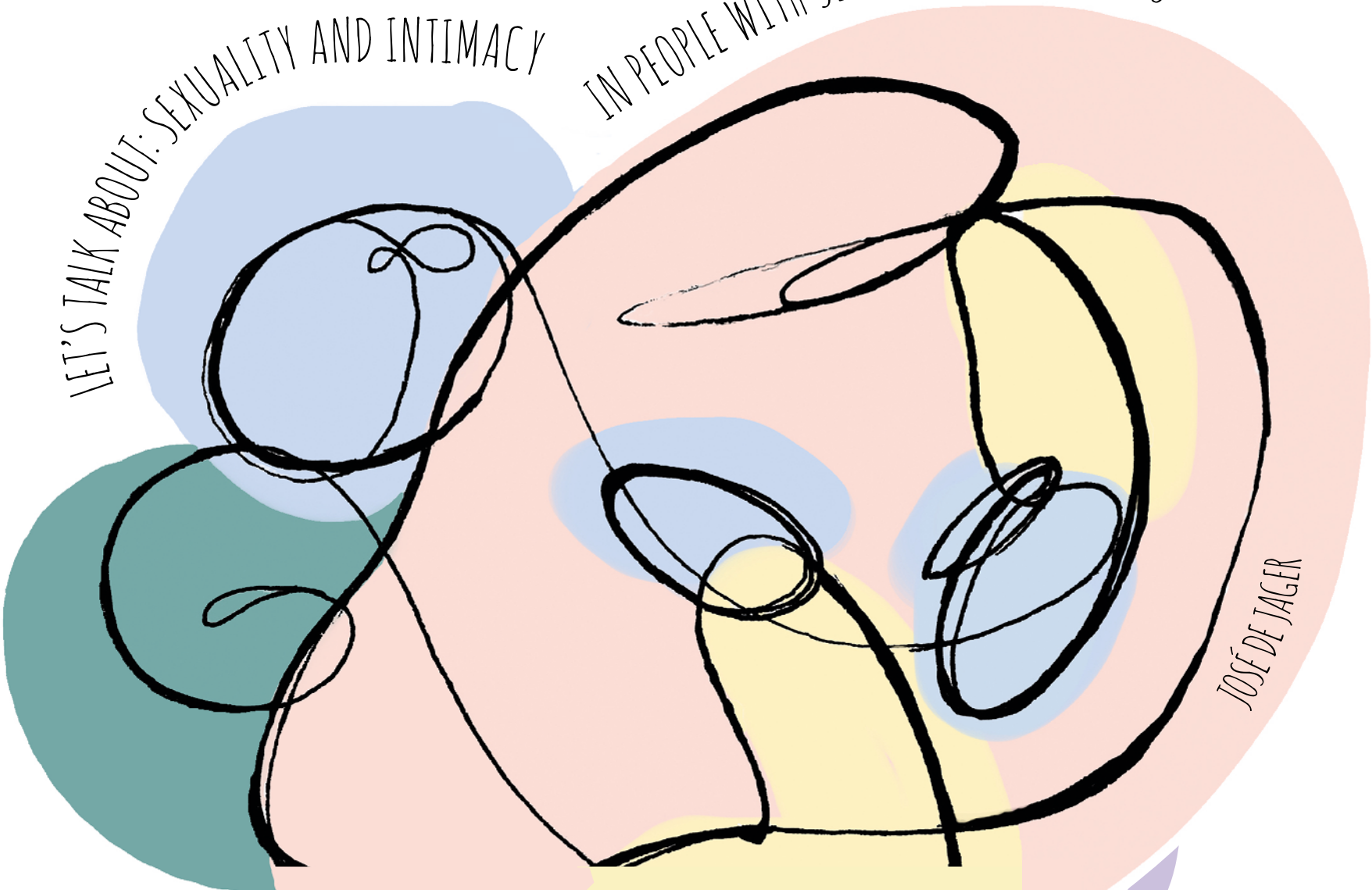
Let's talk about: Sexuality and intimacy in people with severe mental illness



José de Jager

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Let's talk about sexuality and intimacy in people with severe mental illness

Praten over seksualiteit en intimiteit bij mensen met ernstige psychiatrische aandoeningen
(met een samenvatting in het Nederlands)

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GENERAL INTRODUCTION

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Ben (21) has recently been through a first psychotic episode which has led to him moving back in with his parents and dropping out of college. His best mate John comes over to visit him. John tells him about his adventures with Lisa, his girlfriend since a month. John proudly confesses that he has had sex for the first time in his life. Ben, although being happy for john, sadly wonders to himself: "Will those events ever await me again?" "Will I remember how to actually flirt with a girl?" "will a girl ever be interested in me again now that I have had a psychosis?" The knot in his stomach tightens.

Gerard (45) stares at the ceiling of his guest bedroom. His husband Sam, who is in their former shared bedroom, has refused to sleep in the same bed with him for over a year now. About two years ago, Gerard had to increase his Zyprexa dose, which led to a gain in weight of 10 kilogram. His body image changed radically and his self-confidence dropped. Just as his desire and excitement for sexuality and intimacy. Sam feels deeply rejected and yesterday during dinner, he mentioned thinking about divorce.

Sue (33) often fantasized about being in a romantic relationship with a man. In her head, it seems like the most wonderful thing. In reality, however, every time someone actually comes closer, her stress level rises and the voices become stronger. One of these voices pertains to her father who sexually abused her when she was a child. These experiences frighten Sue so strongly that she has decided never to let a man in ever again.

From the day we are born, people long for physical closeness. For most people, this need remains present during the entire lifespan. In adulthood, the need for physical closeness mostly takes shape in the context of a romantic relationship and in sexual encounters. The perception and experience of sexuality, intimacy and relationships however, can be strongly affected by mental health issues.

The research described in this dissertation focusses on the experience of sexuality, intimacy and sexual relationships among people with severe mental illnesses, and factors that may enhance or disrupt these experiences. This introduction provides the background of the dissertation and an outline of the studies that it contains.

Defining intimacy and sexuality

The need for intimacy can be met in relationships with, for example, friends, family and colleagues (Moss & Schwebel, 1993). For the purpose of this thesis however, intimacy is looked at in the context of (potential) partner relationships. It is important to note that because of the contextual and dynamic nature of relationships over time, a simple and static definition of intimacy in relationships is probably "unobtainable" (Prager, 1995). However, despite the variety of definitions and operationalizations of intimacy that appear in the literature (Laurenceau, Rivera, Schaffer, & Pietromonaco, 2004), all seem to have one important aspect in common. This common aspect entails the feeling of closeness and connectedness which develops between partners through mutual communications.

