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# SEXUALITY IN PEOPLE LIVING WITH A SERIOUS MENTAL ILLNESS:

# A META-SYNTHESIS OF QUALITATIVE EVIDENCE

### **ACCESSIBLE SUMMARY**

### What is known on the subject

- A serious mental illness influences sexual life and people affected have worries about their sexual health.
- People living with a serious mental illness can and want to participate in interventions related to sexual health.

### What the paper adds to existing knowledge

- People who suffer a serious mental illness are interested in maintaining an active sex life.
- People who suffer a serious mental illness experience rejection when they open
  up and they lose intimate relationships or possibilities of meeting other people
  because of ignorance and prejudices surrounding mental health.

### What are the implications for practice

- Mental health services must respond to this need, i.e. including sexual needs
  assessment among routine standard practices or training nurses on sexual
  education to allow them to advise patients and their families and friends.
- Health systems should promote awareness programmes and reduce the stigma surrounding mental health and sexuality.

#### **ABSTRACT**

#### Introduction

Sexuality-related nursing care is scarce and mainly focuses on biological issues. There is also a lack of knowledge about how serious mental illnesses affect sexuality.

#### Aim

To explain how people with a serious mental illness perceive and experience their sexuality.

#### Method

A meta-synthesis was conducted to integrate qualitative studies. Four databases were used to perform the search, focused in the last ten years. Nine articles were included, and their results analysed thematically.

#### Results

Four categories were identified: "Pathologized sexuality", which explains how the disorder and treatment affect sexuality; "Not my sexuality anymore", which describes feelings emerging from the perceived limitations and the role of self-acceptance; "Learning to manage intimate relationships", which explains the desire to establish intimate personal relationships and define their meaning; and "Reconstructing my sexuality", which elucidates the influence of the environment on sexuality.

#### Discussion

Sexuality is influenced by several factors, the main ones being: the clinical complications, the side effects of drug treatment, the social support, the relationship with the health sector, and stigma.

### Implications for Practice

Having a serious mental illness affects sexuality and can provoke suffering and social isolation. Mental health services should address this issue and carry out community interventions to reduce stigma.

### RELEVANCE STATEMENT

This study shows that having a serious mental illness affects sexuality and can provoke suffering and social isolation. Also, people living with a serious mental illness have not lost interest in maintaining an active sex life and, therefore, mental health

services must respond to this need. Nurses can develop their role as health educators and should receive training on affective and sexual education to allow them to advise on options to develop the sexual dimension of these people. Additionally, mental health services should address this issue and carry out community interventions to reduce stigma.

# **KEYWORDS**

Bipolar Disorder, Psychiatric Nursing, Qualitative Research, Quality of Life, Schizophrenia, Severe Mental Disorder, Sexuality

### **INTRODUCTION**

The World Health Organization (1948) defines health as a complete state of physical, mental and social well-being, and not just the absence of conditions or diseases. In line with this definition, sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality. It requires a positive and respectful approach to sexuality and sexual relations, as well as the possibility of having pleasant and safe sexual experiences, free from coercion, discrimination and violence. To achieve and maintain good sexual health, the sexual rights of all people must be respected, protected, and fulfilled (World Health Organization, 2006). That is, everyone, regardless of their condition, must be free to live their sexuality as they deem fit.

Serious mental illness (SMI) is a term that includes any mental disorder resulting in serious functional impairment and which substantially interferes with or limits one or more major life activities, such as talking, self-care, and working (Americans with Disabilities Act National Network, 2019). Worldwide, approximately 20 million people suffer from schizophrenia and 45 million from bipolar disorder (World Health Organization, 2018). In the United States, SMI affect an estimated 4.5% of adults, that is, about 11.2 million people (National Institute of Mental Health, 2019).

Despite the high prevalence, few studies have provided evidence of the phenomenon from a qualitative point of view, describing, interpreting, or explaining the experience lived in the first person. Therefore, there is a need to focus research on exploring the sexuality of people with mental health disorders in order to better understand their needs, design more effective interventions and, ultimately, improve their quality of life (incedere & Küçük, 2017).

People living with an SMI (PLSMI) have concerns regarding sex and intimate relationship, and having an SMI can influence sexual life, as the person may lack the assertiveness required to negotiate safer sexual encounters (Quinn & Browne, 2009; Huguelet et al., 2015). A previous study found that PLSMI would be willing and able to participate in interventions related to sexual health (Walsh, McCann, Gilbody, & Hughes, 2014). In addition, PLSMI regain their sense of self, including their sexual self, when they deal with their sexual issues in the same context as managing their illness (Volman &

Landeen, 2007). Therefore, sex remains an important contributor to quality of life in many patients with chronic illness and their partners (McInnes, 2003).

The existence of unmet sexual needs highlights the importance of implementing training for mental health professionals to provide them with the tools and resources necessary to help patients develop greater competence in this area (Huguelet et al., 2015; Quinn & Browne, 2009). Therefore, new opportunities are emerging for nurses specialising in mental health to develop new roles aiming to promote sexual health (Walsh et al., 2014). Given the lack of evidence on the topic, this study aimed to explain how PLSMI perceive and experience their sexuality.

### **METHOD**

### Design, study selection, and search strategy

To group, synthesise and reinterpret the scientific literature, a meta-synthesis was performed following the indications of Tong, Flemming, McInnes, Oliver and Craig (2012) in the ENTREQ statement. According to Sandelowski and Barroso (2007), a qualitative meta-synthesis is an interpretive integration of qualitative findings that includes consistent descriptions or explanations of a phenomenon. These authors indicate that a meta-synthesis is more than a mere sum of parts since this type of study offers a new interpretation of the data.

