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The sexual health and relationship needs of people with severe mental illness.

This paper will explore the sexual health and relationship needs of people with severe mental illness (SMI), as well as develop an argument that positive intimate relationships are a fundamental human right for all, including those with mental health issues.

"Sexual health" as defined by the World Health Organisation (WHO) (2006) is a global term which is not just about being free from sexually transmitted infections, but also about the right to a safe and satisfying relationship, and being able to express ones sexuality. More specifically, it is a right to choose to be sexually active (or not) or to choose to have sexually intimate relationships along with access to information and care in relation to sexual health (WHO, 2006). It is also a human rights issue, not just a health issue where people with serious mental illness (SMI) have just as much right to have an intimate relationship (of their choosing) as anyone else. (Berer, 2004; Perlin, 2008; Dixon-Mueller et al., 2009; McCann & Shareck, 2014; McCann & Sharek 2015).

Sexual health is a global health priority for all. The latest WHO figures of the global prevalence and incidence of chlamydia, gonorrhea, trichomoniasis, and syphilis in adult women and men report nearly one million new infections each day (Newman et al., 2015). These infections can cause infertility and other health consequences (Gottlieb et al., 2014). Strains of infections are emerging that are resistant to antibiotics (Ndowa et al., 2012).

There is also a global human immunodeficiency virus (HIV) epidemic, the WHO estimate that there were approximately thirty seven million people living with HIV at the end of 2014, with roughly two million new infections diagnosed worldwide in 2014 (WHO, 2015). Certain groups have been identified as particularly vulnerable to contracting sexually transmitted infections and blood borne viruses (BBVs) such as men who have sex with men, people who inject drugs, sex workers and people from high prevalence geographical areas such as sub-Saharan Africa (Department of Health, 2013). There is another vulnerable group who should be considered as a high risk group: people with SMI (Lagios, 2007). However the sexual health and relationship needs of this group seems to have been missed off the health agenda (Hughes et al., 2015).

We therefore argue that promotion of sexual health falls into the remit of holistic mental health care, and we further argue that mental health nurses have a clear role to play in this.

Historically, people with mental illness would be incarcerated for life in asylums, a practice that continued into the 20<sup>th</sup> century. Their human rights and citizenship marginalized, and with respect to their sexuality, the general consensus was one that considered them to be asexual (Dobal & Torkelson, 2004). As such, there was no consideration towards the development of sexual health or reproductive health policy (Dobal & Torkelson, 2004). Despite being segregated by gender, people would manage to form relationships in spite of the regime. The closure of the asylums and the advent of "care in the community" has offered people with SMI more

personal freedoms in their adult relationships, however, it has also exposed them to some risks in those relationships too. These include drugs and alcohol (Ford et al. (2003)), exposure to sexual exploitation (Elliot et al., 2004), as well as abusive intimate partners (King et al., 2008). In this transition from institutional care to integration into the community, it is questionable how much mental health services have focused on life skills in order to live well in communities, as opposed to the prevailing focus on psychiatric symptom relief (McCann, 2010a). There is an attitude of low expectation on recovery outcomes both from people who live with mental illness themselves as well as those who provide the service. We see this reflected in low rates of employment of people with serious mental illness as well (Mueser et al., 2001; Henderson et al., 2005). The recovery movement (Boardman & Friedli, 2012) promotes the concept of developing a meaning and purpose in life within the challenges of managing a chronic mental health condition. However, a criticism of the recovery movement is that it has failed to emphasise sexual expression and sexual relationships. Mental health Policy in the UK, Ireland and Australia also fail to acknowledge the importance of sexuality, sexual relationships and sexual health. In the absence of adequate support the sexual health and relationship needs of people with SMI have been overlooked and ignored (Deegan, 2001). For mental health nurses to provide recovery orientated care, in the context of human sexuality they need to support people with SMI with their sexual health and relationship needs (Dein & Williams, 2008; Eklund & Östman, 2010), and the importance of this area of care should be incorporated into mental health policy.

Whilst this topic area has largely been ignored, there are some studies which highlight some of the key concerns regarding sexual health in this population:

- Whilst pregnancy rates are low; the rate of un-intended pregnancy is higher than in the general population (Miller & Finnerty, 1996).
- People with SMI are more likely to experience inter partner violence (IPV) (20% of women with SMI reported IPV compared to 5.3% without and 6.9% of men with SMI reported IPV compared to 3.1% without) (Khalifeh et al., 2015).
- People with SMI are also more likely to experience exploitative or coercive sex (Coverdale et al., 1997; Coverdale et al., 2000; Koen et al., 2007; Miller & Finnerty, 1996) (see risk behaviour section below).
- The prevalence of HIV, hepatitis b and hepatitis c are elevated in this population– this is an objective risk marker for sexual risk taking (as well as intravenous drug use) (Hughes et al., 2015).