According to Laurenceau, Barrett, and Rovine (2005), the interpersonal process model of intimacy, which was originally proposed by Reis and Shaver (1988), and later expanded (Reis & Patrick, 1996), attempts to adequality explain the process of dyadic communications that contributes to the experience of closeness and connectedness. This model provides a conceptualization of intimacy that reflects its multiple aspects, addresses its changeable nature, and enables its operationalization and therefor measurement. In this model, an intimate relationship is operationalized as an "interpersonal process in which two partners share and express feelings, thoughts and experiences, communicated both verbally and non-verbally, and learn more about themselves and the other" (Reis & Shaver, 1988).

Two important concepts in this conceptualization of intimate relationships are self-disclosure and responsiveness. Self-disclosure is the verbal and non-verbal (for example physical and sexual) communication of information about yourself (Jourard, 1971). Self-disclosure thus requires that a person is willing to be vulnerable by revealing intimate and personal information about himself. Communicating personal information about yourself will motivate the other person to share information about oneself as well. This will ultimately contribute to the creation of closeness between people (Laurenceau, Barrett, & Pietromonaco, 1998). Responsiveness refers to a partner's response to the behaviors, wishes and communication of the other person's needs. Ideally, the response is with understanding, recognition and validation (Aron, Mashek, & Aron, 2004). Being open about feelings and thoughts makes a person vulnerable to rejection. Inadequate responses, in other words, low responsiveness, can therefore do actual harm. Individuals who often have had negative experiences with disclosing their own thought world and emotional life, will be more reluctant to disclosure and will experience self-disclosure as difficult and risky (Cordova & Scott, 2001). If the responsiveness is adequate, self-disclosure will be stimulated. Within this exchange of self-disclosure and responsiveness a certain degree of intimacy develops over time, as two partners have more and more knowledge and understanding about and for each other (Righetti & Finkenauer, 2011; Aron et al., 2004).

Sexuality can be seen as a form of intimacy. The phrase "intimate relationship" has been equated with sexual activity in several studies. In a study of the meanings associated with close and intimate relationships among a sample of college students, 50% of the participants referred to sexual involvement as the characteristic that distinguished intimate from close relationships (Parks & Floyd, 1996). However, sexuality can also take place in a context that is not experienced as intimate or even in the presence of another person. Therefore, in this thesis, we choose to work with the concept of sexual expression;

Sexual expression can be described as the expression of sexuality. This term describes the way in which someone expresses sexual experiences (biological, psychological and social) and communicates these experiences with others in his or her environment. More concretely, sexual expression entails sexual behaviour, sexual communications and the sexual identity (Harvey, Wenzel, & Sprecher, 2004). Sexual behaviour, involves frequency, variety, and type of sexual activity. Sexual communication is the way in which an individual selects potential sexual partners and discusses or negotiates topics related to sexuality with a (potential) partner (Metts & Spitzberg, 1996). Sexual identity concerns the sexual self-image, orientation and gender identity. Being able to express sexuality plays an important role in the (development of) identity (Ailey, Marks, Crisp, & Hahn, 2003). In particular, sexual expression plays an important role in self-definition, in which being able to express sexuality confirms the sense of gender, which is important for self-esteem and identity (Volman & Landeen, 2007). Being able to express sexuality is therefore an important aspect of being a human (Volman & Landeen, 2007; Ailey et al., 2003).

Severe mental suffering

About 15% of the general population is dissatisfied with his or her sex life (Mulhall, King, Glina, & Hvidsten, 2008). This percentage is significantly higher in people with severe mental suffering, often referred to as severe mental illness, around 64.1% (Östman, 2014). Despite the fact that 83% experiences sexual feelings, people with a severe mental illness often report not being able to express their sexuality (McCann, 2010; Peitl, Rubeša, Peitl, Ljubicic, & Pavlovic, 2009). It is therefore, that this dissertation focusses on people with severe mental illness.

There are several definitions used to describe people with severe mental illness (Ehrhardt et al., 2002). In the recent literature, the term SMI is often used to describe people with the most serious diseases in mental health care. In these settings, SMI is sometimes referred to as a psychosis, but usually entails a definition that, next to an indication of psychiatric disorder, includes persistent progress (> 2 years care) and dysfunction (eg, a Global Assessment of Functioning (GAF) score <50) (Parabiaghi, Bonetto, Ruggeri, Lasalvia, & Leese, 2006; Ruggeri, Leese, Thornicroft, Bisoffi, & Tansella, 2000).

The restriction of SMI to psychosis is controversial. Non-psychotic mental health problems can also be serious (Delespaul, 2013). Furthermore, the assessment of the long-

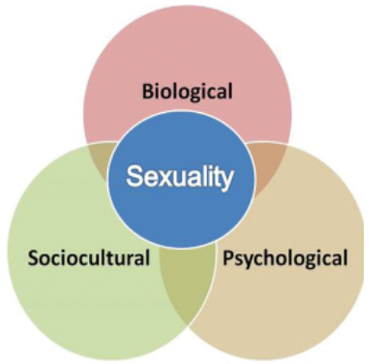
term criterion depends to a large extent on the care organization and funding that differ between countries, which also allows less seriously ill people to be in care or deprive seriously ill people from care. The use of the GAF-score to asses level of dysfunction appears to be unreliable (Grootenboer et al., 2012). For the purpose of this dissertation, that focused on the experience of sexuality and intimacy among people with SMI, we use the term SMI to describe people with 1.) a psychiatric illness which is or could be diagnosed on AS-I of the DSM, 2.) a duration, or presumed duration of complaints for more than 6 months that 3.) seriously affect daily functioning. Individuals living with 'first episode psychosis' are also considered to meet criteria for SMI (NICE 2014).