No very restrictive criteria were used for the initial search of published studies to avoid eliminating data that might be of interest to the study (Jensen & Allen, 1996). The search was conducted in Medline, Lilacs, Scopus and CINAHL. Following the indications of the PRISMA statement (Moher, Liberati, Tetzlaff, & Altman, 2009) and the example of other published meta-syntheses (Barroso & Powell-Cope, 2000; Leyva-Moral, Piscoya-Angeles, Edwards, & Palmieri, 2017), during the last quarter of 2018, an exhaustive search of studies published with the keywords indicated in **Table 1** was performed. The criteria used for the search were: studies published during the previous 10 years and written in Catalan, Spanish, English, German, Portuguese, or French. The studies had to have been carried out in Organisation for Economic Co-operation and Development (OECD) countries, to provide evident data on the experience of sexuality among PLSMI, and avoid political, social and / or economic biases that affect the general population

and, to a greater extent, people with some type of mental disorder (Raisi, Yahyavi, Mirsepassi, Firoozikhojastefar, & Shahvari, 2018).

Due to the design of this study, ethical approval from a committee was not required.

#### Data evaluation

The initial list of titles was screened by five pairs of reviewers. First, article titles were reviewed. A minimum match of 90% was established between the members of each pair and a second review was requested when there was a lower percentage of concordance. Next, article summaries were screened following the same criteria as in the searching phase. Articles without summaries were automatically excluded. The third phase involved the full text of the articles. Full-text articles had to meet the same requirements as in the previous two phases. Because of the low volume of articles per pair of reviewers, a minimum match of 75% was requested. If there was disagreement, the principal investigator acted as a tie breaker. Finally, the principal investigator assessed the quality of the 15 articles included in the full-text phase using the qualitative version of the Critical Appraisal Skills Programme (2018). As a result of this review, six articles were excluded. The reasons for exclusion were: no clear definition of the study objectives, the objectives were not adjusted to the qualitative methodology, or no clear explanation of the results of the research. Finally, nine articles were included. The various search and screening phases are shown in **Figure 1**.

#### Data analysis

Of the nine articles finally included, only the literal quotations of the participants were extracted. The authors' assessments were excluded to avoid biases when interpreting the quotations. Authors' interpretations were only considered when the quotation was highly non-specific, to contextualise it. All extracted citations were included and analysed in a document created with the Microsoft Word® processor.

The analysis of the results was thematic. From a detailed and repeated reading of the data, fragments of the text that made sense and explained something about the phenomenon under study were coded. These codes were analysed and patterns or

themes were described to reach an overall understanding of the phenomenon (Braun & Clarke, 2006; Miles, Huberman, & Saldaña, 2013). Both coding and categorisation were done inductively, without starting from a predetermined structure (Gibbs, 2007). Once this phase was finished, 47 codes were defined. Then, they were compared and contrasted to identify possible relationships.

### **FINDINGS**

Of the nine studies finally included in this meta-synthesis, three were carried out in the United Kingdom (McCann, 2010; Redmond, Larkin, & Harrop, 2010; Robertson, Pote, Byrne, & Frasquilho, 2015), two in Canada (Boucher, Groleau, & Whitley, 2016; Kidd, Veltman, Gately, Chan, & Cohen, 2011), two in the Netherlands (de Jager, Cirakoglu, Nugter, & van Os, 2017; de Jager, van Greevenbroek, Nugter, & van Os, 2018), one in the United States (Jones, Rosen, Kamens, & Shattell, 2018), and one in Sweden (Östman, 2014). All studies focused on aspects of sexuality in PLSMI or people with psychotic disorders, except one that included a participant with a diagnosis of personality disorder (Robertson et al., 2015).

The included studies used qualitative methodology, one of them in a mixed methods study (Östman, 2014). For data collection, most of the studies used semi-structured interviews (de Jager et al., 2017, 2018; McCann, 2010; Redmond et al., 2010; Robertson et al., 2015). The most commonly used method to analyse the results was thematic analysis (Boucher et al., 2016; Kidd et al., 2011; McCann, 2010; Östman, 2014). The characteristics of the nine studies are summarized in **Table 2**.

From the analysis of the data, four categories emerged (**Table 3**):
a) "Pathologized sexuality", b) "Not my sexuality anymore", c) "Learning to manage intimate relationships", and d) "Reconstructing my sexuality". Both coding and categorisation were performed by the principal investigator and were subsequently reviewed and agreed by a second investigator.

### Pathologized sexuality

Sexuality of PLSMI was severely affected. When asked about their sex lives, one of the main features described by PLSMI was involuntary sexual abstinence, usually

linked to a lack of libido: "I have tried Viagra without any improvement in functioning, and since then I am not interested anymore. My sex life has passed away" (Östman, 2014, p.343).

The mental disorder itself can have serious effects on sexuality when there are more acute phases such as not recognizing your partner, believing that he wants to harm you without having any reason or not being aware of what is being done or saying: "Because at the moment I'm having blackouts, I'm not too... I'm not very trusting in myself to do anything else" (Redmond et al., 2010, p.158).

PLSMI may experience intrusive thoughts that interfere with their daily lives and sexual functioning. These thoughts may manifest as repetitive voices that do not allow them to engage in normal social relations or urge them to commit violence against people to whom they are close (Jones et al., 2018). Sexuality is even more affected if it is linked to hallucinations. These can lead affected individuals to interpret sexual behaviours in a mystical-religious way, so that they only practice sex under very specific conditions or are abstinent for fear of suffering consequences such as being under the influence of evil forces:

She would try to like just fuck with me. She would talk about the sex that we had and like rubbing it in my face, like "You know it was against G-d. Didn't you enjoy that filthy —" what do you call not being married? [Later explaining] ...the way the devil gets to you, it gets to you through things that you desire in your heart, that you know are against G-d. He tries to get me through lust, lust of the flesh (Jones et al., 2018, p.126).

