

Consumers living with psychosis: Perspectives on sexuality

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Abstract

Mental health clinicians work within a recovery framework that is rights based and emphasizes positive and respectful approaches to working with mental health consumers. Mental health nurses' practice is also predicated on holism and inclusiveness, yet consumers' sexuality is sometimes neglected and rights in this area overlooked. Also overlooked is sexuality as an area for investigation, particularly from a consumer perspective, even though it constitutes part of consumers' broader remit of sexual health. This paper reports findings from a case study where consumers were asked about their ability to negotiate and sustain sexual expression while residing in a long-stay mental health rehabilitation facility. There were three main findings. First, the physical space of the facility, inclusive of consumers' bedrooms, was policed by mental health clinicians with ongoing intrusions into consumers' privacy, which inhibited their sexual expression. The creation of barriers to sexual expression is counter to policies that promote recovery. Second, consumers reported significant medication-related weight gain which negatively affected their self-image and sexual sense of self. Third, the consumers spoke about their sexuality in ordinary, everyday language devoid of any hallmark of psychosis. This highlights the importance of relating to consumers about their sexuality and sexual needs from a humane rather than technical framework. Further, it foregrounds the relational aspect of the mental health nurses' role rather than the technical aspect. Yet sexuality is a topic that is often neglected, indicating that an upskilling of the mental health nursing workforce is required, to strengthen communication and relationship skills.

INTRODUCTION

Mental health clinicians work within a complex system of competing priorities. One of those priorities is the framework of recovery, the principles of which are embedded in policy approaches in many countries (Higgins *et al.* **2020**; Roberts & Boardman **2013**). Recovery approaches emphasize positive and respectful ways of working with people and promote self-determination, self-management, empowerment, advocacy and hope (Australian Health Ministers' Advisory Council **2013**). While not specifically focused on sexuality, this rights-based approach is vital to informing clinicians' responses to sexuality and sexual needs of mental health consumers.

BACKGROUND

'Sexual health today is widely understood as a state of physical, emotional, mental and social well-being in relation to sexuality. It encompasses not only certain aspects of

reproductive health ... but also, the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence...' (World Health Organization **2015**, p. 1).

Over the last thirty years, there has been an increasing focus on the human rights aspect of sexuality, inclusive of the right to freedom of association, expression and privacy (World Health Organization **2015**). Yet concerns have been raised that sometimes mental health consumers are not afforded these rights. Some studies have found that consumers' rights to privacy have not been upheld (McCann **2010**; McCann *et al.* **2019**; Quinn & Happell **2015b**). Other findings indicate that mental health nurses monitor the risks they consider to be associated with sexual relationships and intervene if they assess consumers progress affected (Quinn & Happell **2015a**), thus potentially restricting freedom of association and sexual expression.

These practices and attitudes can result in infringements on consumers' rights, and as Quinn and Happell (**2015a**) found, this can occur in the context of a recovery framework. Practices such as these are, of course, antithetical to recovery principles, where consumers should be offered avenues to be both engaged and active in the work of their recovery (Roberts & Boardman **2013**), which includes the right to a sexual relationship of one's choice.

The rights-based approach underpinning the idea of recovery was voiced by Deegan (**1996**) more than two decades ago, when she said that consumers had the right to the dignity of taking risks about their own lives. Perhaps, then the aforementioned restrictions on consumer rights highlight the tension that can exist between a culture of risk management that restricts liberties in practice and the principles of a recovery approach that promotes them (Fletcher *et al.* **2019**).

Part of the problem, in relation to sexuality, is the paucity of research examining how mental health services incorporate consumers' sexuality and intimate relationships within the mental health setting (Higgins *et al.* **2009**; McCann **2003**; Urry *et al.* **2019**). This is particularly the case in relation to those diagnosed with specific conditions, for example, schizophrenia (Almeida & Murta **2019**; McCann **2000**; Volman & Landeen **2007**). Increased awareness of this neglected area is important, given how little is known about this topic, particularly from the consumer perspective (McCann **2000**, **2010**; Quinn & Happell **2015b**). Moreover, further knowledge on consumers' sexuality can inform both the promotion of clinical practices more aligned with recovery principles (McCann *et al.* **2019**) and structural changes at a service and system level (Urry *et al.* **2019**).