The impact of SMI on sexuality and intimacy

Difficulty in sexual expression and intimacy manifests itself in people with SMI, among other things, in a reduced sexual activity. People with SMI report a lower frequency of sexual intercourse than people without a SMI (Peitl et al., 2009; Raja & Azzoni, 2003). The percentage of people having had sexual intercourse in one year is 49% for people with SMI compared to 67-86% in the general population (Carey et al., 1999; Herbenick et al., 2010). The practice of masturbation is almost the same for users as for the general population (Bobes et al., 2003; Herbenick et al., 2010; Östman, 2014). The reduced presence of sexual intercourse may indicate (sexual) problems in a relationship or a more limited access to sexual partners (Östman & Björkman, 2013; Wright, Wright, Perry & Foote-Ardah, 2007).

Research on factors that impact sexuality and intimacy among people with SMI is scarce. Studies that have been conducted point towards a combination of different biological, psychological and social factors which may impact the experience and expression of sexuality and intimacy among people with SMI. It is important to note that these biological, psychological and social factors overlap and interact, which makes a strict division between the three impossible. However, models that incorporate biological, psychological and social factors affecting sexuality are needed to understand and reflect the complexity of the concept (Tiefer, 1991; Regan & Berscheid, 1996; Spector et al., 1996; Basson, 2001) Therefore, the bio-psycho-social framework, as pictured in Figure 1 will be used to describe what is known to pose barriers in the experience of intimacy and relationships for people with SMI. From this viewpoint, it is recognized that biological, psychological, interpersonal, and sociocultural factors interact with each other in a dynamic system overtime, which may affect sexual function. In order to understand and address sexuality and related intimacy issues within the context of mental health care, all perspectives need to be taken into consideration.

Figure 1. Biopsychosocial model of sexuality



Biological perspective

On a biological level, medication is often an influential factor and culprit. Several types of psychotropic medication affect sexual functioning in a negative matter in which antidepressants and antipsychotics are particularly notorious. (Clayton & Balon, 2009). de Boer, Castelein, Wiersma, Schoevers, & Knegtering (2015) for example concluded in their study that there are strong positive correlations between the dosage of antipsychotics and sexual problems. Antipsychotic use is associated in as many as 30 to 60% of cases with sexual problems with libido loss, erection or lubrication problems, orgasmic disorders and ejaculation disorders being reported most frequently. Antipsychotics with a relatively high antagonistic affinity for dopamine receptors and antipsychotics that lead to a marked increase in prolactin, most often cause sexual dysfunction. These problems seem to affect the quality of life negatively (de Boer et al., 2015).

Users report sexual dysfunctions as some of the most bothersome side effects of antipsychotics (Lambert et al., 2004). As a consequence, sexual dysfunctions as a result of the side effects of medication plays an important role in the high degree of medication non-adherence among people with a psychotic vulnerability (Malik et al., 2011). In addition to sexual problems, antipsychotics can also affect the self and body image. Volman & Landeen (2007) interviewed ten users (5 women and 5 men) with a diagnosis of schizophrenia and concluded that experiencing sexual dysfunctions due to the side effects of medication affects self-perception of masculinity and femininity. Furthermore, the body image is often negatively affected by the weight gain induced by medication (Volman & Landeen, 2007; Östman & Björkman, 2013). As a result, users feel less attractive and experience sexuality more negatively, as a result of which they would experience difficulty in expressing sexuality (Volman & Landeen, 2007; Östman & Björkman, 2013).

Research suggests that, besides problems with sexual functions, the sexual risks are higher for people with SMI. Research conducted in New York among people with schizophrenia shows that 62% and 73%, respectively, had had sexual contacts with others in the past year, of whom a third rarely, if ever used contraceptives (Coverdale & Aruffo,

1989; Kelly & Conley, 2004). An extensive study of Cournos et al. (1994) of the sexual activities of 95 people diagnosed with schizophrenia resulted in the following figures: 44% of the users had had sexual contact in the previous six months. Of this sexually active group: 93% often not used a condom, 62% had more than one partner, 50% treated sex as “merchandise”, 45% used drugs or alcohol during sexual contact, and another 12% had sexual contact with an intravenous drug user. Although the generalizability of these figures to the Dutch situation needs to be critically examined, these data do suggest that attention for sexual risk behavior might be appropriate.

Psychological perspective

In addition to the consequences of drug treatment on the sexual functioning of people with SMI, the awareness of being sick on a psychological level can also affect well-being and sexual satisfaction. The DSM classification ‘schizophrenia’ for example, describes a serious psychiatric condition that affects an estimated 0.5% of the Dutch population. There are many myths and ghost stories surrounding the diagnosis which leads to stigmatization. Having been labeled with a stigmatizing diagnosis can have a major impact on a person’s self-concept, of which sexuality is a large part, and even influence the course of the disease (Charmaz, 2002; Grytten & Måseide, 2006; Lee, Kochman, & Sikkema, 2002).

People with SMI experience a first episode of mental health problems such as a psychosis usually during adolescence, a phase that focuses on the development of sexuality and psychosocial skills (Whisman, Johnson, Li, & Robustelli, 2014). Problems during this developmental phase due to a psychotic episode can lead to a later onset or even absence of sexual experiences, less knowledge, and fewer skills to develop sexual roles and to enter into relationships (Volman & Landeen, 2007). It can also lead to fears and doubts about the sexual orientation (Skodlar & Nagy, 2009). Partly due to a lack of sexual experience, people with a SMI may experience low sexual confidence (Kelly & Conley, 2004). Peitl et al. (2009) researched the sexual self-perception among 200 people with a psychotic vulnerability. This study shows that people with psychosis experience significantly more feelings of sexual incompetence than people without psychosis (Peitl et al., 2009).

In addition, people with SMI are confronted with the same identity problems and changes in the self-concept as people with a chronic physical condition. This implies the loss of the former self and loss of what they once thought was possible. Also, in the field of sexuality and intimacy. Friedman and Harrison (1984) showed in their study of women with schizophrenia that 60% of these women never had an orgasm compared to 13.4% of the control group. In addition to biological, difficulties in experiencing an orgasm can have various more psychological causes, such as few positive attitudes about sexuality, low self-esteem and difficulty letting go of control (Ijff, 2006). The study also showed a higher prevalence of sexual violence both for and after the occurrence of the first SMI symptoms.

The psychological factors mentioned also have a major influence on the social context in which users find themselves. For example, a state of psychosis can limit the (social) judgment (Green, Horan & Lee, 2015). This may lead to an increase in risky behavior such as the omission of precautions such as contraception.