In addition, PLSMI may have difficulty in understanding non-verbal communication, reaching mystical interpretations of behaviours that may only be seduction:

Then I still kind of – sometimes I'll notice somebody will touch their nose, which I consider to be a sign for sin, or like extending their pinky out, which is a sign for gay, stuff like that... [It] felt like this was like – it felt like I was in some kind of show. I call it the heaven and hell show (Jones et al., 2018, p.125).

Even when there is no delirium, having a psychotic disorder or adverse effects of medication can make people question their own identity and sexual preferences: "I fancy women... but... I mean, if you are psychotic then sometimes... you just don't know" (de Jager et al., 2018, p.1084).

It should also be borne in mind that drug treatment affects libido and may lead to side effects such as erectile dysfunctions, anorgasmia or a generalized slowdown that prevents normal sexual intercourse. This generates feelings of worry and frustration, since they cannot carry out the actions they would like and find no other way out to adapt to these situations and respond to their expectations. In some cases, it can lead to problems with their partner and, even, to break up with them: "To be unable to get an erection affects your whole sense of being a man. Yes, I have been made fun of when I was unable to get an erection. That really sucks" (de Jager et al., 2017, p.305).

PLSMI recognise the difficulty of establishing drug therapy that considers the effects on their sexuality and tries to alleviate them as much as possible. Occasionally, they themselves decide to stop meeting their own sexual needs to focus their efforts on controlling the symptoms of their mental disorder:

The only thing I can think can possibly help is for the psychiatrist to study the medication to find out which one is causing sexual problems. That would be very, very difficult but I think it's something that can be done (McCann, 2010, p.255).

Every day is a struggle, and there is no place for sexuality. Since the illness began, I have prioritized keeping the anxiety away from me and wrestling with my work. The main thing is I have to be strong. That's why I can't prioritize sex life (Östman, 2014, p.342).

### Not my sexuality anymore

When PLSMI talked about their experiences of sexuality, expressions of resignation arose: "In fact, I can understand that she started seeing someone else, since I really wasn't there" (de Jager et al., 2017, p.305).

Along with resignation and frustration, there were also expressions of feeling lonely and isolated. This loneliness was connected to PLSMI's feelings of being disconnected

from the rest of society, preventing them from establishing new social relationships or hindering them from maintaining existing ones. Loneliness was also related to not having stable relationships. Despite having friendships, PLSMI felt lonely because they did not have a partner. Some PLSMI even developed serious addictions to appease the distress generated by their unwanted solitude:

I am not connected to anything personally or spiritually [felt rejected by conventional religion due to sexual identity]. I don't have many friends. I don't have a boyfriend and I don't have a real relationship with God. I am just kind of there (Kidd et al., 2011, p.26).

All these feelings could lead these people to feel insecure and want to please others in personal relationships of all kinds, both friendly and intimate, even if this meant going against their own convictions: "When I was younger, I let people walk over me. Or I would keep pushing my own boundaries. Especially with boys, I found it hard to say no. I kept wanting to please the other" (de Jager et al., 2017, p.306).

Thus, being secure in oneself can decisively influence the development of intimate relationships in which both parties can express themselves freely and maintain their identity and autonomy. This was acknowledged by PLSMI themselves: "The biggest thing is the confidence I suppose. If you haven't got confidence you can't do anything else" (Redmond et al., 2010, p.164). Even so, this confidence can be affected by the weight gain suffered by many people taking antipsychotic medication: "Well, you've become fat. [...] You feel unattractive" (de Jager et al., 2018, p.1084).

The situation was especially complicated if PLSMI identified as lesbian, gay, bisexual, transgender or transsexual (LGBT). They chose sometimes to hide part of their sexual identity, either sexual orientation, gender or both, which could cause them to become hostile to others:

It [hiding] is as natural as anything [...] I could have cut somebody's head off, which went against myself as the "nice guy." But I knew it was there... I stared at myself in the mirror thinking that I am really crazy. And that solidifies that I can no longer repress or pretend that I was somebody that I wasn't because it was just making me too hostile (Kidd et al., 2011, pp.26-27)

In contrast, belonging to two systematically stigmatised groups, PLSMI and LGBT people, could also lead some people to develop contempt for themselves: "I just felt worthless. When you feel worthless you are certainly not going to take pride in anything — never mind your sexual identity" (Kidd et al., 2011, pp. 27-28). One person even compared hiding sexual identity with hiding the mental disorder, indicating that it was easier to hide a mental disorder than sexual identity, especially if the gender or sex with which they identified did not match the one assigned at birth following their biological characteristics: "Being trans is harder to hide from people, but my bipolar is something that I can pick and choose who I tell" (Kidd et al., 2011, p.26).

Feelings of insecurity or confusion when establishing social relationships, whether intimate or not, were common in PLSMI. Lack of experience, living for long periods without normal social relationships, or going through an acute phase of SMI made these feelings play a determining role, and were even more present when affected individuals had to face sexual relations, giving rise to anxiety: "It's not just because of the medication that you can't get an erection, it is also because of performance anxiety" (de Jager et al., 2017, pp. 305-306).

PLSMI did not have a designated person with whom to discuss these concerns. Consequently, when they were in a relationship, they felt strong pressure to remain stable within the disorder, and also felt constrained in their behaviour towards their partner: "You're under a pressure, um, a lot of the time when you're in a relationship to get well" (Robertson et al., 2015, p.270). This pressure could lead to guilt when PLSMI were at a loss about how to address the problems that arose in a relationship: "Feelings of guilt of course, about how you've behaved. [...] We had to sit down and regain trust and respect for each other" (de Jager et al., 2018, p.1085).