In sum, it seems that people with SMI are facing real difficulties in relationships including domestic violence, lack of access (or use) of contraceptives, and risk of BBVs; of which HIV and hepatitis B are sexually transmitted. It is important to raise awareness not only of the increased prevalence of violence and infection in this group, it is also important for mental health nurses (and the other health and social care professionals) to understand the circumstances and risk factors related to these unwanted consequences and be able to screen, educate and intervene if risk behaviours are identified.

#### **Risk Behaviour**

All sexual activity carries some element of risk of infection, unintended pregnancy and other health risks (Brown et al., 2011a, 2011b; Grassi et al., 1999). However, we know that some sexual behaviours carry higher risks than others. For example, anal sex (condomless) is more likely to lead to anal and rectal tears and bleeding. This means that the HIV virus (and other infections) can more easily enter the blood stream from body fluids of the other person (such as semen and vaginal fluid). In addition to sexual transmission, some BBVs such as hepatitis C are transmitted by sharing injecting equipment and can also be transmitted via sharing of household equipment such as toothbrushes and razors if the virus is in dried blood (Sawayama et al., 2000). This has specific implications for educating people about avoiding sharing razors and toothbrushes (in hospital wards or shared accommodation for example).

Whilst there are many studies that have identified rates and types of risk behaviours engaged in by adults with SMI, only 6 studies have provided comparative data with the general population. A number of sexual behaviours that are considered 'high risk' in terms of contracting a BBV or other STIs were consistently reported in six case-control studies (Brown et al., 2010, 2011a, 2011b; Coverdale et al., 1997; Coverdale et al., 2000; Grassi et al., 1999; Koen et al., 2007; Miller & Finnerty, 1996).

**1. Substance use**- Substance use is common in the general population as well as in people with SMI. Of specific interest is intoxication with drugs or alcohol when sex occurs. It can significantly impair a person's capacity to

consider or use condoms (Weinhardt et al., 2001). However it seems that in the general population (as well as SMI) that substance intoxication at the time of sexual activity is fairly common (Brown et al. (2010, 2011a, 2011b). Grassi et al. (1999) Coverdale et al. (2000) Koen et al. (2007)).

An additional factor to consider is sexual partners who are substance users 'sex with a partner who uses drugs' (Brown et al., 2010, 2011a, 2011b; Coverdale et al., 1997; Coverdale et al., 2000; Grassi et al., 1999; Koen et al., 2007). Brown et al. (2010, 2011a, 2011b) found that twice as many (44.8%) people with SMI, compared with a non-SMI group had had sex with someone who had taken drugs or alcohol prior to sex (p< 0.05). Grassi et al. (1999) also reported higher rates of sex with a partner who uses drugs in an SMI population (16.7%) compared to a non-SMI group (4.5%) (p=0.016). Similar trends were also reported in other studies, however, their results were not statistically significant (Coverdale et al., 1997; Coverdale et al., 2000; Koen et al., 2007). This indicates the importance of not just asking about the individual's risk behaviours but also about the behaviours of the people that they have sex with (long term partners as well as more casual encounters).

**2. Exploitative or coercive sex**- Coverdale et al. (1997) reported that people with SMI were significantly more likely to report being pressured into sex compared with non-SMI group (34.3% v 7.7% p=0.001). Coverdale et al. (2000) found that 11% of people with SMI reported that they had been pressured into having unwanted sexual intercourse compared to 1% of the control group (p= 0.016). Other studies that compared SMI and non-SMI groups found non-significant results although, continued trends where

people with SMI reported being pressured into unwanted sex more often than the control groups (Koen et al., 2007; Miller & Finnerty, 1996).

**3. Sex trading**- This involves sexual acts being exchanged for a commodity (often drugs, a place to stay, a meal etc.). This has been found to be more common in people with SMI (Brown et al 2010, 2011a, 2011b; Coverdale et al., 1997; Coverdale et al., 2000; Grassi et al., 1999). Koen et al., 2007 reported higher rates in SMI but this didn't reach statistical significance.

### 4. Multiple sexual partners (reported within a 12 month period) -

Hyper-sexuality phases of illness may increase the risk of having multiple sexual partners (Meade et al., 2008). Coverdale et al. (1997) found a statistically significant difference between cases and controls for this risk behaviour, 36.4% of cases compared to 11.5% of the controls (p= 0.006). Grassi et al. (1999) also found a statistically significant difference; 53.1% of adults with SMI compared to 30% of the control group reported having multiple sexual partners (p< 0.01). Two other studies (Brown et al., 2010, 2011a, 2011b; Coverdale et al. 2000) also found that people with SMI were more likely to report multiple sexual partners in a twelve month period than healthy controls. However, the results were not statistically significant.