Social and interpersonal perspective

People with SMI may experience limitations in their social skills. In particular, users with psychosis often report to experience emotional flatness and limitations in assessing the meaning of others’ behavior or their own behavior for others (social insight) (Peitl et al., 2009; Savla, Vella, Armstrong, Penn, & Twamley, 2013). Multiple studies show that these restrictions hamper the ability to enter into or maintain romantic or sexual relationships (Pinkham, Penn, Perkins, Graham, & Siegel, 2007; Lysaker, Davis, Warman, Strasburger, & Beattie, 2007; Van Sant, Ahmed, & Buckley, 2012). People with a psychotic vulnerability indicate that they have few interpersonal relationships (Kelly & Conley, 2004). The limitations in social skills can make users appear clumsy in contact with potential partners and are therefore less attractive (Van Sant et al., 2012; Cook & Razzano, 2000). According to Peitl et al. (2009), these limitations make it difficult to engage in emotional contact and build intimacy. Communication problems within a relationship may also occur: a qualitative study by Östman and Björkman (2014) among five users with a psychotic disorder and their partner showed that users and their partners hardly communicate about problems related to their sexual relationship, while on the other hand, the need to communicate about problems in the sexual relationship is high (McCann, 2000).

Another social factor that can hinder sexual expression is stigma, or prejudice and discrimination against people with SMI (McCann et al., 2019; Thornicroft et al., 2009). Public stigma can lead to situations in which people with SMI are kept at a distance by others, leading to (sexually) isolation (Angermeyer & Matschinger, 2003). Previous research shows that stigmatization has adverse effects on self-confidence and is a barrier to the expression of sexuality (McCann, 2003). Wright, Wright, Perry & Foote-Ardah, (2007) found a similar result in their study in which 261 people with severe mental illness were interviewed. Internalized stigma for example, proves to be an obstacle in forming relationships because of the fear of being open about a psychotic vulnerability and avoiding sexual contact for fear of rejection.

Rationale for this dissertation

The topic of sexuality and intimacy is beginning to receive more attention within the current recovery-oriented framework in mental health, but the experiences of sexuality and intimacy among people with SMI have not been extensively researched yet. This lack of attention can be found in clinical practice as well. Even though some people with SMI report (temporarily) decreased needs in the field of sexuality and intimacy due to mental health problems, most have the same desires when it comes to sexuality and intimacy as the general population. However, the amount of unmet needs in these fields seems to be

much higher. In terms of intimate relationships, people with SMI are more often single and/or divorced when compared to the general population. In addition, partner relationships are often characterized by less intimacy and satisfaction. This is significant for many reasons. If a person fails to form relationships, some basic psychological needs remain unfulfilled and refuge cannot be sought from another in times of stress (Baumeister & Leary, 1995; Prager, 1995). Relationships make it possible to receive support and comfort during periods of stress, which has a beneficial effect on health and well-being (Feeney & Collins, 2015; Prager, 1995). Lack of significant relations may thus lead to social isolation, which can generate feelings of loneliness, fear and sadness (Baumeister & Leary, 1995). This might explain why research has shown that relationship status in people with SMI is correlated with wellbeing, quality of life and the development and course of psychiatric disorder.

Although these unmet needs and related issues are common and significant, both health care providers and users often avoid talking about sexuality and intimacy within the context of mental health care (McCann, 2003; Shell, 2007) and as a consequence the door towards help usually remains closed. Even though some users have fear of being labeled or ridiculed by the staff for their interest in sex (McCann et.al., 2010), most users report being eager and receptive to discuss these issues (Kelly & Conley, 2004). Most studies show that they welcome the opportunity to discuss sexual health concerns, especially when caregivers are willing to raise the topic (McCann, 2000; Kelly & Conley, 2004). So, for users, the issue might not be their willingness to discuss their sexual concerns but their caregivers not creating opportunities or providing permission to discuss the topic.

In appreciating an intimate relationship and the experience of sexuality as a fundamental part of a person's identity and environment, it becomes increasingly evident that this area of life should not be ignored when trying to support recovery and enhancement of lives of people with mental illness. It is often stated that it has been insufficiently explored how and why having a severe mental illness may hamper the process of establishing and maintaining intimate relationships and sexual expression. There for, the question remains why the (physical and emotional) intimacy and sexuality needs of people with SMI remain unfulfilled. With this thesis we aim to explore experiences in people with SMI with sexuality and intimacy in depth. By learning from these experiences, the ultimate goal will be to develop general knowledge on how to meet the need for care in the field of sexuality and intimacy among people with SMI.

Integration of qualitative and quantitative data

Qualitative research methods involve the systematic collection, organization, and interpretation of textual material derived from talk or observation. It is used in the exploration of meanings of social phenomena as experienced by individuals themselves, in their natural context (Malterud, 2001, p.483). As this thesis primary focuses on personal experienced of people with SMI regarding sexuality and intimacy, the decision was made to start our research in a qualitative manner.

It is important to note that in some fields, qualitative research is still regarded with skepticism, accused of its subjective nature and the absence of facts. Counterparts however argue that the underlying principles in qualitative and quantitative research are much the same (Malterud, 2001; Pope & Mays, 2000). Obviously, procedures for textual interpretation differ from those of statistical analysis, because of the different type of data used and questions to be asked. That does not mean that qualitative research methods aren't founded on a systematic and reflective process for development of knowledge that can be contested and shared, implying transferability beyond the study setting (Malterud, 2001). Instead of looking at quantitative and qualitative research as two separate worlds, in this thesis we use them as complementary. Malterud argues that no research method will ever be able to describe people's lives, minds, and realities completely. Therefore it is important to keep in mind that quantified scientific knowledge is not always the most important or relevant type of information when dealing with people.

In line with what has been argued by colleagues, united under the umbrella 'science in transition' we strongly wished to gather, not just numbers, but data that have added value for clinical practice. By starting with qualitative research we aimed to gather in depth insight to the topic of interest before quantifying into numbers.

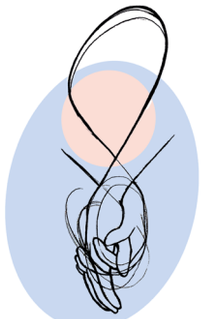
General outline of this dissertation

This thesis consists of three parts. In the first part, the focus is on mapping the yet existing knowledge on sexuality, intimacy and relationships among people with SMI and entails two literature reviews. In chapter 2 we provide an overview of literature published in the last decade on sexuality and intimacy among people with psychosis. Chapter 3 entails a broader systematic literature review with the aim of synthesizing the best available qualitative evidence on the experiences and support needs of people with serious mental illness (Ehrhardt et al., 2002) regarding sexuality and intimacy within hospital and community settings.

