate finishing the handshake).
  - **If it feels like he is gripping on for too long**, say "I'm going to take my hand away now, please let go."
- Overall, **strategies for inappropriate touching are the same as for inappropriate comments** (ie., provide immediate feedback and ultimately discontinue the session if it doesn't stop).
- **Staff should try to place themselves in positions that would make it more difficult for Michael to reach out and touch inappropriately (e.g., out of arm's length) if they are not engaged in a task requiring contact.**
  - **Where staff need to come closer to Michael, he may benefit from a pre-emptive explanation** (e.g. "Michael, I'm going to be helping to wash you now, so we will be keeping this professional.")
- **If Michael does reach out to touch you, step out of the way (if safe) and provide immediate feedback** ("Michael, I don't feel comfortable with you touching me like that, can you please stop").

Michael's Behaviour Guidelines

<u>Strategies for Inappropriate Touching of Self:</u>

If you accidentally walk in on Michael doing something private**, immediately leave him while closing the curtains around him.**

Tell Michael you will return at a later time for your planned session (around 5- 10 mins).

When you return later, call out to Michael before opening the curtains to check if he is ready.

If Michael misses a session due to these behaviours, feedback to Michael that he has missed out on his session because of it. **Do not reschedule.**

Please continue to complete ABC charts as behaviours occur. This will allow us to update these Guidelines as we get to know Michael better

Case Study
Intervention

Other nonpharmacological interventions of Michael's ISB:

- Promoting emotional intimacy between him and his partner
- Ensuring privacy through environmental modification where possible
- Distraction techniques, and involvement in activities.

Ensuring staff safety - Michael to be seen by 2 members of staff for personal care tasks or in a private room

The pharmacological treatment needs was considered by Michael, family and medical team. Michael did not consent to this.

Case Study
Intervention

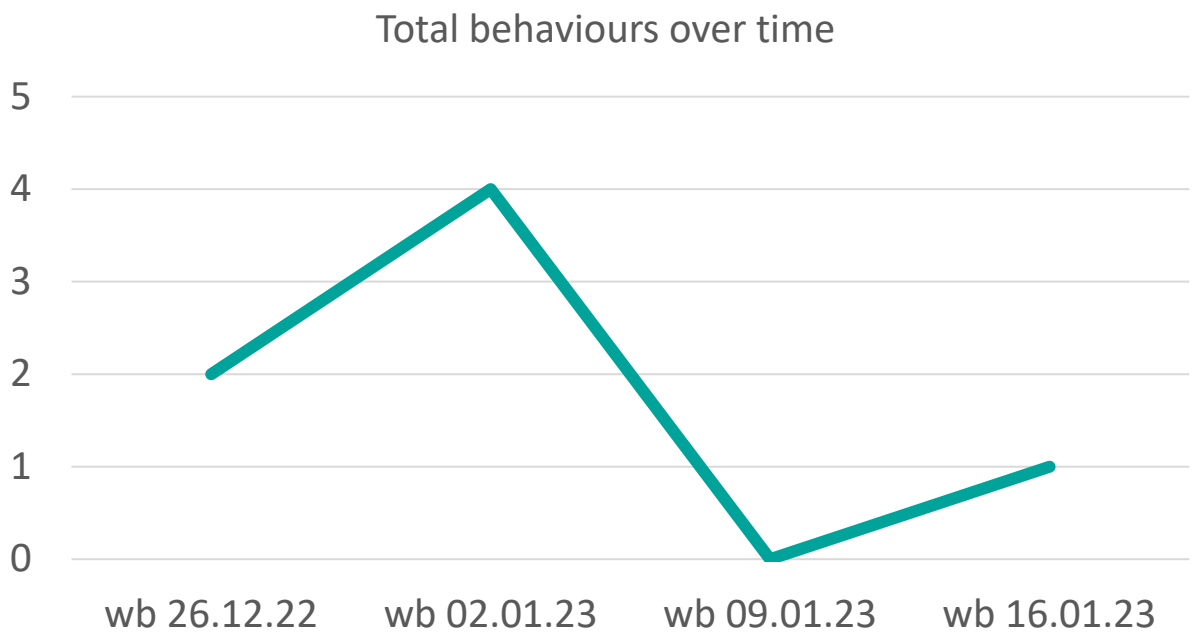
Partner discussion

- *Discussed management of behaviours (comments/ touching staff)*
- Joy reported that the current management plan of immediate feedback and clear boundaries was appropriate and had been effective in the previous hospital (where these behaviours were reportedly more frequent than here). Specifically, therapists telling Michael that they will not work with him if he continues the behaviour/comments is effective in him immediately stopping it.