One way to help overcome this insecurity and guilt was to encourage acceptance of their identity, incorporating both SMI and sexuality:

It was the first time that anyone really asked me to relate my sexuality to my mental health issues. Not in the way that one caused the other, but how the two interact in my life. It wasn't really something I had thought much about before, so it was interesting to think about... About how the two of those things are parts of

who I am as a person. It's been a useful exercise for me, I think (Kidd et al., 2011, p.22).

Promoting this acceptance led the person to feel happier and more able to face the problems that may arise. It also encouraged recognition of the right to enjoy personal relationships without having to prioritise the needs of others over their own: "You know what? Deep down I am happy with who I am. I am sure we all have problems with society and people against us. I can deal with that" (Kidd et al., 2011, p.28).

### Learning to manage intimate relationships

PLSMI wanted to establish intimate personal relationships and recognised the importance of having self-confidence to do so. Some people went further and identified having an intimate personal relationship as a necessity and a way to improve their state of health. Others wanted not only to establish an intimate relationship, but also to have children, although they were pessimistic about their possibilities because of their age or medication intake, or because of financial difficulties due to their clinical status: "I'd really like to have children, but maybe it's too late now" (McCann, 2010, p.255). Despite acknowledging this desire, many PLSMI expressed shame when talking about their sexuality, especially if they were sexually inactive. Some people even experienced talking about sex as traumatic due to abstinence: "I have no sex life, and on the other hand I don't dare to talk about it" (Östman, 2014, p.342).

Participants believed having an intimate relationship was a sign of improvement and some stated it was the last barrier to overcome. Having a person with whom to share experiences and support was perceived as a return to a certain normality and to being able to get on with life: "Sexuality is like the ultimate barrier to overcome, that I have the desire to let someone that close shows the progress I have accomplished..." (Boucher et al., 2016, p.181). Even so, participants were also aware that these types of relationships are not established easily or quickly and must be based on mutual trust, with small daily actions: "Yes, taking care of each other, talking with each other, discussing your feelings with each other, yes that's what makes love. You make someone happy then it makes you happy" (McCann, 2010, p.253).

In this sense, having sexual relations is contextualised as the expression of a deep intimate relationship and as a result of being in love with the other person.

In contrast, other people, aware of the emotional burden of intimate relationships, preferred to have relationships of a sexual nature only: "It would be better to have purely sexual relationships, um, because then I'd only need what... (laughs) you know...I don't need the, the, the emotional stuff you get from relationships" (Robertson et al., 2015, p.269). Despite this, bad prior experiences or close relationships could influence the development of new relationships. Some participants classified previous relationships as toxic: "It has tainted my view of relationships because it, because it ended so badly in my, in my first admission and, um, it kind of put me off getting close to people again" (Robertson et al., 2015, p.270).

In an attempt to gain a closer understanding of what was happening to them, some PLSMI sought relationships with people who also had a mental health problem. Although understanding was easier, this type of relationship could lead to more serious problems when the disorders become more acute due to the risk of interaction between them:

I had had a boyfriend who wasn't mentally healthy himself [...] You pull each other into areas of madness [...] I had hoped that starting a relationship with someone who is struggling with mental symptoms as well, would be easier. Well, I was wrong. It's difficult (de Jager et al., 2017, pp. 304-305).

#### Reconstructing my sexuality

Affective and sexual education play a decisive role in how people learn to manage their emotions and understand and accept their sexual identity, especially if non-normative. However, this education is often scarce or non-existent in PLSMI. Some PLSMI realised that if they had been able to accept their sexual orientation much earlier, their lives would have been very different: "It started off with us being taught about the human body, biology...Male and female, to say we received sexual education - no not really. Oh no, nothing in the hospital, it was never discussed" (McCann, 2010, p.254).

Other crucial factors were the family environment, friendships and the support received by PLSMI. When positive, these aspects were described as an aid to moving

forward and even as a means to meeting people and establishing new relationships. PLSMI could show themselves to be empathetic towards other people and realised the importance of having someone to support them and listen to them without making value judgements: "I am lucky to have a relationship with my dad...I know a lot of people with mental illness who don't have that kind of family connection, never mind being gay" (Kidd et al., 2011, p.28). Sometimes, the environment was less favourable to PLSMIs establishing intimate relationships, possibly due to overprotection. Then, family members advised ending the relationship, which could lead PLSMI to perceiving a lack of support:

Oh, my family aren't supportive... they've got too many problems... they never, I mean all the relationships I've been in, my mum and dad never supported me, they never liked them. My mum used to say that they're not good enough for you... and used... and used to try... to try and put me off relationships (Redmond et al., 2010, p.160).

Many PLSMI were not legally qualified to work and had to survive on benefits, which were usually meagre. If they could work, they usually found low-paid employment that did not allow them to lead a normal life: "I'm on ODSP [disability benefits], I'm not working...I don't have a lot of money and I'm in and out of the hospital all of the time. Yeah, [sarcastically] I'm a great catch!" (Kidd et al., 2011, p.26).

A major external barrier to having an intimate partner was stigma. PLSMI commonly felt rejected by the rest of society when they disclosed they had a mental health problem and even stated that people ran away from them or feared them for this reason. Thus, it is extremely difficult for them to become close to others and to feel comfortable opening up and expressing themselves as they are. This often led them to hide part of their identity. Sometimes they hid psychotic symptoms from their own families because of fear of their possible reactions, leading to symptom exacerbation: "If they hear you have mental illness forget it! They run the other way. I was happy with someone but then he found my medication...I never heard from him again" (Boucher et al., 2016, p.181). This type of stigma was so widespread that PLSMI self-stigmatised, either undervaluing and considering themselves unsuitable to maintaining a stable relationship or rejecting other PLSMI: "I thought to myself; of course, you will lose him,

who would want someone with a psychosis? I would not have chosen someone like that for myself" (de Jager et al., 2018, p.1085).

