Rehabilitation of Sexual Needs after TBI

This talk does involve sexually explicit information and language
(although that disclosure probably makes it sound far more interesting than it

actually is)

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How does this topic make us feel?

- For survivors of brain injuries and their partners.. Were you asked about your sexual needs after injury?
- Professionals do you feel comfortable asking about this?
- Do you feel comfortable supporting people with this?
- Is it something we need to consider? Someone elses job?

- I don't have any special knowledge or training (shhh don't tell the instructing case managers and solicitors)

..but I realised that I wasn't doing this as much as I could and simply taught myself on the legal side.. started asking patients about it more often and then it snowballed!

Today I am just going to share some of the cases I have worked with in the last few years and things I have been learning along the way. What I have learned is it just rehabilitation still.

Brain injury might cause….

Difficulties with disinhibition- it can be harder to form relationships when this is a difficulty
Impact sexual drive or drive generally
Impact erectile functioning
Impact physical coordination ability -apraxia, tremor, hemiparesis..
Change body image- facial droop, amputations, scaring, craniotomy, increased weight..
Impact social cognition –ability to read others emotional states, understand others thoughts and perspectives
Change the relationship with your partner into a carer role
Reduce privacy/ Change living situation
Continence- catheters, pads preventing access
Be something that has to be planned rather than spontaneous
Your sexual choices might be seen as inappropriate (open relationships?) by staff or other residents
Anxiety – is it safe? I.e. post stroke
Anxiety for staff- are we doing the right thing? Is it safe? Will we get in trouble?
Loss for a future that the person thinks may not happen- meeting people, marriage, kids.. Need support for psychological adjustment
Something that isn't talked about..

The list could go on… sounds like a main area for an MDT to think about in rehabilitation recovery

TBI and changes with sex

- Ponsford 2010 survey

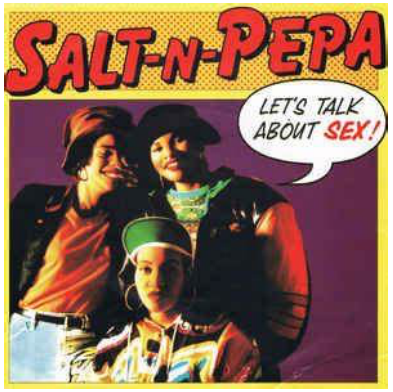
- 36-54% reported:
- decrease in the importance of sexuality,
- Reduced opportunities for sex and frequency of engaging in sexual activities
- Reduced sex drive
- Decline in ability to give partner sexual satisfaction
- Decreased enjoyment of sexual activity and ability to stay aroused to climax

- Frequency of this was significantly higher than control population

- High frequency of decreased self confidence, perceived sex appeal, higher depression, decreased communication levels and relationship quality with their sexual partner

- Lots of research showing it's a common difficulty, that it impacts on peoples wellbeing and that we don't always ask/support this area.

Who's job is this?



Many people feel nervous of capacity assessments anyway
People can feel unsure about asking clients about sex and relationships
Many (Most of us? All of us?) of us get no/minimal training on this area
Difficult conversation?

Who is having this conversation? With clients? With families? With staff?
Don't assume others have asked about it.
Do they ask clients of the same sex as them but not the opposite? Any worries of how they might be perceived asking about this topic?
I presumed the medics would ask about that… they might presume the psychologists?

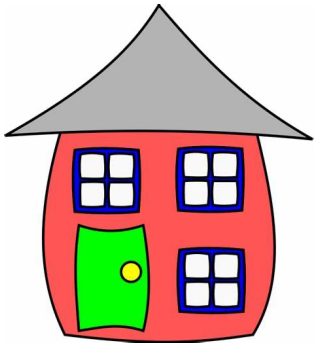
It is all of our job?

Problems of timing…

- Brain injury might make sex the last thing on someone's mind. Make it the last thing on professionals mind.

- When is it time to think about this? Day 2? Month 2? Year 2?

- I assessed a 60 year old woman last week, 2 years post injury, and she cried and said no one had asked about this. She was so worried that loss of sex drive and no sex might mean her husband would leave her. She had had about a year of outpatient physio/OT/neuropsychology.
- It might be on a clients mind but not talked about.



What impacts on people's actions and emotional responses?