METHODS

The findings reported here arose out of a case study that aimed to explain how mental health consumers residing in longer-stay mental health services were able (or not) to

negotiate and sustain sexual expression. The case study methodology allowed us to address the research aim and investigate in-depth and with respect to the particular context and complexity of the topic (Yin **2014**). We framed the case as one of the governance of consumers' sexuality in a recovery-oriented mental health service. In this paper, we report consumers' perspectives on how their sexuality was governed and how that governance influenced consumers' capacity for sexual expression while they lived there.

The study site

The study site was an adult (16–64 years) mental health service in an Australian inner-city location that provided intensive mental health rehabilitation. It was established to provide recovery-oriented mental health rehabilitation with the aim of improving the consumers' psychosocial functioning. The psychiatrist had the capacity to admit consumers who were subject to compulsory treatment under the Mental Health Act. It was a long-stay facility, thus the consumers' admission could be twelve months or more.

The criteria for admission to the facility were a mental health diagnosis considered to be moderate to severe that had resulted in significant reduction in psychosocial functioning. Twenty full-time mental health clinicians staffed the facility, comprising mental health nurses, allied health clinicians and psychiatrists. The facility accommodated twenty consumers who lived in two-bedroom units, clustered together within grounds that also included communal and staff facilities. All amenities and environments were well maintained. Consumers were able to come and go from the facility throughout the day.

3.2 Research team and reflexivity

Three of the authors are mental health nurses with extensive clinical and research experience in the mental health field and one author is a sociologist with an extensive research background. The interviews were conducted by the first and second authors and none of the participants were known to them. All authors were involved in the data analysis as the manuscript was developed and redrafted, and they critiqued each other's assumptions and ideas in the process.

Sampling and recruitment

A purposive sampling approach was undertaken, in that we aimed to interview all those who met the inclusion criteria and were able to provide us with information relevant to our study aim. Participants were consumers with a diagnosis of schizophrenia or schizo-affective disorder, prescribed anti-psychotic and other neuroleptic medication, and were currently residing at the facility. Consumers were excluded from the study if

the clinical treating team determined they lacked capacity to provide informed consent or if they had a diagnosis other than that stated above.

Recruitment and interviews commenced following approval from a fully constituted ethics committee (MH Project Number 2015.064). Interviews were conducted during 2016. Of the twenty consumers approached, 11 consented to participate in the study. We did not seek information as to whether they were subject to compulsory treatment orders.

Data collection

Semi-structured interviews with consumers were oriented around their experience of mental illness as it pertained to sexuality, but also ensured they could include information they deemed relevant. Participants were asked to speak about whether they had been able to have sexual experiences while resident at the facility. For example, they were asked if they were interested in having a sexual relationship with someone else and whether that had been possible. They were asked about anything or anyone that either facilitated or obstructed their capacity to have their sexual needs met. Finally, they were asked about safe sex and sexual health. Interview prompts were used to elicit additional information where needed (for example, 'Can you tell me some more about that?'). All audio recorded interviews were transcribed verbatim and pseudonyms allocated. Extensive notes were taken during and following the interview with the one participant who did not wish to be audio recorded.

Data analysis

Case study data analysis, according to Yin ([2014](#)), involves the first step of looking for patterns and concepts in the data and coding them as they emerge. The data from the consumers' interviews were initially coded by two authors, comparisons made and consensus reached. All authors worked on multiple drafts of the current paper. Three main themes emerged from this inductive coding of the data.