In the second part, results of qualitative research focusing on creating a deeper understanding of personal experiences of people with SMI will be described. Through these qualitative studies, we aim to develop theories on how to understand (barriers towards) sexuality and intimacy among people with SMI. In chapter 4, we describe a focus group-based study on the needs for care regarding sexuality and intimacy of young adults with psychosis within the context of their treatment program. In chapter 5, the personal experiences and possible barriers of people with SMI concerning their sexual expression are explored through in-depth interviews. In chapter 6, the same is done for the experiences of, and possible barriers toward intimacy.

The third part of this thesis is focused on testing the hypotheses that were formed in the second part of this thesis. In chapter 7, we report a study using longitudinal data of

1119 people diagnosed with a psychotic disorder. In this study, the relationship between childhood sexual abuse and sexuality and intimacy needs is tested. In chapter 8, a cross-sectional data study is described in which the more specific relationships between variables related to sexuality and intimacy, based on chapter 5 and 6, are tested. In chapter 9, the relationship between sexual abuse and PTSD on one hand and sexual dysfunctioning on the other is explored. In chapter 10 main findings are summarized and clinical implications, methodological considerations and directions for future research are discussed We also provide an overview of the studies that are still ongoing in chapter 10.



References

Ailey, S., Marks, B., Crisp, C., & Hahn, J. (2003). Promoting sexuality across the life span for individuals with intellectual and developmental disabilities. *The Nursing clinics of North America, 38*, 229-252. doi:10.1016/S0029-6465(02)00056-7.

Angermeyer, M. C., & Matschinger, H. (2003). The stigma of mental illness: effects of labelling on public attitudes towards people with mental disorder. *Acta Psychiatrica Scandinavica, 108*(4), 304-309. doi:https://doi.org/10.1034/j.1600-0447.2003.00150.x.

Aron, A. P., Mashek, D. J., & Aron, E. N. (2004). Closeness as Including Other in the Self. In *Handbook of closeness and intimacy*. (pp. 27-41). Mahwah, NJ, US: Lawrence Erlbaum Associates Publishers.

Basson, R. (2001). Human Sex-Response Cycles. *Journal of Sex & Marital Therapy, 27,* 33-43. doi:10.1080/00926230152035831.

Baumeister, R. F., & Leary, M. R. (1995). The need to belong: Desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin, 117*(3), 497-529. doi:10.1037/0033-2909.117.3.497.

Blankertz, L. E., Cnaan, R. A., & Freedman, E. (1993). Childhood risk factors in dually diagnosed homeless adults. *Social Work*, 38(5), 587-596.

Bobes, J., Garc, A. P. M. P., Rejas, J., Hern Ndez, G., Garcia-Garcia, M., Rico-Villademoros, F., & Porras, A. (2003). Frequency of sexual dysfunction and other reproductive side-effects in patients with schizophrenia treated with risperidone, olanzapine, quetiapine, or haloperidol: the results of the EIRE study. *Journal of Sex & Marital Therapy, 29*(2), 125-147. doi:10.1080/713847170.

Carey, M. P., Carey, K. B., Maisto, S. A., Gleason, J. R., Gordon, C. M., & Brewer, K. K. (1999). HIV Risk Behavior among Outpatients at a State Psychiatric Hospital: Prevalence and Risk Modeling. *Behavior Therapy, 30*(3), 389-406. doi:10.1016/

Charmaz, K. (2002). Stories and Silences: Disclosures and Self in Chronic Illness. *Qualitative Inquiry, 8*(3), 302-328. doi:10.1177/107780040200800307.

Clayton, A. H., & Balon, R. (2009). Continuing Medical Education: The Impact of Mental Illness and Psychotropic Medications on Sexual Functioning: The Evidence and Management (CME). *The Journal of Sexual Medicine, 6*(5), 1200-1211. doi:https://doi.org/10.1111/j.1743- 6109.2009.01255.x.

Cook, J. A., & Razzano, L. (2000). Vocational rehabilitation for persons with schizophrenia: recent research and implications for practice. *Schizophrenia Bulletin, 26*(1), 87-103. doi:10.1093/oxfordjournals.schbul.a033448.

Cordova, J. V., & Scott, R. L. (2001). Intimacy: A behavioral interpretation. *The Behavior analyst, 24*(1), 75-86. doi:10.1007/bf03392020.

Cournos, F., Guido, J. R., Coomaraswamy, S., Meyer-Bahlburg, H., Sugden, R., & Horwath,

E. (1994). Sexual activity and risk of HIV infection among patients with schizophrenia. *American Journal of Psychiatry, 151*(2), 228-232. doi:10.1176/ajp.151.2.228.

Coverdale, J. H., & Aruffo, J. A. (1989). Family planning needs of female chronic psychiatric outpatients. *The American Journal of Psychiatry, 146*(11), 1489-1491. doi:10.1176/ajp.146.11.1489.

de Boer, M. K., Castelein, S., Wiersma, D., Schoevers, R. A., & Knegtering, H. (2015). The facts about sexual (Dys)function in schizophrenia: an overview of clinically relevant findings. *Schizophrenia Bulletin, 41*(3), 674-686. doi:10.1093/schbul/sbv001.

Delespaul, P. H. (2013). [Consensus regarding the definition of persons with severe mental illness and the number of such persons in the Netherlands]. *Tijdschrift voor Psychiatrie, 55*(6), 427-438.

Ehrhardt, A., Exner, T., Hoffman, S., Silberman, I., Yingling, S., Adams-Skinner, J., & Smart-Smith, L. (2002). HIV/STD risk and sexual strategies among women family planning clients in New York: Project FIO. *AIDS and Behavior, 6*, 1-13. doi:10.1023/A:1014534110868.

Feeney, B. C., & Collins, N. L. (2015). A New Look at Social Support:A Theoretical Perspective on Thriving Through Relationships. *Personality and Social Psychology Review, 19*(2), 113-147. doi:10.1177/1088868314544222.