We all have our own backgrounds and beliefs around sex and how comfortable we are talking about it.

Easy for any of us to make assumptions or for there to be subtle differences in how we support people
It can be helpful to stop and think what we do ourselves and whether out team have any training needs in this

Asking men about libido but not women.

Sexuality assumptions on the bases of current partner

Assuming someone is not managing self care as they are not wearing bra's

Asking men with tremor/limb weakness if they are managing their sexual needs such as masturbation but not women

Asking younger people about their sexual needs but not a 70 year old

Believing a young person with an intellectual difficulties/tbi does not understand his sexual actions and was "misguided" rather than the possibility of deliberate sexual predatory behaviour

Older woman and younger man relationship "disgusting"

Timing. Early stages post injury this is not the priority. But time goes on and we just don't get around to asking about it or asking all clients.

Discuss in your team

Do we do training on this? Do we repeat it over time?

Who's job is it to talk to clients about this? It's everyone's. But do we need an allocated person or embed it in certain tasks (admissions, health checks, psychology reviews) to ensure we are asking the questions?

How do we review it over time? Brain injury needs can change rapidly

How do staff feel about talking about this? How do they feel raising it with the opposite sex? Its amazing how we might feel more comfortable asking about peoples bladder/bowels/suicidal thoughts more than asking about sex.

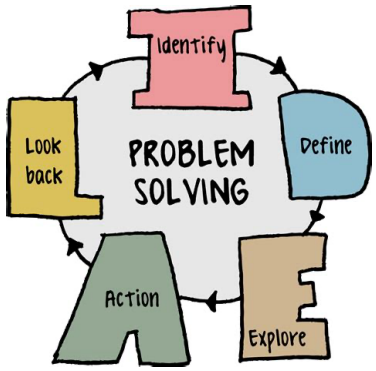
Important to normalise these conversations, build it into our work.
If you have a structured interview build it in with your other health questionnaires.
Sexual orientation/identity questions
Asking permission questions
"*this may or may not be relevant to you but some people with brain injuries can experience changes to their libido/ erectile functioning post brain injury and I just wanted to check if you have any needs in this area?*
And some people find that physically its all working ok but feel its harder to meet people now/ relationship with partner or actually having sex has changed. How are things for you?"

What about any impact of tremor? Muscle weakness? Apraxia? Limb amputations? Changed body/body image?

This can be exposing work –

- People may not feel comfortable
- I suddenly realised mid discussion with a man in the trust IT department that it was very obvious to both of us who had better knowledge of porn options for my patient and who didn't…
- We don't get any training so generally basing this on our own education and life experiences..
- Something we need to be sensitive to, or aware that it may come up. Some people are comfortable with this and some may not be.

Interventions



- I really don't have a clue… just seems to work.

- What I have noticed.. Its not really any different from any other aspect of rehabilitation.
- Client shares a problem or goal
- We might help make sense of it
- Help them problem solve and break it down in more manageable steps and help them progress through these.
- No one ever trained the team in helping the electrician re pass his exams.. Get the nurse back to work but somehow this area can make us think that we are unsure.
- On the medical side.. Refer to the GP… but almost all of my work hasn't involved this.. Its been more openness to talking and applying therapy and rehab skills.

Don’t underestimate asking and talking as a simple intervention- Client G “paranoid”

My wife is going to leave me, she is looking for someone else

She doesn’t want sex with me, she said “it would be taking advantage of someone with a disability”

Physically is everything working ok?

I had a catheter… “Dr gave me a look and said things wont be the same now”

Have you tried masturbating? – no… staying at my parents for six months.. Wouldn’t be proper
What about here? I don’t know…is that ok?

“I shouldn’t be telling you these things”

Intervention – it was pretty much giving permission and go and test it out …some more complex couples work but that was the starting point.

Sexual needs can be a rehabilitation goal

Lydia is a young person who was recently a resident at Daniel Yorath House. In 2020 she sustained
a severe hypoxic brain injury via overdose. She struggled with her memory, vision, apraxia and bilateral limb coordination
Prior to injury she was a sex worker and loved her work. She was keen to return to this and it was important to her identity and ability to to be financially independent.

We started with asking permission to have a frank discussion regarding her work and what could be barriers.