RESULTS

The first theme focused on restrictions on privacy as a result of the way physical space was policed in attempts to govern the consumers' sexuality. The second theme related to weight gain experienced as a result of taking psychiatric medication and how this affected the consumers' sexual sense of self and sexual activities. The third theme was the 'everyday' and 'ordinary' heterogeneity of sexual and relationship needs. This last finding refers to the variance in the consumers' sexual and relationship needs and how it was not dissimilar to the variance that might be expected to be found in the general population.

Restrictions on privacy

Consumers experienced serious restrictions in relation to their privacy due to the enforcement of rules governing the physical spaces at the facility, both communal and individual. Consumers described how the clinical staff strictly policed the physical spaces at the facility in order to enforce rules that governed where consumers could spend time with co-consumers and visitors.

The enforcement of the rules meant that some physical spaces were prohibited for visitors and fellow consumers of the facility. The consumers' bedrooms were off limits for co-consumers and visitors, including partners. Sometimes the prohibited area seemed to include the loungeroom of the consumer's unit as well. Thus, when consumers received visitors, including their partners, the visitors and the consumer needed to physically remain within the communal spaces of the facility. Communal spaces included the recreation rooms and the area at the front of a consumer's unit.

No boys are allowed to go into the girls' houses at the [facility] and no girls are allowed to go into the boys' houses (Lennie)

The consumers were clear that the purpose of this rule was to prohibit sexual activity at the facility. Keeping relations between consumers and co-consumers, and consumers and their visitors, out in the open was therefore a mechanism to ensure that things did not go on behind closed doors. This meant that even consumers who were in long-term relationships could not have any moments of physical intimacy or even privacy with their partners while together at the facility. They needed to go elsewhere to have private and intimate time together.

Consumers in long-term relationships reported difficulty with this, given that the length of stay at the facility could exceed twelve months and that sexual relations at the partner's home were not always complication-free. Moreover, this rule was heteronormative in that, it only referred to a person of the opposite gender being in the consumer's bedroom with them yet the rule, as consumers communicated it, related to any sexual activity with others. Each of these related issues is described by Megan below:

Once my boyfriend was over. And we were sitting on separate bean bags. We weren't even playing tootsies but were watching a film and staff came in saying: 'What's going on here, that's not appropriate,' and were told we weren't allowed... It was inappropriate lying on separate beanbags. We had a doona over us because it was still winter and cold... She said: 'Close contact in the room is inappropriate.' (Megan)

We're not allowed in the bed together, which makes it really difficult for me so I have to go to his house. His bedroom is right next to his parents' room and they don't go to bed until 11 each night. And I have to take medicines at 9:30 or 10 so I fall asleep on the job, and I find it really annoying. The medication I'm on is Clozapine. And I go down like a

sledge hammer, I go down hard after I take it, just drop half an hour after I take it, I black out (Megan)

While the physical spaces at the facility were strictly governed in relation to the consumers and their visitors, the opposite was the case for the clinical staff who had full access to all private spaces. Clinical staff could access any area of the facility and at any time. Participants described the intrusion by the clinical staff into the bedrooms of consumers where they would enter these areas without either warning or request and could inspect any part of the consumers' belongings. The capacity to lock bedroom doors was not available to consumers.

Lack of privacy meant that it was difficult for consumers to masturbate in private as they were concerned they would be in the middle of this activity and be disturbed by the clinical staff bursting in on them. It also meant that they needed to be quite discreet, to the point of secrecy, around any sexual aids such as pornography or vibrators.

Consumers would keep these private and they had various ways of doing this. They described strategies such as keeping pornography on their mobile phones instead of using magazines and hiding a vibrator in the bedroom in a place they did not think the staff were likely to look. This lack of privacy is described below by participants:

Yes, they do (laughs) [staff just walk in here] yes they do, but what can you do about it? ... they must be worried about you so they just walk in and I've been busted [masturbating] ... I had track pants on and pulled them up. ...[It was] a bit awkward (Colin)

Well they just come in, they just open the door and come in. It's their policy or something. [if I'm masturbating] I just try and cover things up. I'm worried someone might walk in (Quentin)