The feeling of being stigmatised also affected LGBT people and hindered full expression of their sexuality. These people were constantly afraid of rejection or being attacked and some even feared for their lives. The feeling of rejection was even stronger if the non-accepting person was a family member. Some LGBT people blamed the feeling of rejection on the development of mental health problems:

Because of the gay situation, because of the hatred of someone gay, and then the hatred by anyone who's gay or lesbian for any truth coming out about anything that might possibly be detrimental to them-in other words, people's fear... Because of that, I'm highly conscious of being able to be killed at any time (Jones et al., 2018, p.126).

This stigmatisation, however, was not universal. Contrary to what some LGBT people previously believed, homosexuality was sometimes accepted by others in the environment. Some people also had greater confidence in themselves and felt vindicated by reactions to their sexual identity: "I was terrified that nobody in my life would accept the fact that I was gay. I thought I would lose everyone in my life that was important to me. But I didn't. Most people seemed surprised by the news" (Kidd et al., 2011, p. 24).

In contrast, double stigmatisation of LGBT people was not uncommon. This further aggravated social isolation because affected individuals felt they were not accepted by either of the two groups separately. Some participants chose to hide part of their identity, usually the mental disorder, since they believed that others found mental illness more difficult to accept than homosexuality. This situation could result in a feeling of hopelessness about ever being able to be truly authentic: "It's hard to predict who you can trust and who will be understanding. That's true for both coming out as trans and coming out as having a mental illness…It's a bit of a double whammy in some ways" (Kidd et al., 2011, p.25).

An area that, due to its impact on the lives of PLSMI, must be specifically analysed is healthcare. The relationship between PLSMI, healthcare professionals and the

information received by PLSMI are fundamental to the acceptance of their disorder and to learning to live with it. PLSMI often felt that they were treated as having a simple disorder and not as a person as a whole, with expectations and life goals. This was evident when they were only questioned about factors that might aggravate their disorder or when PLSMI mentioned issues that concerned them, but with which healthcare professionals had no experience, and who then made a note but did not delve deeper. In these cases, PLSMI could feel that the health professional did not worry about them directly, but only about the items specified in the assessments: "I had a male doctor and he, when I brought that up the subject [sexual dysfunction] he just went red, (laughs), really, really, red. Really red. He said, "OK I'll note it" and that was all was said about it" (Robertson et al., 2015, p.274).

Lack of experience in caring for LGBT people with an SMI, or prejudices around this issue, could lead health professionals to jump to conclusions that made participants feel misunderstood. When dealing with such sensitive issues, professionals need to be sensitive, empathetic and assertive if they must give messages that can be confusing or hard for the people who receive them:

I've had several doctors and nurses tell me that I must be depressed because I'm a lesbian and I haven't dealt with that. That's bullshit. I was a happy, out, and proudin-a-relationship lesbian before I got depressed for the first time. I don't think it has anything to do with my being gay (Kidd et al., 2011, p.29).

Treating participants holistically and with empathy led to much more positive results, not only in terms of acceptance of the messages imparted but also in terms of establishing a stronger therapeutic bond: "Some staff did make me feel like a real person, a whole human being, and made it OK for me to talk about anything, including my girlfriend at the time" (Kidd et al., 2011, p.31).

To protect people admitted to mental health centres from possible abuses, these centres usually have strict regulations regarding sexual behaviours and perception of them. This could lead inpatients to feel very restricted regarding intimate relationships and/or lead to misinterpretations by health professionals about situations that did not have a sexual or abusive component by either party:

It was in [hospital service] and I gave my partner a kiss and we were holding hands. It wasn't anything sexually inappropriate. And the therapist said that I need to tone it down because there are people that are offended by it. I got a little pissed off. It was not like [we were] making out (Kidd et al., 2011, p.29).

In addition to their strict regulations, mental health centres do not offer private spaces where admitted patients can develop relationships without feeling constantly monitored. This greatly limited the possibilities of establishing social relations with some normality. Moreover, if people wanted to have sex, they had to do it secretly: "Everyone else could come and just sit down beside you or the staff can just wander past and listen in... So there, there is a real lack of private space" (Robertson et al., 2015, p.271).

### DISCUSSION

The main finding of this study is that the sexuality of PLSMI is mediated by several factors, the main ones being: the complications of the mental disorder itself, the adverse effects of drug treatment, the support of close people, the relationship with the health sector, and stigma. It is from the interaction of these factors that these people construct their reality.

The complications of the disorder itself hamper the establishment and maintenance of social relationships, such as suspicion of the environment or difficulties in interpreting non-verbal communication. A review published by Hoertnagl and Hofer (2014), which compared social cognition between people with schizophrenia and those with bipolar disorder, indicates that both disorders have similar characteristics in terms of social skills, such as recognition of facial expressions and processing of emotions. Some studies suggest that the implementation of a structured social skills training programme, including tools to improve understanding of various social situations and their implicit norms, significantly improves the social functioning of PLSMI and helps to reduce the severity of negative symptomatology (Baez et al., 2013; Peña et al., 2016).

The adverse effects of drug treatment can also be a major barrier to the normal and satisfactory development of sexuality in PLSMI. Another study has shown that antipsychotic drugs can cause sexual dysfunctions such as loss of libido, erectile

dysfunctions, or anorgasmia (Waterreus et al., 2012). The findings of the present study lend support to the recommendation by Montejo, Montejo and Baldwin (2018) that people taking these drugs should be systematically questioned about their sex lives to preserve their quality of life and relationships and reduce discontinuation of drug treatment.

Another complication of medication, also supported by the results of this metasynthesis, is weight gain, which, as stressed by Shrivastava and Johnston (2010), can lead to psychological problems. It is therefore important to highlight the need to address this problem with both pharmacological and non-pharmacological treatment such as diet and physical activity.