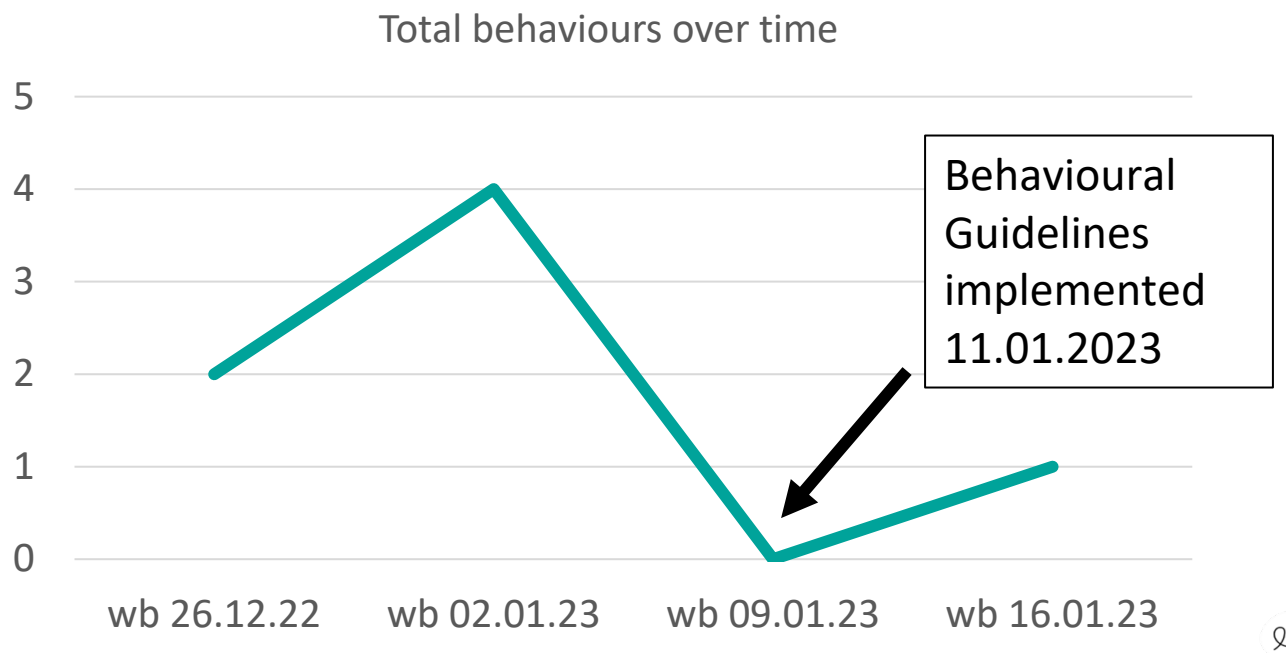
- *Discussed facilitating intimate time with Michael's partner:*
    - Discussed one option which may be considered could involve them booking a hotel room. Joy agreed this was a good solution, and she would be happy to book a room as needed.
    - She reported that Michael is seeking the intimate, private time with his partner.

- *Discussed sexual needs:*
- Joy advised that she would be happy to take Mark to the lockable bathroom to allow him privacy as needed. She estimated she would only have to do this once every few weeks, but would keep in contact with the MDT about this plan.

Case Study
Outcome



Case Study
Outcome



Therapist Reflections (OT)

Can you summarise your experience of working with Michael?