If you are being intimate with yourself you need to be aware of the time. I don't want staff to come in when I'm at it. It's happened a couple of times. I've got half an hour or an hour and tip-toeing around and I feel disgusted, I feel grossed out ... We can't even lock our door. Sometimes I just want some privacy but you can't lock it. If I want to touch myself, I want to be able to snuggle up to my pillows and be happy ... [I just want staff to] show more respect for us (Megan)

Medication side effects

Consumers spoke about how the psychiatric medication had caused them to gain weight. This was not weight that could be easily lost by staying on a diet, but substantial weight gain that altered their entire body shape that would take a long time to lose. Many did try to diet and had had many unsuccessful attempts at this. However, they were in the unenviable position of needing to diet at the same time as needing to take

the medication that caused their weight gain in the first place and would continue to cause them to gain weight.

For the women particularly, this weight gain affected their sexual sense of self. They no longer felt attractive in the way they did previously. They wondered how attractive they were to potential or actual sexual partners. It led them to avoid looking at themselves in the mirror and taking the level of care of themselves that they might have previously taken. For example, Megan stated:

The medication I'm taking makes me feel fat and unattractive ... it is very hard to feel attractive when you have put so much on. I look fat with this big stomach ... In one year I put on 15 kilos ... My arse, my stomach my chin is fat ... the medication makes me feel like I just don't want to have sex.

This sense of loss of attraction also affected their sexual relations as it impacted on their interest in sex. They felt fat and unattractive, and so less interested in sexual encounters and had reduced libido. Again, this was something expressed mainly by the women:

I don't take as many showers as I used to. I don't like looking at myself in the mirror. When I look at myself I look like I am 8 months pregnant. I've never been this fat before in my life, and it definitely makes me think about other people's attraction to me ... I feel bloated, it's a bloated feeling. My tummy feels stretched, and I try to stay on diets, I have three different books on diets and lifestyle changes with eating ... I also have suffered with poor libido ... No nobody talks about that, it's a no-go subject (Karen)

For the men, there were issues of sexual performance such as difficulty with either getting an erection or ejaculating. It was something they either attributed to the psychiatric medication or suspected it was to do with this:

I masturbate occasionally but this has been difficult lately. I'm finding it difficult to get an erection and sometimes can't ejaculate (Connor)

The 'everyday' and 'ordinary' heterogeneity of sexual and relationship needs

Due to the admission criteria of the facility, the consumers had diagnoses of schizophrenia or schizo-affective disorder in common and they had similar experiences of the longevity of this diagnosis in their lives. But there were many differences among them. For example, there were demographic differences. The consumers were both male and female although there were many more men than women at the facility. They varied in age so that some consumers were in their thirties and some in their sixties. Of significance to this study, the consumers' disclosures about what they wanted in terms of sexual and partnership needs were also far from homogenous.

Some consumers yearned for the intimacy that an ongoing relationship could bring while others preferred to stay single. Women spoke about concern that some men just

wanted to have sex with them rather than an ongoing relationship or the yearning for a child and the obstacles in the way of this for them. Some consumers felt they lacked confidence to attempt to form a relationship. There were over-emphasized statements about the nature of their sexual orientation from some and an ease with their sexual orientation for others. Some consumers yearned for closeness while others wanted to keep their distance. There were concerns about rejection.

I have had so many relationships with people who just want to hook up for sex. One of the things that I'm so attracted to Matt is that he wants to have conversations with me, not just sexual conversations. If he started talking about it I would definitely think differently about our relationship (Karen)

Yeah, you know, I want a girlfriend. I want an active sex life. It's like it's always holding me back. (Interviewer: What's holding you back?) Oh I don't know. Maybe it's my confidence level. My confidence is poor ... (Colin)

A further aspect to their discourse on this topic was how ordinary it was. They spoke of their needs, wishes and dreams in the everyday language of the times. There were no neologisms used, nor was there any apparent mingling of ordinary talk with delusions or hallucinations. It is noted that this was a long-term facility and consumers would not be able to participate in this program if they were assessed as acutely psychotic. However, there were no psychotic features to their speech when disclosing their sexual needs and wishes or certainly no more than one might expect to find in any other sample of the general population.