This evidence suggests that people with SMI are more likely to engage in 'high risk' sexual behaviours and as such, are more at risk of contracting a BBV or other STI. The elevated prevalence rates of HIV and other STIs provide objective evidence that there is a real need to address sexual health in mental health. The following sections will address the perceptions of sexuality and expression in people with SMI and then we will consider the role of mental health nurses in promoting positive sexual relationships and lifestyles.

#### Perceptions of Sexuality and Expression in people with SMI

There are two stereotypes 'over-sexed' and 'under-sexed' that exist when we consider adult mental health and sex. The experience of 'over-sexed' has been acknowledged by Judd et al. (2009) for both men and women as a characteristic from psychotic disorders and bipolar disorder. In contrast, 'Under-sexed' is frequently seen for people experiencing depression, and as discussed by Krebs (2007) is poorly recognised and treated by health professionals. As with any stereotype, the truth lies somewhere in the middle and consistent with other stereotypes, should not be considered as universal truths. Sexual desire and expression can be seen as symptoms of mental illness and dismissed as such. This is especially true for people who express a desire to transition to another gender (transgender), and in order to do this have to undergo psychiatric assessment to "prove" that this is not simply the manifestation of a mental illness (Drescher, Cohen-Kettenis and Winter, 2012).

# The role of Mental Health Nurses in Promoting Sexual Health

Despite the emerging evidence of sexual health and relationship needs, the area of sexual health in mental health nursing has received limited attention. McCann (2010a) undertook a study, which explicitly sought services user's views and opinions regarding intimate relationships in a mental health service in North London, UK. The majority of respondents (90%) felt that they had needs in relation to sexual expression and 83% were interested in having intimate relationships (McCann 2010a). Although 43% of staff were unable to say whether their clients had intimacy needs, the clients themselves were fully able to articulate their hopes and expectations on the topic (McCann 2010b). In terms of psychosocial aspects of recovery, holistic assessments of need should include intimate relationships and address the person's desires and wishes around forming and maintaining meaningful relationships (Government of Scotland, 2006).

In another UK study, Hughes and Gray (2009) undertook a survey of mental health staff about their knowledge and practice in relation to HIV and schizophrenia in a large mental health care provider in South London. The response rate was 44% (n=283) and half the respondents were registered nurses. The majority (80%) agreed that it was part of their role to discuss sexual health and that only 14% agreed that they felt uncomfortable discussing sexual health issues. Yet despite this, only 30% reported that they routinely discussed sexual health. The vast majority of respondents (81%) said that they did not assess for sexual side-effects of medication. There was a range of responses to clinical scenarios that suggested a lack of consistency of approach in the workforce. Around 2/3 of the respondents felt they needed access to more training and information on sexual health and topics suggested included challenging attitudes to sexual health, communication skills to help feel more comfortable in talking about this topic, as well as more information on infections such as hepatitis B and C, and ethical issues and dilemmas.

Quinn and colleagues have examined this issue in Australia and found that (like McCann and Hughes and Gray studies in the UK) nurses in mental health settings tend to avoid starting a dialogue about sexual health and rarely addressed it in their role (Quinn, et al., 2011) even though these mental health nurses were aware of the sexual health problems experienced by people with a SMI (Quinn, et al., 2011).

However, in a further study Quinn was able to demonstrate that a specific training session on sexual health, could have an impact on nurse's behavior. They found that after training nurses increased their dialogue around sexual health describing the change process with a 5-As framework (Quinn, et al., 2013). The 5-As framework acknowledges the difficulties and avoidance for nurses in including sexual health in care. The change process relying on education, awareness building and permission to engage with people regarding sexual health for people with SMI, becoming part of the nurses' routine repertoire (Quinn, et al., 2013). Whilst promising, its design, as well as being delivered in one service in Australia, limit the implications of this study. However this is an area that needs to be explored in further studies.

# Conclusion

Sexual health needs are significant in people with SMI, yet have not been addressed in assessment and care planning in mental health. There is an important role for mental health nurses in promoting safe and accepting environments for people with SMI, ensuring that they have access to information and adequate sexual health assessment to promote optimal

sexual health. Research has indicated areas where need is greatest. The next step is to develop assessment tools and interventions that will meet this need in order to promote sexual health in the widest sense and to empower people with SMI to have safe, satisfying and supportive intimate relationships. The locus of care is firmly established in the community and in order for people to thrive and live independent lives, then the area of sexuality and sexual expression should be recognized, emerge from the shadows and be firmly placed on the activities of living agenda. Whilst evidence suggests that mental health nurses tend to avoid talking about sexual health and relationship issues with service users, they are aware of their sexual health needs. Nurses are well placed to not only discuss sexual matters, but to enable people to develop the necessary life skills to promote sexual expression and to impact positively upon a person's recovery experience. Further research is needed to develop pragmatic interventions to be delivered in mental health services, as well as supporting staff to feel more comfortable in talking about sex and relationships.

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