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Women with intellectual disabilities

A study of sexuality, sexual abuse and protection skills

Background

Sexual abuse and abusive relationships are known to be especially common in people with intellectual disability. This study explored how women with intellectual disability understand sex, relationships and sexual abuse, the effects of sexual abuse on their lives, and how successfully they protect themselves from abuse.

Method

Semistructured narrative interviews with nine women with mild intellectual disability in Queensland, Australia. Interviews were audio recorded, transcribed, coded and analysed qualitatively.

Results

Major themes that emerged were: sexual knowledge and sources of knowledge; negotiating sexual relationships; declining unwanted sexual contact; self protection strategies; sexual abuse experiences; and sequelae of sexual abuse.

Discussion

Most participants reported unwanted or abusive sexual experiences. They described sequelae such as difficulties with sex and relationships, and anxiety and depression. They described themselves as having inadequate self protection skills and difficulty reporting abuse and obtaining appropriate support. Their understanding of sex was limited and they lacked the literacy and other skills to seek information independently. It is important for general practitioners to be aware of the possibility of sexual abuse against women with intellectual disability, and to offer appropriate interventions.

Keywords: sexuality; disability, intellectual; sexual abuse

Anxiety, depression and relationship difficulties are common presentations in general practice and other healthcare settings. Many women with such difficulties report previous sexual abuse or previous or current abusive relationships.¹ Sexual abuse is known to be very common in the community,^{2,3} and people with intellectual disability have been found to be at particularly high risk.⁴⁻⁸ People with intellectual disability experience difficulty in forming intimate relationships and are highly vulnerable to abuse in their relationships.⁹ Abuse may be difficult to detect in people with intellectual disability as they may lack the verbal skills to report the abuse, or may be assumed not to be sexually active.

Sequelae of sexual abuse in the general population include psychiatric and behavioural disorders, sexual dysfunction and revictimisation,^{10,11} but research in people with intellectual disability is scarce.

There is evidence that people with intellectual disability who have more sexual knowledge are better able to negotiate appropriate relationships.¹² However, compared with the general population, people with intellectual disability have been shown to have less sexual education and knowledge,^{6,12-14} less understanding of sexual abuse,^{15,16} poorer self protection skills¹⁷ and higher levels of belief that someone other than themselves should decide whether they should have sex.⁵ While this evidence has been recognised and programs have been developed for sexuality education^{6,13,18} and sexual abuse prevention,^{19,20} many people with intellectual disability lack access to such programs.

Available research indicates that people with intellectual disability have similar desires for relationships and sexual intimacy to other people.^{9,21} However, those caring for people with intellectual disability may persist in believing that people with intellectual disability are 'asexual' or 'childlike'.²² Sexual behaviour considered appropriate for other people may be dismissed or treated as inappropriate for people with intellectual disability²³ and opportunity for appropriate sexual expression is often limited.²¹ Relationships may therefore be secretive, with limited opportunity to practice safer sex or use contraception. Laws and guidelines about a person's capacity to consent to sexual relationships are inconsistent and confusing to both people with for people with intellectual disability and those supporting them.²⁴⁻²⁶

Few studies have directly explored the sexual and relationship experiences of women with intellectual disability. This study aims to further explore the sexual knowledge, relationship experience and self protection skills in adult women with intellectual disability.

Method

Semistructured interviews were conducted with women with mild intellectual disability between May and September 2009. Intellectual disability was identified if the woman received educational or social support or a disability support pension. Eligible participants were aged 18 years or over; able to participate in an interview in English without support; and able to demonstrate capacity to consent to participation according to the principles outlined in the New South Wales Attorney-General Department's 'Capacity Toolkit'.²⁷

A 'snowballing' sampling technique was used to recruit participants. Four community

organisations supporting people with intellectual disability approached potential participants and invited them to a pre-interview session. At this session the interviewer (a general practitioner with experience in women’s health and intellectual disability health) explained the project verbally and via a simple language information sheet, and assessed eligibility and capacity to consent. The interview was scheduled for a different day to allow participants time to consider their involvement. Most interviews took place at the participant’s support organisation, in a private room with support workers present in the building. Women were offered referral to an appropriately trained counsellor following the interview if required.

An interview outline was used to prompt discussion in the areas of relationships, sexual ‘literacy’ and self protection skills. Interviews were between 45–75 minutes, and were audio recorded and transcribed. Coding was carried out using NVivo® software by the interviewer, with review by a co-author.

Ethical approval for the study was granted by Bond University Human Research Ethics Committee.

Results

Twenty-one women were approached by their support organisations. Twelve attended the introductory session and nine completed the interview process. An unknown number of women declined to participate, or were not approached due to concerns about capacity to participate or perceived risk of distress.

Participants were aged 21–46 years. All identified as primarily heterosexual; two reported previous same-sex experiences. Six women reported having a current sexual partner. One had children, and one was pregnant at the time of the interview. One lived in a hostel, one lived with her mother, and three lived alone. Three lived with a partner and one with a partner and other family members. *Table 1* provides an overview of participants’ demographic and personal information.