Friedman, S., & Harrison, G. (1984). Sexual histories, attitudes, and behavior of schizophrenic and “normal” women. *Archives of Sexual Behavior, 13*(6), 555-567. doi:10.1007/BF01542090.

Green, M. F., Horan, W. P., & Lee, J. (2015). Social cognition in schizophrenia. *Nat Rev Neurosci, 16*(10), 620-631. doi:10.1038/nrn4005.

Grytten, N., & Måseide, P. (2006). `When I am together with them I feel more ill.' The stigma of multiple sclerosis experienced in social relationships. *Chronic Illness, 2*(3), 195-208. doi:10.1177/17423953060020030101.

Harvey, J. H., Wenzel, A., Sprecher, S. (2004). *The Handbook of Sexuality in Close Relationships*: Psychology Press.

Herbenick, D., Reece, M., Schick, V., Sanders, S. A., Dodge, B., & Fortenberry, J. D. (2010). Sexual behavior in the United States: results from a national probability sample of men and women ages 14-94. *Journal of Sexual Medicine, 7 Suppl 5*, 255-265. doi:10.1111/j.1743- 6109.2010.02012.x.

Ijff, M. (2006). *Sexcounseling. Handleiding voor seksuologische hulpverlening*. Assen: Van Gorcum.

Jourard, S. M. (1971). *Self-disclosure: An experimental analysis of the transparent self.* Oxford, England: John Wiley.

Kelly, D., & Conley, R. (2004). Sexuality and Schizophrenia: A Review. *Schizophrenia Bulletin, 30*, 767-779. doi:10.1093/oxfordjournals.schbul.a007130.

Lambert, M., Conus, P., Eide, P., Mass, R., Karow, A., Moritz, S., Naber, D. (2004). Impact of present and past antipsychotic side effects on attitude toward typical antipsychotic treatment and adherence. European Psychiatry, 19(7), 415-422. doi:10.1016/j.eurpsy.2004.06.031.

Laurenceau, J.-P., Barrett, L., & Rovine, M. (2005). The Interpersonal Process Model of Intimacy in Marriage: A Daily-Diary and Multilevel Modeling Approach. *Journal of family psychology : JFP : journal of the Division of Family Psychology of the American Psychological Association (Division 43), 19*, 314-323. doi:10.1037/0893-3200.19.2.314.

Laurenceau, J.-P., Barrett, L. F., & Pietromonaco, P. R. (1998). Intimacy as an interpersonal process: The importance of self-disclosure, partner disclosure, and perceived partner responsiveness in interpersonal exchanges. *Journal of Personality and Social Psychology, 74*(5), 1238-1251. doi:10.1037/0022-3514.74.5.1238.

Laurenceau, J.-P., Rivera, L. M., Schaffer, A. R., & Pietromonaco, P. R. (2004). Intimacy as an Interpersonal Process: Current Status and Future Directions. In *Handbook of closeness and intimacy.* (pp. 61-78). Mahwah, NJ, US: Lawrence Erlbaum Associates Publishers.

Lysaker, P. H., Davis, L. W., Warman, D. M., Strasburger, A., & Beattie, N. (2007). Stigma, social function and symptoms in schizophrenia and schizoaffective disorder: Associations across 6 months. *Psychiatry Research*, 149(1-3), 89-95. doi:10.1016/j.psychres.2006.03.007.

Lee, R., Kochman, A., & Sikkema, K. (2002). Internalized stigma among people living with HIV/AIDS. *AIDS and Behavior, 6*, 309-319. doi:10.1023/A:1021144511957.

Malterud, K. (2001). Qualitative research: standards, challenges, and guidelines. *Lancet, 358*(9280), 483-488. doi:10.1016/s0140-6736(01)05627-6.

McCann, E. (2003). Exploring sexual and relationship possibilities for people with psychosis--a review of the literature. *Journal of Psychiatric Mental Health Nursing, 10*(6), 640-649. doi:10.1046/j.1365-2850.2003.00635.x.

McCann, E. (2010). The sexual and relationship needs of people who experience psychosis: Quantitative findings of a UK study. *Journal of Psychiatric and Mental Health Nursing, 17*(4), 295-303. doi:10.1111/j.1365-2850.2009.01522.x.

McCann, E., Donohue, G., de Jager, J., Nugter, A., Stewart, J., & Eustace-Cook, J. (2019). Sexuality and intimacy among people with serious mental illness: a qualitative systematic review. *JBI Database System Rev Implement Rep, 17(*1), 74-125. doi:10.11124/jbisrir-2017-003824.

Metts, S., & Spitzberg, B. H. (1996). Sexual Communication in Interpersonal Contexts: A Script- Based Approach. *Annals of the International Communication Association, 19*(1), 49-92. doi:10.1080/23808985.1996.11678928.

Moss, B. F., & Schwebel, A. I. (1993). Defining Intimacy in Romantic Relationships. *Family Relations, 42*(1), 31-37. doi:10.2307/584918.

Mulhall, J., King, R., Glina, S., & Hvidsten, K. (2008). Importance of and Satisfaction with Sex Among Men and Women Worldwide: Results of the Global Better Sex Survey. *The*

Journal of Sexual Medicine, 5, 788-795. doi:10.1111/j.1743-6109.2007.00765.x.

Östman, M. (2014). Low satisfaction with sex life among people with severe mental illness living in a community. *Psychiatry Research, 216*(3), 340-345. doi:10.1016/j.psychres.2014.02.009.

Parabiaghi, A., Bonetto, C., Ruggeri, M., Lasalvia, A., & Leese, M. (2006). Severe and persistent mental illness: A useful definition for prioritizing community-based mental health service interventions. *Social psychiatry and psychiatric epidemiology, 41,* 457-463. doi:10.1007/s00127-006-0048-0.

Parks, M. R., & Floyd, K. (1996). Making friends in cyberspace. *Journal of Communication, 46*(1), 80-97. doi:10.1111/j.1460-2466.1996.tb01462.x.

Peitl, M., Rubeša, G., Peitl, V., Ljubicic, Đ., & Pavlovic, E. (2009). Aspects of sexual self-perception in schizophrenic patients. *European Journal of Psychiatry - EUR J PSYCHIAT, 23*. doi:10.4321/S0213-61632009000100004.