Goals

- To be able to put on condoms safely
- To be able to go into a café/bar and find a table/ find the toilet
- To be able to call a taxi and use it to to a bar independently
- Practice sex when covid allowed (she would take the lead on this bit with a willing friend)

This goal involves me having no special skill set. Just goal setting, breaking them down in to steps and helping her think about how she could progress in these. I'm not knowledgeable on the sex industry but we just had a very open conversation and a lot of laughter together.

Concerns from staff that she should not return to this job. Concern about increased risks - but that is her choice. Sometimes by trying we figure out how to adapt or what we can or cant do. Is this different to any other client? Staff support when this came up.

And recently at Goal Settin

- What do you want to do while here?
- Strippers!!!!!!

- From sitting on the sofa every day to investigating options, planning outings, considering the finances.

- It’s a lot more motivating than a trip to tescos!

Clients want/may need support with planning

- Generating solutions to how to meet people
- Practicing social skills
- Help finding accessible options
- Understanding social norms
- Ways to keep safe
- Social presentation/Hygiene norms – We aren't even discussing dating until you start showering is a lot more motivating when you live in care and lack drive..

Working with teams – Confusion over capacity

- Staff can understandably feel worried
- The training they/we get is often not enough to support them in this role. It may focus on assume, enable, decision specific, comprehend, retain, weigh and communicate. No information on case law or specifics. Which makes it very hard to follow the law.

- P and G. ….. Issues of staff attitudes.. “its disgusting”
- Back together and keeping things lively if still anxiety provoking for others..
- Safeguarding – lets not mix up sexual acts with assault..or confuse capacity for sex and capacity for contact…
- My role here is not therapy.. But on advocating and helping teams understand the legal situation…putting in some safeguard supports.

Similarly with S age 20

- Assessed as lacking capacity for sexual relationships… concerns of getting into cars of men she has met on the internet. Concerns that men were strangling her. Concerns that they were paying her with alcohol. Concerns for casual sex with men.

- In the interim – don't have sex… but on leave…

- Assessment – on leave she thought she had found a get around. This might have been more our fault than hers? Good problem solving skills?
- Cars- when she was a teenager..twice. Not got into cars since. A focus on the past?
- Strangling was sexual choking… The real problem was she was verbally disinhibited and told her mother everything in very dramatic accounts.
- Others judgements.. When I spoke to mum to gather information she said .. It would be fine if he took her out for dinner.. Showed some interest in her..
- So its ok for her daughter to have a relationship but not a Fuck Buddy? When I explained that not having capacity for sex means her daughter couldn't have sex ever mum was horrified! We got to an agreement.. Mum was actually concerned currently for men she meets on the internet.

- A reframe…. She has capacity for sex… but not, currently, for contact/social media…. This massively reframes the intervention/need for rehabilitation. Work with the solicitors and family around respecting her choices and positive risk taking with therapeutic support.

S made me think a lot

- Sex education varies a lot
- I'm a middle age straight white woman… was sexual choking a known thing when I was younger? What do I know about assessing knowledge of gay sex? Kink?
- People of other cultures and religions? In a recent capacity assessment the woman was mixing up forms of sex but then told me that these are forbidden in Islam. I have to take this into account in my assessment.
- Recently Hull students educated me but gave the opinion that sex education was inadequate for them as well.
- We approach capacity assessments and consequently rehabilitation often using our own knowledge and experiences.
- We need to be very careful that we are not forming decisions or judgements on our norms/experiences.

S made some unwise decisions. But how much weighing up do people do with sex?

British 16-19 year olds in 2009

61% have had sex

43% who were sexually active admitted to having had sex with a new partner without using contraception.

Factors raise were getting drunk, partner not wising to use it and reported lack of sex education on contraception

Who hasn't made an unwise sexual decision?

The intention of the Act is not to dress an incapacitous person in forensic cotton wool but to allow them as far as possible to make the same mistakes that all other human beings are at liberty to make and not infrequently do

Hedley J in A NHS Trust v P [2013] EWHC 50 (COP) para 10

Is this a healthy part of growing up?
Did we have the luxury that our decisions and mistakes had (hopefully) a bit more privacy to them?

Mr Justice Mumby's
*'What good is it making someone safer if it merely makes them miserable?' (*in
Re MM (an adult) [2007] EWHC 2003 Fam)

Supporting families

- People with a childhood brain injury may be less likely to have developed typical separation from parents over time with family used to seeing them with a partner.

