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

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This paper will explore the sexual health and relationship needs of people with severe mental ill- ness (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 only 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 & Sharek 2014, 2015). Sexual health is a global health priority for all. The latest WHO figures of the global prevalence and incidence of chlamydia, gonorrhoea, 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 37 million people living with HIV at the end of 2014, with roughly two million new infections diagnosed worldwide in 2014 (World Health Organization 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 & Deane 2007). However, the sexual health and relation- ship 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 20th 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 consid- eration 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 (Elliott *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 peo- ple 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 emphasize sexual expression and sexual relation- ships. 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.

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

- While pregnancy rates are low, the rate of unintended 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 (Miller & Finnerty 1996, Coverdale *et al.* 1997, Cover- dale & Turbott 2000, Koen *et al.* 2007) (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 (Grassi *et al.* 1999, Brown *et al.* 2011a,b). However, we know that some 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 per- son (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).

While there are many studies that have identi- fied rates and types of risk behaviours engaged in by adults with SMI, only six 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 (Miller & Finnerty 1996, Coverdale *et al.* 1997, Grassi *et al.* 1999, Coverdale & Turbott 2000, Koen *et al.* 2007, Brown *et al.* 2010, 2011a,b).

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) substance intoxication at the time of sexual activity is fairly common (Grassi *et al.* 1999, Coverdale & Turbott 2000, Koen *et al.* 2007, Brown *et al.* 2010, 2011a,b).

An additional factor to consider is sexual part- ners who are substance users 'sex with a partner who uses drugs' (Coverdale *et al.* 1997, Grassi *et al.* 1999, Coverdale & Turbott 2000, Koen *et al.* 2007, Brown *et al.* 2010, 2011a,b). Brown *et al.* (2010, 2011a,b) 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 & Turbott 2000, Koen *et al.* 2007). This indicates the importance of not only just asking about the individual's risk behaviours but also about the behaviours of the people whom they have sex with (long-term partners as well as more casual encounters).

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% vs. 7.7% $P = 0.001$). Coverdale & Tur- bott (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 (Miller & Finnerty 1996, Koen *et al.* 2007).

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 (Coverdale *et al.* 1997, Grassi *et al.* 1999, Coverdale & Turbott 2000, Brown *et al.* 2010, 2011a,b). Koen *et al.* (2007) reported higher rates in SMI but this did not reach statistical significance.

Multiple sexual partners (reported within a 12 month period)

Hypersexuality 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 signifi- cant 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 (Coverdale & Turbott 2000, Brown *et al.* 2010, 2011a,b) also found that people with SMI were more likely to report multiple sexual partners in a 12 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 'undersexed' 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 recognized and treated by health profes- sionals. 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, they have to undergo psychiatric assessment to ‘prove’ that this is not simply the manifestation of a mental illness (Drescher *et al.* 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 service 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 rela- tion to sexual expression and 83% were interested in having intimate relationships (McCann 2010a). Although 43% of staff members 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 & 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 of 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 sug- gested 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 dia- logue 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 behaviour. 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 frame- work acknowledges the difficulties and avoidance for nurses in including sexual health in care. The change process relies on education, awareness building and permission to engage with people regarding sexual health issues. The practice evolves, acknowledging the importance

of sexual health for people with SMI, becoming part of the nurses' routine repertoire (Quinn *et al.* 2013). While 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. 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 promot- ing 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 indi- cated 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, the area of sexuality and sexual expression should be recognized, emerge from the shadows and be firmly placed on the activities of living agenda. While evidence suggests that the 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 also to enable people to develop the necessary life skills to promote sexual expression and to impact posi- tively upon a person's recovery experience. Further research is needed to develop pragmatic interven- tions 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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