Just knowing what to say to them [is a barrier to meeting someone] (Quentin)

... they keep telling me that it's not the right time for me, it's not the right time, you're not well enough. I really want a child now. I don't want to wait until next May and I'm 38. I want one now (Megan)

... I'm scared of being rejected, scared of rejection, it scares me. ...Yes, I guess, and I want to have a family and things. I want to have kids and things like that... (Colin)

Discussion

Similar to our findings, McCann *et al.*'s (2019) recent systematic review on sexuality and intimacy, in those diagnosed with a serious mental illness in both hospital and community settings, found it was not uncommon for mental health consumers to report a lack of privacy afforded to them and that this acted as one of the barriers to the expression of sexuality. The creation of a barrier to a consumer's expression of sexuality can be seen as a contravention of state legislation that governs mental health practice at the study site. This legislation lays out the principle that consumers 'should have their rights, dignity and autonomy respected and promoted [and] ...their individual needs (whether as to culture, language, communication, age, disability, religion, gender,

sexuality or other matters) recognised and responded to' (Parliament of Victoria **2014**, p. 22–23). This requires that a degree of privacy be afforded to consumers.

The creation of barriers to sexual expression is also counter to policies that promote recovery, such as those in place at the study site. Recovery is aligned with a rights discourse and with the principle of least restrictive practice. Moreover, a recovery approach encompasses the idea that sexual expression is a fundamental basic right, regardless of 'disability' (Hunter & Ahmed **2016**). Given this, the lack of privacy afforded consumers in our study contravened their right to sexual expression and policies that promote a recovery-oriented approach to treatment.

Some may argue that the matter is far from this simple. In more recent years, there has been increasing concern about sexual activity and sexual assault on inpatient wards (Ashmore *et al.* **2015**; McGarry **2019**). In an acute mental health ward, consumers are highly vulnerable and clinical staff have a duty of care to protect them from sexual assault. Mental health services have instituted both policies that prohibit sexual contact on inpatient facilities and structural measures, such as same gender ward areas, that promote a safe environment during an acute admission, in response to these very real concerns (for example, see Department of Health **2009**).

However, the study reported here was conducted in a rehabilitation facility of relatively long-stay where the consumers were not in an acute stage of their experience of psychosis and the over-arching policy directive was one of recovery (Australian Health Ministers' Advisory Council **2013**). The study findings indicate that consumers were at times patronized, particularly in relation to taking risks. This contrasts with Deegan's (**1996**) view that consumers have a right to the dignity of taking risks about their own lives and we suggest that this includes the right to take risks about their sexual practices. Indeed, this is affirmed in state legislation, which makes it clear that mental health consumers 'should be allowed to make decisions about their assessment, treatment and recovery that involve a degree of risk' (Parliament of Victoria **2014**, p. 22).

Risk-taking might raise a concern about the capacity of consumers to give consent. Informed consent needs to be considered for each consumer and not as a blanket measure for an entire residential population (Hunter & Ahmed **2016**). The study reported here received ethical clearance to proceed. One of the conditions was that senior clinical staff, and a psychiatrist attached to the study site, were asked to screen the participants both at the time of consenting and at the time of interview. This was in relation to their capacity to consent. All consumers were deemed to have capacity to give consent. Thus, while consumers were all considered to have capacity in relation to the interviews, their capacity to make decisions about how to exercise their own sexual needs did not appear to be considered in a similar way.