- Be more likely to be in a situation where family are used to providing higher amount support for a persons age - Family may be concerned that they would have responsibility if someone became pregnant (often concerns is for the risk not the sex?)

- Sex can be a difficult conversation for people to have
- Family will have their own values and beliefs about sexual relationships
- There can be misconceptions on who has the 'right' to make decisions

- Emotive area

Family members and staff naturally often do not have knowledge that the 'bar' for sexual relationships capacity is so low with little emphasis on ability to think it through or manage risks. So its not really surprising that peoples assumptions might be that there would be greater 'safeguards' for people family view as vulnerable

- This can be exacerbated when post 18 (often younger) we may have greater issues of confidentiality to consider

Working with families

- Communication and education are really important
- Preparation- if we know a young person is approaching these issues can we help family understand in advance that soon they will have an increased right to privacy/confidentiality?
- Help people understand that the legal framework is very different from parental responsibilities when the person was legally a child. I.e. that family have no right to make a decision once the person is an adult but we can all continue to support the person
- Often the concerns are more about contact and risks such as pregnancy rather than sex itself. Where possible, discuss the support plans that might be appropriate as these might be very reassuring after an initial “you are letting them do what?!”
- Support to discuss their own worries, adjustment and emotions to the situation.

The shift from family being informed to the person having right to confidentiality

- 17 year old woman of Pakistani ethnic origin. Had been sexually active prior to her brain injury
- Commenced a sexual relationship in the rehabilitation unit
- Was assessed as having capacity for sexual relationships but neither party able to use contraception safely. Supported both with condom practice. This was kept confidential as per their wishes. Supported staff to understand their rights to a relationship and how to support their privacy.

- Family found out and were very distressed.

- Concerns of vulnerability in relationships
- Concerns she might get pregnant
- Concerns we were encouraging sex
- I was sent letters by their solicitor challenging the work I was doing

- Equally working in a case where rehabilitation goals of independence in the community. P has been going out with a support worker but wishes to go out alone. Family view of not appropriate as she is not married.

Working with patients: Capacity for a decision vs being able to sort the practicalities

- The relevant information for capacity for sex makes it clear the person should understand contraception but does not mean they need to be able to use contraception.

- This means that this is excluded from any capacity assessment
- However, it does not mean that we can't assess this area. I would advise making it clear that its irrelevant to the decision. You could even do this at a later date and keep it completely separate.
- Ask permission. Your client may even welcome it as they may not have considered this themselves
- Simple condom and banana or condom demonstrator
- If they struggle, a couple of sessions of practice can sometimes improve ability
- You may need a support plan to help them access contraception

- Top tip- warn your cleaner what you are up to. My office had a strong smell of spermicide!

Support to access to sexual health care

Research in 2019 by Jo's Cervical Cancer Trust found that 88% of women with a physical disability reported barriers to cervical screening.

Half said they didn't attend due to previous bad experience

Essential equipment not available to access a test at their GP
Difficulties getting a home visit
1 in 5 said that they experienced stigma as they were assumed to not be sexually active because of their disability

We may have a role here as advocates and supporting access to healthcare.

What about clients who ask for support to access a sex worker to meet their sexual needs?

- We should support clients to access options such as porn, vibrators or other sexual aids if they wish these
- It is legal for a sex worker to go into a care home or private home. It is not legal to have more than one sex worker in the home at any one time or two different sex workers visit a home.
- Historically, carers/professionals could not actively facilitate or set this up. I.e. we cannot book this or make payment on someone's behalf.
- Under the Sexual Offences Act 2003 a care worker who “intentionally causes or incites” someone in their care with a “mental disorder” to engage in sexual activity can be jailed for up to ten years
- Recently this changed and then changed back again.

TLC

Tender Loving Care TLC-trust.org.uk

Not for profit charity run by volunteers

LLC started in 2000 at a sexual conference when a disabled man spoke about his sadness about being a virgin in his mid 40's. He joined up with Dr Tuppy Owens to create the site.

Aims to put disabled people in touch with sex workers and sexual therapists who work with people with disabilities. You can book appointments via the site.

You must be 18+

Sex workers are not DBS checked (its not so easy to get references in this industry) but current sex workers vet new people to check real identities/they are responsible.