- **Great for my learning** as a newly qualified b5, particularly around communicating (sometimes awkward) conversations with patients and families.
- I found it interesting to work with someone who presents differently due to their stroke than what I had been used to.
- **Sometimes frustrating** not being able to carry out the treatment plan in the usual way. For example, ensuring I had a male/family member present during personal care/ADL sessions.
- An overall positive experience from a learning perspective, although I feel **Michael crossed the line with physical touch.**

Describe your rapport with Michael

- I feel that **I had a good rapport with Michael,** he was always friendly, open and honest. He was always receptive to advice given whether that was negative or positive.

How did you feel working with Michael at the start of his admission, and did this change over time? If so, why do you think this was?

- Yes, I do feel my **tolerance level decreased over time.**
- I think there are only so much inappropriate verbal comments you can take, this also progressed over time and Michael began physically touching which further decreased my tolerance level.
- It is difficult but **touching a member of staff is completely inappropriate.**

Therapist Reflections (OT)

Did your input change because of the disinhibited behaviours? / did you avoid any care tasks / conversations?

- Yes **I avoided being alone with Michael** and towards the end **avoided all personal care tasks,** asking family to support with this.

What did you feel was the most significant barrier to Michael getting support?

- I think, due to Michael's personal situation (having a wife and a girlfriend) with one of them explaining that this is how Michael can behave, it was taken as this may be baseline behaviour for him.
- This could have been a barrier, as we may have been more accepting of his behaviours.

How supported did you feel managing this? Did this change over time?

- The ward consultant was supportive; the team were also supportive in agreeing he should be seen as a double.
- **It was helpful having a behaviour plan** from psychology & SLT.

Therapist Reflections (OT)

Do you feel you would have benefited from training on topics such as sexuality after stroke, managing disinhibited behaviours and following CCD guidelines?

- Yes **training would have been helpful;** it is hard to understand as a newly qualified member of staff.

On reflection, would you do things differently? If so, what would you do? (as an individual clinician and as a wider service)

- With more experience now, I would have communicated more efficiently and **been firmer with my approach**.
- For example; continued with personal care/wash and dress sessions but explained to Michael if there are any inappropriate comments or touching that the session would be terminated immediately.

Any other comments?

- On the whole, I enjoyed working with Michael and his family, I hope they are doing well and he has continued to recover ☺

Therapist Reflections

Building rapport was harder - avoided seeing alone, and conversations were limited to certain topics and it was harder to use humour because we're being cautious not to stumble onto an overly-familiar or inappropriate exchange.

Barriers to support: care tasks avoided in therapy, sessions were 2:1 reducing intensity of rehab

Junior members of the team feel less confident in knowing how to respond to ISB in the moment

Blurring between personality and what was brain injury

Training needs!

Consultant Reflections

Staff considerations working with CCD and ISB:

- Working in neuro-rehab, **staff may consider behaviours that challenge as normal**.
  - *Staff are likely under-reporting.*
  - *Therapists feel more comfortable/empowered to report it than nursing.*
- **Impact of nursing working pattern**
  - Short shifts on the ward may lead to *lack of accountability and not thinking about the consequence of a management plan***.**
- **Embarrassment relating behaviours to family** and embarrassment with discussions around sexuality to team / family
- **Staff experience of sexuality in rehab is severely limited**
  - It has not come up much in [my] neurorehab experience; more so in spinal and young male patients.

Consultant Reflections

Further considerations working with CCD and ISB:

- **Ward environment not set up for allowing time for intimacy** between patient and partners.
  - Could issues such as insurance arise from this-what if there was an injury on the ward because of this intervention?
- **Consideration of medication management**
  - Need to consider capacity and patient wishes in this
- In regards to behaviours that challenge, sometimes the decision to follow a **zero tolerance policy, vs. behaviour agreement can be blurred.**
- **Management for this is often reactive rather than proactive**
  - Something comes up and then we manage it, then we leave it and the behaviour recurs.
  - There isn't a preventative approach.

Consultant Reflections

What would help:

- **Only when questioned is the behaviour picked up**
  - ***We need to explore ways to empower nursing team to identify, report and address it in the moment.***
- **Junior members of the therapy team may be tolerating it**
  - we could consider *awareness and training of CCD and ISB as part of an induction to the ward.*
- **We need to think about ways of incorporating the discussions about sexuality more in rehab.**
- **There is a need to ensure safety of staff**
- Need to **review guidelines & management approach**

Patient Reflections
Summary of Experience

I’m still not back to where I was before stroke. **It’s been a long slow process.**

I think given that when I first went into hospital I was practically in a coma and I couldn’t do anything, by the time after the care I had from you all after that I was able to come out here and live independently.