Several themes emerged from the interviews, giving insight into the experiences of sex and the sexuality of adult women with intellectual disability.

Sexual knowledge

Participants’ understanding of sexual intercourse varied from very simplistic, with no apparent understanding of the process of sexual intercourse: ‘When you haven’t got any clothes on and the person lies on top of you,’ (Interview 3) to a broad, relatively sophisticated understanding of sexuality: ‘In a girl, I think that every couple months or something there is an egg release... and the guy’s sperm basically goes up them into the girl’s eggs and basically makes a baby... the guy ejaculates his semen into the girl’s vagina... [sex is] basically from head to toe like with your lips, your breasts, your vagina.’ (Interview 8)

Participants could identify some form of sexual activity other than penetrative intercourse, but struggled to outline a progression from touching or kissing to penetrative intercourse.

Concept of same-sex relationships varied from none to reasonably comprehensive.

Sources of sexual knowledge

School was the most frequently mentioned source of sexual knowledge. However, participants varied greatly on how much they had learned or remembered learning at school.

One participant aged 40–49 years said: ‘We did not talk about anything about sex at school

cos I think we couldn’t, I dunno was it illegal for us to talk about it?’ (Interview 5). Another in the 20–29 year age group described receiving quite comprehensive education at school: ‘We had to learn how to put a condom on so we basically do it on a banana or a zucchini... how a male injects like the sperm into a girl’s, I mean a woman’s vagina... your eggs and how you get your monthlies and everything, how it all works.’ (Interview 8)

Some described school education programs that sounded like they were designed for lower literacy levels, with pictorial material and practical learning. Other sources of sexual knowledge included books, sexuality educators, counsellors and their mothers. No participant reported any regular source of sexual information since leaving school. One woman said she first found out about sex: ‘Because I was raped.’ (Interview 6)

Negotiating sexual relationships

Participants were positive about relationships in general. Some clearly preferred nonsexual relationships, some wanted physical intimacy but not sexual intercourse, while others wanted satisfying sexual relationships.

All participants described strategies for starting a relationship with a potential partner, including going out for coffee, a meal or a movie.

Table 1. An overview of participants’ demographic and personal information

Age group of participants	20–29 years: two participants 30–39 years: four participants 40–49 years: three participants
Sexual identification	All identified as heterosexual: two reported previous same-sex experience
Relationship status	Current partner: six participants Previous but no current partner: two participants No partner: one participant
Housing status	Living alone: three participants Living with partner: three participants Living with partner and others: one participant Living in hostel: one participant Living with family: one participant
Children	No children: seven participants Children: one participant Currently pregnant: one participant

All participants were also aware of appropriate, private places for sexual activity.

Two participants mentioned involving parents or support workers in a decision to start a sexual relationship: 'You'd definitely have to go back to [support workers]... tell them about it before... and telling your mum.' (Interview 7)

These two participants were supported by the same organisation. Informal discussion suggested that this organisation had relatively positive attitudes toward supporting clients' sexual relationships.

When asked about negotiating sexual activity within a relationship, participants discussed their response when their partner requested sex. No participant described initiating sexual contact.

Declining unwanted sex within a relationship

Participants varied in their understanding of their rights in a relationship, and in their ability to decline unwanted sex. Some participants understood that they could refuse sex with their partner and had strategies for doing so: 'Well just with my husband, he wants sex all the time, I says no, I won't, wait till I'm ready or don't do it at all and that's it.' (Interview 6)

Some participants were quite confused about refusing sex with an established partner. One expressed a view that to refuse sex was to end the relationship. Forced sex with a partner caused some confusion: 'I knew it was wrong to hit me [but] I actually didn't know that him forcing me to have sex was wrong.' (Interview 1)

Several participants knew about Domestic Violence Orders. However, only one had actually taken out an order, and she had required support to do so.

Declining unwanted sexual advances from nonpartners

All participants reported receiving unwanted sexual attention and all understood that it was appropriate to refuse unwanted sexual advances from nonpartners. Strategies for dealing with such advances varied. Some reported responding quite assertively: 'He thought I was the perfect come-on but I wasn't interested, and if they don't accept no's no then just call the police and they'd put a stop to it.' (Interview 6). 'I stopped him from kissing me now cos I just don't feel

comfortable with him.' (Interview 3)

Other participants found it more difficult to refuse unwanted advances: '[A "friend"] just woke me up in the middle of the night wanting to have sex and I just didn't really want it, and in the end I enjoyed it, I shouldn't have, it was a bad mistake.' (Interview 2)

One participant said that she was able to refuse unwanted advances, but kept returning to a situation in which she had unwanted sex with 'friends': 'Because I was lonely.' (Interview 9)

Accounts of sexual abuse

This topic generated the most spontaneous responses from participants. Most were keen to tell their stories and vent their feelings. Several described abuse occurring in childhood, adolescence or adulthood. Some had experienced repeated abuse from multiple perpetrators.