Another determining factor for the construction and development of sexuality in PLSMI is the support of significant people. Wang, Mann, Lloyd-Evans, Ma and Johnson (2018) report that loneliness and a perception of poor social support is related to worse results in terms of symptoms, recovery, and functioning in people with bipolar disorder. They also state that there is preliminary evidence that, in the case of schizophrenia, a greater perception of social support is related to better quality of life and functioning. Koenders, de Mooij, Dekker and Kikkert (2017) conclude that the support network of PLSMI is usually close to 2.5 times lower than that in the general population, which reduces relationship satisfaction. Therefore, in the treatment of these disorders, more attention should be paid to social isolation and the involvement of the environment.

The results of this study indicate that holistic treatment of PLSMI and empathy with them among healthcare professionals encourages a stronger therapeutic bond. This is consistent with the findings obtained by Borg and Kristiansen (2004) in a qualitative study that sought to explore helping relationships from the perspective of PLSMI, in which they described empathy, respect, and treatment. Ådnanes et al. (2019) conducted a study that investigated satisfaction with the health services among people with a mental disorder, whether severe or non-severe, among other aspects. The authors concluded that PLSMI had a worse connection with health services and that, to address this problem, these services needed to enhance the involvement of these people and their perspectives in the treatment process, since this increases not only their satisfaction, but also their quality of life. In this regard, Boyer et al. (2013) propose

the inclusion of quality of life in clinical practice. These authors conclude that seeking quality of life feedback from users enhanced their satisfaction, provided that the feedback was considered in subsequent treatment.

The results of this meta-synthesis suggest that sexuality and sexual health needs are not currently addressed with the necessary depth, either because of embarrassment or ignorance of the subject. A recent systematic review by Fennell and Grant (2019) concludes that sexual health information is not being widely imparted. These authors describe four main factors that influence the provision of sexual health education to patients by nurses: lack of knowledge about sexual health, the attitude of nurses and their belief that sexual health is private and not a priority, nurses' discomfort when addressing sexual health, and perceived barriers related to time, responsibility, and organisational support. Similarly, Mellor et al. (2013) conducted a qualitative study on the views of different types of health professionals of talking about sexual well-being with patients who have had a stroke and identified a clear lack of motivation, confidence and skills to talk about sexual well-being routinely. These authors recommend normalising the inclusion of sensitive topics during treatment after a stroke. To do so, they recognise that some structural changes would probably be necessary, but that major changes could be produced by only small actions, such as providing information to patients or adding these issues in standard care policies.

Regulating intimate relationships within psychiatric inpatient units has been addressed by some publications (Kastner & Linden, 2014; Warner et al., 2004). These reports highlight the controversy generated by this type of relationship. They emphasise that, despite having to respect the freedom of people to choose their sexual partners, it is also important to protect those people unable to give consent. They also warn about the possible legal implications of non-consensual relationships, which would be even more serious if they resulted in pregnancy or a sexually transmitted disease. They also insist on the importance of establishing guidelines for action in these situations to avoid possible confusion and arbitrary actions by the therapeutic team.

Another major barrier to establishing and maintaining relationships, whether intimate or not, is stigma. The results of the present study reveal that people with an SMI perceive both fear and rejection by other people because of the prejudices

surrounding mental health. Similar results have been found by studies dealing with stigma in distinct mental health disorders, including those considered SMIs (Bonnington & Rose, 2014; Reavley & Jorm, 2011). Reavley and Jorm (2011) collected the results of a survey of 6,019 people in Australia and concluded that, among the disorders included in the survey, the most strongly stigmatised was schizophrenia, largely related to a perception of danger, although only a few respondents had had a violent experience involving a person with this diagnosis.

Stigma is not exclusive to mental health. Also affected are LGBT people and people infected with HIV (Logie et al., 2018). Tinney et al. (2015) reported that older LGBT people were more likely experience anxiety and depression and that experiences of discrimination based on their sexual orientation or gender identity could be one of the factors promoting these problems. Thus, as indicated by the results of this metasynthesis, cases of double stigmatisation are not uncommon among people who identify as LGBT and who also have a mental disorder. This issue has been addressed before, exposing the additional difficulties encountered by these individuals in their personal and work lives, as well as in relation to health services (Holley, Tavassoli, & Stromwall, 2016; Mizock, Harrison, & Russinova, 2014). Mizock et al. (2014) identified several factors influencing acceptance of mental disorders among LGBT people. Those classified as barriers were stigma by family or health professionals, stigmatising diagnostic labels, and stigma within the mental health system with respect to LGBT people. In contrast, facilitators consisted of social support, the use of inclusive and self-defined language, and inclusive mental health services.

#### Limitations

This study has some limitations. On the one hand, few qualitative studies focus directly on the sexuality of PLSMI and therefore there may be other studies that include data on this subject, but they were not identified. In addition, the concept of SMI varies in the different countries studied. To address these limitations, a structured and systematic search of articles was carried out including different keywords that would help to maximise retrieval of articles related to the study phenomenon. On the other hand, the screening system of the selected studies, which excluded articles without an

abstract or available full text, may have left out of the analysis some studies that could have provided additional data.

### Implications for further research

Looking ahead, research into this topic must continue to deepen overall understanding of the phenomenon and identify other circumstances that may influence the sexuality of PLSMI. It is also necessary to continue analysing the impact of frustrations on sexuality and on mental health itself. It is also important to conduct studies attempting to explain the possible impact of culture and beliefs on the experience of sexuality. In this regard, there is a need for more in-depth study of persons whose sexuality may be affected by the delusional component of their disorder. Finally, the pharmaceutical industry should attempt to create pharmacological treatments with a lower risk of adverse effects and attempt to reduce the adverse effects that directly impact the daily lives of people taking psychotropic drugs.