I remember I was having speech therapy to improve my speech, physio to improve my walking, **it took a lot of therapy to even do things that were basic.**

2 good things: able to get back a fair amount of speech and became more mobile again.

Difficulties: **being surrounded by beautiful young women like you - I was told off for inappropriate behaviour.** I also lost some of my memory.

Patient Reflections
Disinhibited Comments

I've got the greatest respect…I'm sorry if I upset anybody.

Now that I'm out of hospital **I haven't got the temptation around me** all the time.

The environment and stroke - a bit of both

I think it [the behaviours] did [impact on therapists] and **make it harder for them to work with me**

Patient Reflections
What Helps?

Sometimes it was a simple comment if I tried to touch, or said something, **that would be the end of the session. That was quite effective** because I didn't want to screw up my session like that

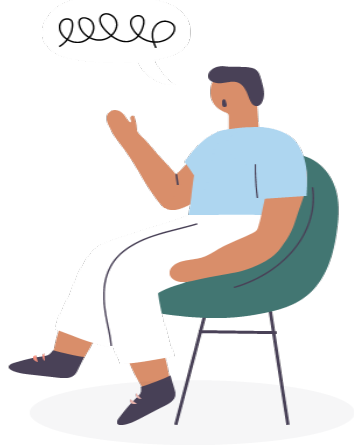
Tell me not to say things like that- I tried to modify my conversation not to ask personal questions. I thought it was quite reasonable…because you've got your own private life, you don't want your patient to be asking about that.

It did upset me [to get feedback] because I wanted to get away with things.

It didn't change my view- **I still liked the therapy** . I don't know if anyone was upset long term because of anything I did but that certainly wasn't the intention.

I thought the [GPMS] were useful to establish what the goals were.

I didn't like the recommendation on discharge was to be looked after by male carers, but I think I'm well behaved now



Partner Reflections

“Michael was looked after so well and you brought him back to life as much as you can. At the start he couldn’t talk, move, swallow, he was weak and vulnerable. The improvement…the family feel so lucky he was able to go to St Georges hospital.”

Partner Reflections

What worked well:

- The timetable & structure helped.
- Weekly goal meetings
- Neuro-education group - that was really marvelous to learn how these things affect your brain and behaviour and supporting them

Difficulties:

Noisy environment.

Partner Reflections
Inappropriate Sexual Behaviours

- “The behaviours started when he woke up. We had multiple meetings. **I was angry- I felt so sad...I was really angry with him.”**
- “I was impressed **you still tried to treat him, know him, help him and respect him, help to face this problem** and help his behaviour, mentality and his actions.”
- **“I could see the attitude of your professional people and we are so lucky – you guys talk to him, face the problem, but still love him and try to help him” .**
- **“You guys’ attitude really changed me a lot”.**
- **“I’m not sure I would still be with him”**

Partner Reflections

Ongoing strategies:

- I talked to the community therapists… so they could understand Michael. He is doing so well and only a couple of times was inappropriate with the physio.
- Therapists stop, go to another room, then return.
- “Michael, remember don’t touch me”
- Use of yellow card strategy
- In the last 1 year he has improved a lot.

Patient & Partner Reflections

Could anything have been done differently?

Partner: More space, more facilities. The bays can be crowded.

Maybe a meeting twice a week, or every day. More regular opportunities for contact to talk about the behaviours. Reminders/ feedback on behaviours from the wider staff (e.g., catering staff, cleaners).

Michael: “I don’t necessarily agree with that and think it was enough”.

“it wasn’t practical- we couldn’t sleep together” –

“I would like more but I’m aware it’s not possible”.

“I’ve got no complaints”

Things We Did Well: What Helped Michael?