Tender Loving Care

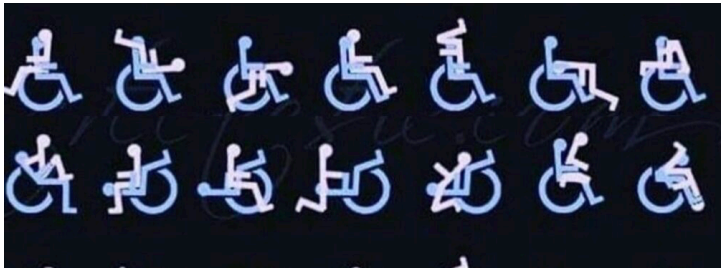
If clients who need assistance have been prevented from accessing sex workers, then sex workers may not know as much about their needs?

So I had a look at their website and viewed the workers profiles….(it was an education)

“Mute, Deaf, Wheelchair user, Blind/partially sighted, Use of hoist, Carer/support worker involvement, Open wound (dressed), Communication difficulties, Speech impediment, Lack of sensation/paralysis, Learning disability, Lack of motor control, Stoma’s, Amputee, Arthritis, Fibromyalgia, Heavy Scarring, Cerebral Palsy, Multiple Sclerosis, Muscular Dystrophy”

None of the ones I looked at listed brain injury as a disability they work with

I set up a chat with Bea



Bea works via TLC specialises in more therapeutic sex than being an escort. She described her work as being a sexual coach for people with disability. Helping people find how what they enjoy and creating intimacy.

I asked Bea about the profiles not mentioning brain injury.. Her thoughts was that most TCL workers may not work with many people with brain injury and not thought of listing it.. Many of them might be a bit unsure about some of the complexities and worried about capacity. Bea herself has never had training in brain injury.

Her only brain injury client

“uncomfortable”

“if he has a solicitor he clearly has issues with capacity”

”he hassles me- sends me dick pictures”

“I'm not like a restaurant, order of the menu”… “its more lets learn how to cook together”

It’s a mutually consensual discussion and relationship.

Bea and I agreed

If possible and a client gives permission, it may be really helpful for professionals and sex workers to chat
It might be useful to explain a bit about someone's brain injury

Clarify capacity for sex

That they might be verbally disinhibited but would like the opportunity to try and have a consensual experience

We might need to help the client understand”

- Boundaries and explanations (for all parties)
- That this is a consensual experience. They can ask the sex worker for things but the sex worker can say no to them and this must be respected.
- A clients preconceptions of sex workers may be different to the reality.
- That it is a financial exchange

Do we need goals for behaviour prior to this? Better management of disinhibition? Respecting choices?

Ask how the person prefers to be paid e.g. bank transfer or cash– can your client manage this type of financial transaction or need support?

Bev hadn't thought of a situation where someone might have capacity for sex but not for their finances.
We might need to give support around that

She can give receipts! I explained this can be useful if someone needs to account for their money to a deputy.

The sex workers boundaries may be different for different clients. Some people they may feel more comfortable with than others. They have a right to decide in the moment

How do we set this up well?

What sort of beds do you have? Medical beds are not sexy!
Profiling bed mattresses are far from ideal. Single or double?
What messages do we send in our settings?

Do we need to set up an alternative?

Are are staff supported with what is and isn't professional?

"they were so professional.. I really appreciate it when carers are like that. I've had the opposite, when I'm leaving its wink wink"

Does your client want privacy? Does the sex worker need to follow a story to support this? I'm so and so visiting..

What is your client expecting to happen? "they think they want sex but they want cuddling/ intimacy". Our clients can be the most and the least touched of people.

Do we need to support the client afterwards? Boundaries and support?

Bea's advice:

"*When clients lose their virginity they can be so excited they tell everyone. Not everyone wants to hear. Its important they consider the consent of carers to listen and respect that.*"

Bea said that she likes to ask people what are they doing after. Can they spend time with someone they trust and who is happy to listen to share with afterwards if want to?

Recommended watching -Rachael and Mark

Scarlet Road: A sex workers journey
Documentary on You Tube covering sex workers working with disability
https://www.youtube.com/watch?v=DMXjc_Ow4mg


k 23:27 Mon 28 Jun

Any Questions?

Thank you very much for listening

Please feel free to contact me on

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