### CONCLUSION AND IMPLICATIONS FOR MENTAL HEALTH NURSING PRACTICE

The results of this meta-synthesis highlight the lived experience of PLSMI in terms of their sexuality. Both the disorder itself and the treatment can directly interfere with sexuality. Unless this is taken into account in health interventions, or minimised, and unless the person has solid external support, this can lead to frustration, loneliness, suffering, and social isolation.

This study shows that many PLSMI have not lost interest in maintaining an active sex life and, therefore, mental health services must respond to this need, within their possibilities. Nurses can develop their role as health educators and should receive training on affective and sexual education to allow them to advise PLSMI and people in their environment on their options to develop their sexual dimension. This situation needs to be addressed by all levels, not only nurses' daily clinical practice. Mental health services should include assessment of sexual needs among routine standard practices, including training in this area if necessary.

The results of this meta-synthesis also reveal the rejection felt by PLSMI when they disclose their disorders and how they lose close relationships or possibilities of meeting other people because of ignorance and prejudices surrounding mental health. Therefore, to provide a comprehensive response, health systems should promote awareness programmes and reduce the stigma surrounding mental health in general and about their sexuality in particular, including LGBT issues. These programmes would need to target both health personnel and the general population.

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# **TABLES**

Table 1. Keywords used in searching, grouped in categories.

| Sexuality                                 | Mental Health   | Qualitative Methodology                  |
|---|---|--|
| Sexualidad / Sexuality                    | Trastorno mental severo /<br>Serious mental illness /<br>Severe mental disorder | Cualitativo / Qualitative                |
| Salud sexual / Sexual health              | Esquizofrenia /<br>Schizophrenia  | Fenomenología /<br>Phenomenology         |
| Sexo / Sex                                | Trastorno bipolar / Bipolar<br>disorder   | Teoría fundamentada /<br>Grounded theory |
| Afectividad / Affectivity                 | Esquizotípico / Schizotypal   | Metasíntesis / Meta-<br>synthesis        |
| Libido / Libido                           | Psicosis / Psychosis  | Metaetnografía / Meta-<br>ethnography    |
| Disfunción sexual / Sexual dysfunction    | Trastorno obsesivo-<br>compulsivo / Obssessive-<br>compulsive disorder          | Revisión narrativa /<br>Narrative review |
| Disfunción eréctil / Erectile dysfunction |   | Etnografía / Ethnography                 |
| Orgasmo / Orgasm                          |   | Observación / Observation                |
| Identidad de género /<br>Gender identity  |   | Investigación-acción / Action research   |
| Orientación sexual / Sexual               |   | Entrevistas / Interviews                 |
| orientation                               |   | Grupo focal / Focus group                |

Table 2. Summary of the studies included in the meta-synthesis.

| Article  | Aim  | Participants/Environment   | Design   | Main findings   |
|--|--|--|--|---|
| Boucher, Groleau and<br>Whitley (2016)                     | To examine the self-defined role of romantic relationships, intimacy and sexuality in recovery from SMI†   | 35 adult participants with SMI† and users of the mental health services Montreal (Canada)  | Qualitative Data collection: Semi-structured interviews and participant observation Data analysis: Thematic analysis   | Indicator and facilitator of recovery Barriers to recovery Barriers to intimacy   |
| de Jager, Cirakoglu,<br>Nugter and van Os<br>(2017)        | To explore what problems people diagnosed with a psychotic disorder experience in the field of intimacy and relationships, and what factors underlie these problems  | 28 participants (19 men and 9 women) between 22 and 62 years old with a psychotic disorder diagnosis Noord-Holland-Noord mental health services (The Netherlands)  | Qualitative; Grounded theory Data collection: Semi- structured interviews Data analysis: Grounded theory   | Factors influencing establishing and maintaining intimate relationships: side effects of medication, mental symptoms, stigma and self-stigma, sexual abuse and lack of social skills and experience |
| de Jager, van<br>Greevenbroek, Nugter<br>and van Os (2018) | To explore and understand, from a patient's perspective and within a bio-psychosocial model, the sexual needs of people with psychotic disorders, the problems they experience in sexual expression and the factors involved | 28 participants (19 men and 9 women) between 22 and 62 years old with a psychotic disorder diagnosis  Noord-Holland-Noord mental health services (The Netherlands) | Qualitative; Grounded theory Data collection: Semi- structured interviews Data analysis: Grounded theory   | Factors that affect sexual expression: direct and indirect effects of antipsychotics and psychotic symptoms, sexual trauma, social skills and stigma  |
| Jones, Rosen, Kamens<br>and Shattell (2018)                | To explore themes related to gender and sexuality among individuals diagnosed with a psychotic disorder  | 49 participants (48% men and 52% women) between 18 and 67 years old with a psychotic disorder diagnosis United States of America                                   | Qualitative; Descriptive<br>phenomenology<br>Data collection: Semi-structured<br>interviews and focus groups<br>Data analysis: Phenomenology<br>and content analysis | Psychotic experiences related to sexuality Shame and persecution Sexual or sexualized violence Gender, sexuality, agency and power Positive experiences of the erotic                               |