- **Assessment of CCD** – using La Trobe Communication Questionnaires (self & other) to determine change since stroke, supported self-reflections with patient, exploring patient values / social and work roles.
- **Michael played an active role in writing his own Behaviour Guidelines**
  - His role, values and preferences for feedback were respected (e.g., the "*2-shake handshake*", direct feedback in the moment)
  - Thorough and directive guidelines *ensured consistency for everyone* involved in Michael's care and *helped therapists identify the line between acceptable and unacceptable behaviour.*
  - *Example scripts & structure* enabled the whole team to know how to respond
- Ensuring Michael was **not made to feel ashamed or "punished"** by emphasising "his *brain* (rather than *he*) was having difficulties" due to the stroke

Things We Did Well: What Helped Michael?

- **Provision of groups to promote understanding of stroke** (ie. Neuro-ed group) and **opportunities to practice social communication** (e.g., Coffee Club, Current Affairs)
- **Regular contact with therapists, Michael and his family** during fortnightly goal-setting meetings.
  - This enabled good rapport and a “safe space” for Michael and Joy to **openly discuss concerns** or seek information
- **Regular, repeated 1-1 discussions with Joy** about behaviours, CCD and sexuality.
  - Inclusion of Joy in management decisions.
- **Knowledgeable staff who understood CCD and ISB in the context of acquired brain injury**
- **Ad hoc, informal support of junior members of staff** in how to understand and manage challenging behaviours, reflect on their experiences and feelings, and ‘tune in’ to their own discomfort.

Barriers to Effective Intervention

- **Staff embarrassment** re: discussions about ISB and sexuality after brain injury
- **Staff lack of experience and confidence** working with CCD and sexuality after brain injury; particularly more junior staff
  - **Identifying premorbid personality traits vs behaviours directly caused by the brain injury**
- **Reactive, rather than proactive management** of the behaviours
- **Effect of behaviours on staff-patient rapport**
- **Impact of therapy intensity/ provision of sessions** (e.g., requirement for two members of staff for all intimate care, recommendation for male staff)
- **Ward environment:** difficulties with facilitating intimacy and privacy

Future Considerations

- **Staff embarrassment** re: discussions about ISB and sexuality after brain injury
  - Provision of a safe environment to empowering staff to discuss ISB, particularly more junior members of staff
  - Culture change with normalising and incorporating discussion of sexuality regularly
- **Staff lack of experience and confidence** working with CCD and sexuality after brain injury; particularly more junior staff
  - Provision of training in CCD and ISB as part of standard induction for all new staff (including nurses, HCAs, therapists and other ward staff like cleaners, catering staff and receptionists)
  - Regular team meetings with therapists and nursing staff to promote team cohesion and a consistent approach
  - Empowering staff to identify and report ISB
  - Collaborative, MDT approach to problem solving and sharing effective strategies
- **Identifying premorbid personality traits vs behaviours directly caused by the brain injury**
  - Use of detailed corroborative history with families and partners, with effective dissemination to the treating team.
  - Improved communication of formulation and social history to all team members
- **Effect of behaviours on staff-patient rapport**
  - Improved understanding of CCD and ISB in the context of acquired brain injury via bespoke training

Future Considerations

- **Reactive, rather than proactive management** of the behaviours
  - Proactive, rather than reactive management of the behaviours
    - Detailed handover from previous care providers specific to behaviour management
    - Proactive implementation of ABC/ behaviour monitoring
    - Faster implementation of broader initial behaviour & communication guidelines, which are frequently reviewed and become increasingly detailed as the staff get to know the patient better
- **Impact of therapy intensity/ provision of sessions** (e.g., requirement for two members of staff for all intimate care, recommendation for male staff)
  - Ongoing consideration of balancing staff safety and therapy provision or patient's preferences
- **Ward environment:** difficulties with facilitating intimacy and privacy
  - Solution focused approach to exploring emotional and physical intimacy for couples (e.g., discussions of home leave, use of hotels etc)
  - Culture change to openly discuss and problem solve issues relating to sexuality
- **Lack of formal guidance specific to CCD and ISB in the context of stroke rehabilitation**
  - There is a need for bespoke, specific advice for practitioners and services for both the use and delivery of evidence-based interventions for behaviours that challenge.

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Thoughts/ Questions?

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The Wolfson Neurorehabilitation Centre

NHS
St George's, Epsom and St Helier
University Hospitals and Health Group