Pinkham, A. E., Penn, D. L., Perkins, D. O., Graham, K. A., & Siegel, M. (2007). Emotion perception and social skill over the course of psychosis: a comparison of individuals "at-risk" for psychosis and individuals with early and chronic schizophrenia spectrum illness. *Cognitive Neuropsychiatry, 12*(3), 198-212. doi:10.1080/13546800600985557.

Pope, C., Ziebland, S., & Mays, N. (2000). Qualitative research in health care. Analysing qualitative data. BMJ *(Clinical research ed.), 320*(7227), 114-116. doi:10.1136/bmj.320.7227.114.

Prager, K. J. (1995). The psychology of intimacy [Guilford Press]. Retrieved.

Raja, M., & Azzoni, A. (2003). Comparison of three antipsychotics in the emergency psychiatric setting. *Hum Psychopharmacol, 18*(6), 447-452. doi:10.1002/hup.509.

Regan, P. C., & Berscheid, E. (1996). Beliefs about the state, goals, and objects of sexual desire. *Journal of Sex & Marital Therapy, 22*(2), 110-120. doi:10.1080/00926239608404915.

Reis, H., & Shaver, P. (1988). Intimacy as an interpersonal process. *J. Pers. Soc. Psychol., 74.*

Reis, H. T., & Patrick, B. C. (1996). Attachment and intimacy: Component processes. In *Social psychology: Handbook of basic principles*. (pp. 523-563). New York, NY, US: Guilford Press.

Reis, H. T., & Shaver, P. (1988). Intimacy as an interpersonal process. In *Handbook of personal relationships: Theory, research and interventions.* (pp. 367-389). Oxford, England: John Wiley & Sons.

Righetti, F., & Finkenauer, C. (2011). If you are able to control yourself, I will trust you: The role of perceived self-control in interpersonal trust. *Journal of Personality and Social Psychology, 100*(5), 874-886. doi:10.1037/a0021827.

Ruggeri, M., Leese, M., Thornicroft, G., Bisoffi, G., & Tansella, M. (2000). Definition and prevalence of severe and persistent mental illness. *The British journal of psychiatry : the journal of mental science, 177*, 149-155. doi:10.1192/bjp.177.2.149.

Savla, G. N., Vella, L., Armstrong, C. C., Penn, D. L., & Twamley, E. W. (2013). Deficits in domains of social cognition in schizophrenia: a meta-analysis of the empirical evidence. *Schizophrenia Bulletin, 39*(5), 979-992. doi:10.1093/schbul/sbs080.

Shell, J. A. (2007). Including sexuality in your nursing practice. *Nursing Clinic of North America, 42*(4), 685-696; ix. doi:10.1016/j.cnur.2007.08.007.

Skodlar, B., & Nagy, M. Z. (2009). Sexuality and psychosis. *Psychiatr Danub, 21 Suppl* 1, 111-116.

Spector, I. P., Carey, M. P., & Steinberg, L. (1996). The sexual desire inventory: development, factor structure, and evidence of reliability. *Journal of Sex & Marital Therapy, 22*(3), 175-190. doi:10.1080/00926239608414655.

Thornicroft, G., Brohan, E., Rose, D., Sartorius, N., & Leese, M. (2009). Global pattern of experienced and anticipated discrimination against people with schizophrenia: a crosssectional survey. *Lancet, 373*(9661), 408-415. doi:10.1016/s0140-6736(08)61817-6.

Tiefer, L. (1991). Historical, scientific, clinical and feminist criticisms of "The Human Sexual Response Cycle" model. *Annual Review of Sex Research,* 2, 1-23.

Van Sant, S. P., Ahmed, A. O., & Buckley, P. F. (2012). Schizophrenia, sexuality, and recovery. *Journal of Ethics in Mental Health, 7*, 1-5.

Volman, L., & Landeen, J. (2007). Uncovering the sexual self in people with schizophrenia. *Journal of psychiatric and mental health nursing, 14*, 411-417. doi:10.1111/j.1365-2850.2007.01099.x.

Whisman, M. A., Johnson, D. P., Li, A., & Robustelli, B. L. (2014). Intimate relationship involvement, intimate relationship quality, and psychiatric disorders in adolescents. *Journal of Family Psychology, 28*(6), 908-914. doi:10.1037/fam0000026.

Wright, E. R., Wright, D. E., Perry, B. L., & Foote-Ardah, C. E. (2007). Stigma and the Sexual Isolation of People with Serious Mental Illness. *Social Problems, 54*(1), 78-98. doi:10.1525/sp.2007.54.1.78.

2

Psychosis as a barrier to the expression of sexuality and intimacy: An environmental risk?

de Jager, J., McCann, E. (2017)
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PSYCHOSIS AS A BARRIER TO THE EXPRESSION OF SEXUALITY AND INTIMACY: AN ENVIRONMENTAL RISK?

ABSTRACT

People diagnosed with schizophrenia and related psychotic disorders often have unmet needs around sexuality and intimacy issues. This can impact negatively upon a person's recovery and the need to lead a fulfilling and satisfying life. The aim of the current review was to explore the available qualitative literature that addressed sexuality and intimacy issues published between the years 2006 and 2016. Records were screened for eligibility. Finally, 56 studies that addressed the aims were included in the review. The main themes that emerged are briefly discussed. The implications for clinical practice and future research are presented.

INTRODUCTION

Several studies have highlighted the often unmet needs in intimate and sexual relationships among people diagnosed with schizophrenia and related psychotic disorders. If someone has difficulty forming intimate relationships or expressing sexuality, some basic psychological needs may remain unfulfilled and, in times of stress, there may be no significant other to turn to for support. This poses an environmental risk as single relationship status has been associated with low quality of life and correlates with a poorer prognosis for people with psychosis.1 The question remains why the needs of people with psychosis in the area of sexuality and intimacy remain unrecognized and unfulfilled and what might help in the establishment and maintenance of satisfying intimate relationships and the full expression of sexuality. Also, service providers and clinicians have shown an increased interest in the psychosocial aspects of psychosis and the supports, interventions, and treatments available to people who experience the condition.2 Therefore, the main aim of the present study was to discover what is known about sexuality and intimacy among people with psychosis in order to highlight the factors that may underlie these often unmet needs. The secondary goal was to explore the current role of sexuality and intimacy in the field of research and clinical practice. Therefore, we performed a qualitative review of the

literature on intimacy and sexuality in schizophrenia or related psychosis over the past decade.