| Kidd, Veltman, Gately,<br>Chan and Cohen<br>(2011) | To examine the interaction of sexual identity and SMI† among three stigmatized groups that have been largely neglected in the literature to date: lesbian, gay and transgender individuals with SMI†  | 11 participants (8 women and<br>3 men) between 15 and 54<br>years old with SMI <sup>†</sup><br>Hamilton (Canada)  | Qualitative Data collection: 3 in-depth interviews to each participant Data analysis: Thematic analysis   | Stigma Interactions between identities and mental illness Sources of strength Psychiatric service settings  |
|--|---|---|---|---|
| McCann (2010)                                      | To explore the personal experiences of the people living with and recovering from schizophrenia   | 30 participants (15 men and 15 women) between 22 and 57 years old with a schizophrenia, schizotypal disorder or delusional disorder diagnosis London (United Kingdom) | Qualitative Data collection: Semi-structured interviews Data analysis: Thematic analysis  | Perceptions of intimacy Establishing and maintaining relationships Sexual concerns and issues Sexual knowledge and understanding Stigma and self-esteem Family planning and parenting Views about prescribed medication Formal and informal supports              |
| Östman (2014)                                      | To learn how people with SMI† living in a community experience satisfaction with their sex lives in comparison to other life domains measured by the Manchester Short Assessment of Quality of Life (MANSA). In addition, to use in-depth interviews to illuminate the everyday sexuality and sex lives of this special needs population. | 80 participants in the quantitative part 20 participants in the qualitative part (16 men and 4 women) between 33 and 82 years old with SMI† Malmö (Sweden)            | Mixed methods Data collection: Sociodemographic Questionnaire, MANSA and indepth interviews Data analysis: Descriptive statistics tests for MANSA results, $\chi^2$ test for categorical values, one-way analysis for continuous variables and thematic analysis for qualitative data | MANSA satisfaction with sex life and other domains of quality of life Honesty and straightforwardness in sex life and relationships Sexual relationships secondary in the case of SMI† Engagement needed for sexual functioning Lack of support from care systems |

| Redmond, Larkin and<br>Harrop (2010)               | To explore the meaning of romantic relationships from the perspective of young people who have experienced psychosis                                 | 8 participants (5 men and 3 women) between 21 and 31 years old with a schizophrenia diagnosis Birmingham and Wolverhampton (United Kingdom)          | Qualitative; Interpretative phenomenology Data collection: Semi-structured interviews Data analysis: Interpretative phenomenological analysis | Romantic relationships as incompatible: lack trust of self or other, negotiating identity Romantic relationships as normalizing: important part of life, outward sign of recovery, personally beneficial Romantic relationships as high risk: traumatic, difficult, reactions of others, threat to self, being used Risk reduction: trust, taking it slow, friendship, understanding Lack of experience/resources: difficulty meeting people, conventional expectations, experience, difficulty reading romantic signals, lack of confidence and energy |
|--|--|--|---|---|
| Robertson, Pote,<br>Byrne and Frasquilho<br>(2015) | To explore how the intimate relationship experiences of LGB‡ inpatients influenced their mental health recovery whilst resident on psychiatric wards | 6 participants (3 men and 3 women) between 31 and 57 years old with schizophrenia, bipolar disorder or personality disorder diagnosis United Kingdom | Qualitative; Interpretative phenomenology Data collection: Semi-structured interviews Data analysis: Interpretative phenomenological analysis | Redefining intimate relationships A reciprocal relationship in recovery: intimate relationships and mental health The ward environment: a barrier to forming and maintaining same-sex intimate relationships Attitudes within services: prejudice and discrimination as barriers to service users forming and maintaining intimate relationships Being a service user: the loss of power and personal identity as barriers to forming and maintaining intimate relationships  |

Table 3. List of codes and categories.

| Code   | Subcategory               | Category  |  |
|--|---------------------------|---|--|
| Anorgasmia                                     |                           |   |  |
| Clinical complications affecting relationships |                           |   |  |
| Erectile dysfunction                           |                           |   |  |
| Interpreting seductions signs                  |                           |   |  |
| Intrusive thoughts                             |                           | 5 d d d d d                                     |  |
| Libido   |                           | Pathologized sexuality                          |  |
| Self-questioning                               |                           |   |  |
| Self-stigmatizing the medication               |                           |   |  |
| Sexual abstinence                              |                           |   |  |
| Sexual hallucinations                          |                           |   |  |
| Compliance                                     |                           |   |  |
| Concealment                                    |                           |   |  |
| Feeling trapped                                |                           |   |  |
| Guilt  |                           |   |  |
| Insecurity in sexual relationships             | C. b C C                  |   |  |
| Loneliness                                     | Submission and insecurity |   |  |
| Obligation of being well                       |                           |   |  |
| Relationships difficulties                     |                           | Not my sexuality anymore                        |  |
| Resignation                                    |                           |   |  |
| Scorn  |                           |   |  |
| Self-image                                     |                           |   |  |
| Future perspective                             | Looking to the            | _   |  |
| Self-acceptance                                | future                    |   |  |
| Self-confidence                                | Tuture                    |   |  |
| Desire of establishing intimate relationships  |                           |   |  |
| Desire of progeny                              | Inner self                |   |  |
| Need for affectivity                           |                           |   |  |
| Building a relationship                        |                           | <ul> <li>Learning to manage intimate</li> </ul> |  |
| Contextualizing love                           |                           | · ·   |  |
| Intimate relationship as recovery              | Interacting with          | relationships                                   |  |
| Meaning of the sexual activity                 | the environment           |   |  |
| Talking about sexuality                        |                           |   |  |
| Toxic personal relationships                   |                           |   |  |
| Affective and sexual education                 |                           |   |  |
| Economic difficulties                          |                           |   |  |
| Health care personnel                          |                           |   |  |
| Lack of private spaces                         |                           | Pacanetructing my covertity                     |  |
| LGBT† stigma                                   |                           | Reconstructing my sexuality                     |  |
| Mental health stigma                           |                           |   |  |
| Sexuality prejudices in healthcare             |                           |   |  |
| Social support                                 |                           |   |  |

<sup>†</sup> LGBT – Lesbian, gay, bisexual, transgender, and transsexual

# FIGURE LEGEND

Figure 1. Search and screening flowchart based on PRISMA.