'[My grandfather] touched my breasts, he touched my vagina... Mr J used to touch me all the time.' (Interview 5)

'My brother... I was 12... he put his finger, his pizzle, he was on me he put it in me.' (Interview 6)

'At school when I was 15... I got raped... by... another student. I... kept saying no.' (Interview 9)

Disclosure of abuse

All participants who described previous abuse viewed it as 'wrong' or 'bad'. Several described attempts to disclose abuse. Some had been unsuccessful,

'I said mum I don't want to go and see grandpa because pop touched me, and then, then my mum talked to my grandma and... my gran said I was a liar.' (Interview 5)

Despite these experiences, all participants said that abuse should be disclosed. Some expressed anger and frustration at the lack of effective action when they had disclosed abuse: 'If I put him in a court right, it would be my word to his word... Mum said we should have cut his tushie off... that's what I thought too.' (Interview 5)

Some indicated more positive responses: 'I rang mum and dad, I went to hospital for a while and while I was in hospital dad called the police.' (Interview 1)

Sequelae of abuse

Participants reported a number of sequelae of sexual abuse, including inability to have sexual intercourse, fear of sex and avoidance of relationships: 'Ever since [abuse] I tighten up down there before he gets full penetration.' (Interview 4). 'How do you stop being scared?' (Interview 1)

One participant had left school prematurely because of sexual advances from other students: 'Peer pressure... too many people were asking me for doing the wrong things and I decided not to.' (Interview 9). This participant expressed confusion about her role in an episode of abuse: 'I feel guilty... trying to be like too friendly because I'm a really good person.' (Interview 9)

Discussion

As has been found in previous studies,^{15,17} some participants had so little knowledge that it was difficult to see how they could negotiate sexual relationships or protect themselves from abuse. Some older participants reported receiving little or no sexuality education at school; they may also have forgotten what they learned at school. However, it is also likely to reflect conservative policies regarding sex education in Queensland in the 1970s and early 1980s.²⁸ Some younger participants reported receiving sex education at school. Participants had received some information from other sources. Since leaving school, few reported receiving any information at all, and none had access to regular education.

Participants in this study were assessed as having decision making capacity, and most lived in the community with minimal support. However, as has been found in other studies,^{9,15,16,21} participants described difficulty in negotiating the often complex nuances of an intimate relationship. They expressed difficulty behaving assertively in relationships, and limited ability to protect themselves from unwanted sexual contact. Few women had anyone with whom they could discuss sex or relationship issues.^{6,13}

The accounts of severe, repeated abusive sexual contacts in both childhood and adulthood are of grave concern, as is the apparent lack of intervention and support, and participants' limited strategies for preventing and reporting abuse. The women in our study were keen to

speak about their experiences, and expressed the need to be heard, believed and supported. Their stories add a uniquely personal dimension to the grim statistics regarding sexual abuse of people with intellectual disability.^{4–7,29}

Participants reported sequelae of abuse including avoidance of relationships, lack of libido and inability to have intercourse, while repeated victimisation was a particularly striking finding. These sequelae were similar to those described by women without intellectual disability who have been sexually abused.^{5,10,11}

This study has some limitations. The sample size was small: however, the lack of new themes emerging in the last few interviews suggests that the sample was at least close to saturation. Only women with mild intellectual disability were interviewed. However, the authors recruited women of a broad age range, living situation and type of support. It is unlikely that this study overstates the risk and impact of sexual abuse.

The findings of this study have implications for any professional involved with people with intellectual disability. For those providing direct support, they point to a large unmet need for ongoing training and guidance for people with intellectual disability and their families and support workers. The issues around appropriate sexuality education, support and protection from abuse are highly complex. Innovative programs such as Johnson and Frawley's, 'Living Safer Sexual Lives' program²⁰ have demonstrated that people with intellectual disability are not only able to learn new skills, but can actively participate in developing programs. However, the process is slow and painstaking and effective learning and support requires ongoing funding and significant attitudinal change.

For health professionals, the findings should serve as a reminder to consider the likelihood of past or current abuse in people with intellectual disability. People with intellectual disability may not volunteer such a history, and those caring for them may be unaware of, or even complicit in, abuse. People with intellectual disability may need to be asked directly about sexual relationships and abuse. Eliciting such a history may influence management in many areas including the need or otherwise for Pap tests and testing for sexually transmissible

infections; the need to facilitate access to information or support; and the management of the often complex mental health and behavioural challenges presented by these patients. Our findings should be a reminder that sexual health and sexual abuse are vital issues for everyone in the community, and people with intellectual disability are no exception.

Resource

For further information about responding to sexuality issues in people with intellectual disability, please see the accompanying article: 'Sex, and intellectual disability: dealing with sexual health issues' in this issue of *Australian Family Physician*.

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