Further, we note that consumers in our study were both willing and interested in talking about their sexuality and intimacy concerns. They did so without distress, as McCann *et al.* (2019) also noted in their review. One issue that the consumers raised was how the medication-related weight gain affected their sexual lives, either in relation to feeling fat and unattractive or in terms of sexual performance. This has been reported in the literature previously (for example, see de Jager *et al.* 2018) as has women's sense of shame, embarrassment, negative impact on identity (Davison & Huntington 2010) lowered self-worth and other negative emotions (Usher *et al.* 2013) due to medication-induced weight gain. These concerns should be given serious consideration in relation to the choice of anti-psychotic medication prescribed. There is a reduced benefit to any medication that introduces other untoward outcomes, either in relation to general health outcomes or, in this instance, the effect on one's sexual life. Moreover, as Usher *et al.* (2013) perhaps unsurprisingly found, consumers can be inclined to stop taking the second-generation anti-psychotic medication as a result of unwanted side effects such as weight gain.

Another notable aspect of the findings was the ordinary and everyday way that the study participants spoke. By this, we mean the way that the variation in their sexual and relationship needs was not dissimilar to what one would hear in social discourse outside of a mental health facility. This highlights the importance of relating to consumers from the humane and non-technical aspect of one's clinical role. It might be surprising for clinicians that sometimes consumers appreciate clinicians' relational capacity and find it more helpful than their technical knowledge and skill. This is what has been called the clinician's 'personal perspective'; their capacity to relate to the consumer more as another person than as a health professional (Roberts & Boardman 2013). This underlines the importance for mental health clinicians to relate therapeutically while foregrounding the relational aspects of their role rather than from their technical (psychiatric) knowledge. Such relational approaches matter because perhaps because sexuality and intimacy are not highly technical issues. They are to do with the very human aspects of living: communicating and relating to others.

Yet little is written from a humane aspect in relation to the sexuality of those diagnosed with schizophrenia (Volman & Landeen 2007) and it is important to consider why this is so. While it is outside the scope of this paper, recommendations from McCann *et al.*'s (2019) systematic review on the topic include improved engagement with consumers on sexuality and intimacy, greater access to talking therapies for consumers and an upskilling of the mental health workforce. This latter point supports Urry *et al.*'s (2019) view of the importance of service and system initiatives to improve clinical practice in this area.

There are a number of ways to support the capacity of mental health nurses to talk in more meaningful ways to consumers about their sexuality and intimacy needs. McCann

et al. (2019) recommend education of the workforce in relation to skills training. Previous work by Quinn *et al.* (2013) supports this approach. Clinical supervision could also be considered, which is likely to assist mental health nurses to overcome associated barriers. It could also strengthen capacity for the development of new ways to go about talking about sexuality and intimacy with consumers.

CONCLUSION

The consumers in our study reported a lack of privacy and this acted as a barrier to sexual expression. This contravenes the recovery approach, which enshrines consumer rights as does legislation and policy, at both a national and international level. As well as being afforded sexual privacy, consumers should be afforded the right to take risks with respect to their sexuality.

This study also found that consumers spoke about their sexuality and their sexual needs without reference to psychotic phenomena. Their psychiatric diagnosis did not interfere in this aspect of their lives. They had no difficulty in talking about the way they felt fat and unattractive or had difficulty with sexual performance, some of which may have been medication related. This highlights the importance of relating to consumers from the humane and non-technical aspect of self and foregrounds the relational aspect of the role rather than the technical (psychiatric) knowledge aspect.

RELEVANCE FOR CLINICAL PRACTICE

An upskilling of the mental health nursing workforce would lend support to the capacity of mental health nurses to talk in an open and enquiring way to consumers about their sexuality and all that impacts it, including medication-related weight gain and other side effects that impact sexual functioning. Issues of consent need to be addressed on an individual basis and the skill to undertake such an assessment is required so as to allow clinicians to uphold their duty of care without blanket and prohibitive rules that do not take individual differences into account.

In this era of biological psychiatry, perhaps, it is time for a turning back to some of the wisdom of the talking therapies. Such therapies allow for the development of a strong human connection between two individuals as they speak about the life of one, in the interests of what recovery is essentially about: finding one's own path and leading one's own life. To get back to that level of knowledge and skill in the mental health workforce though, much work needs to be done. Clinical supervision is a good way to underpin this necessary endeavour.