Method

The review included literature on sexuality and intimacy among people diagnosed with schizophrenia or related psychosis published between 2006 and August 2016. The databases used included PUBMED and PsycINFO. A search strategy was developed using the Boolean operators AND/OR with the following search string: psychosis, schizophrenia, intimacy, sexuality, and romantic. Reference sections of articles were used to identify papers that may have been missed. Case studies, books, non- English articles, and articles that focused on psychotropic side effects in which sexual function was not the focus were excluded. The articles were checked for relevance and duplicate articles were rejected. The remaining 56 articles that addressed sexuality and intimacy issues and psychosis were logged and qualitatively classified. The search results are presented in a flow chart[3] (see figure 1). An indexed bibliography of all the articles is available from the authors.

Results

A content analysis of the selected studies identified several themes that will be discussed briefly:

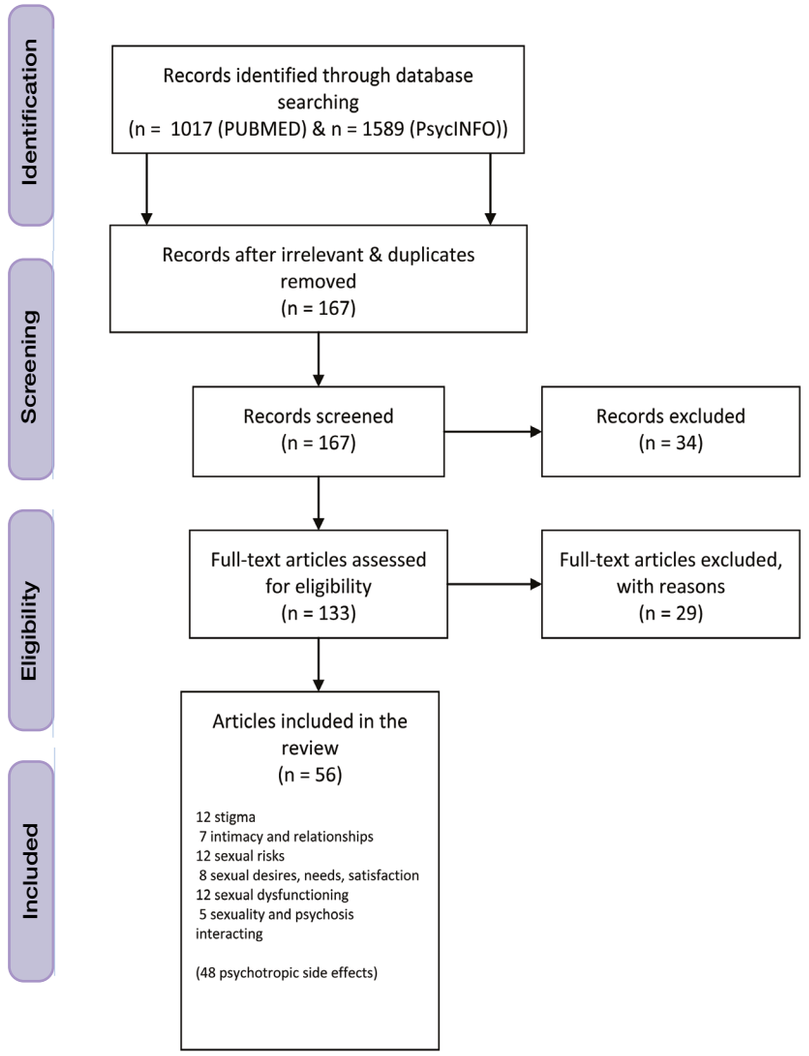
Sexual Needs, Satisfaction, and Desires

A total of 7 studies addressed the needs, desires, and satisfaction of people with psychoses concerning intimacy and sexuality. All studies report sexuality and intimacy as unsatisfactory among people with psychosis, while the needs and desires did not differ largely from the general population. Clinicians often overlook these needs, even when patients express their need to talk about these issues.

Sexual Risks and Risk Behavior

In the 1980s and 1990s, it became known that people diagnosed with severe mental illness were at greater risk of sexually transmitted infections (STIs), including HIV, than the general population. In the past decade, little research exists concerning sexual risks and risk behavior among people with psychosis. The few studies that have been carried out reveal a need for preventive interventions targeting sexual risks among people with serious mental illness (SMI) such as psychosis. A recent review by Walsh et al[4] showed that, although effect sizes were extremely variable, there is some evidence suggesting that behavioral interventions have a potential to reduce sexual risks in people diagnosed with SMI. However, further high-quality research is needed in this area.

Figure 1. Identification, retrieval, and inclusion of relevant studies



Sexual Dysfunctions

The available research regarding intimacy and sexuality issues shows that sexual dysfunctioning due to psychotropic side effects is the topic most studied. We found over 50 articles addressing this issue, even after excluding articles on antipsychotic side effects in which sexual dysfunctions were mentioned but with no particular focus. Discussing the specific interactions between types of antipsychotic drugs and sexual dysfunctioning in depth is beyond the scope of this review. We refer to a recent review by de Boer et al,[5] which provides an overview of current knowledge on this specific issue.

Stigma and Social Functioning & Intimacy and Relationships

Some studies show that about a quarter of the people with psychosis are confronted with prejudice and negative discrimination in the context of sexual and intimate relationships.[6,7] Self-stigma, the internalization of prejudice, can lead to social withdrawal and feelings of worthlessness in relation to sexuality and intimacy. The increase in social isolation and feelings of sexual worthlessness decreases social functioning and opportunities for sexual and intimate engagement. This feature might be stronger for people living in the community compared to inpatients.[8] A related struggle that appeared common is the issue of disclosing psychiatric vulnerabilities toward a (potential) partner. Some commentators believe that staged and careful disclosure is preferred over non-disclosure. For many, the fear of rejection is a reason to avoid self-disclosure or even sexual or intimate relationships at all. Targeting the internalization of stigma among people suffering from psychosis seems an important aim in order to improve sexual self-concept, self-esteem, and social functioning in the context of sexuality and intimacy.

Sexual Fantasies

The nature of sexual fantasies among people suffering from psychosis is no different than that of healthy individuals even though there is some evidence suggesting that sexual obsessions are more frequent. Gender may play a role in the nature of symptoms with sexual content.

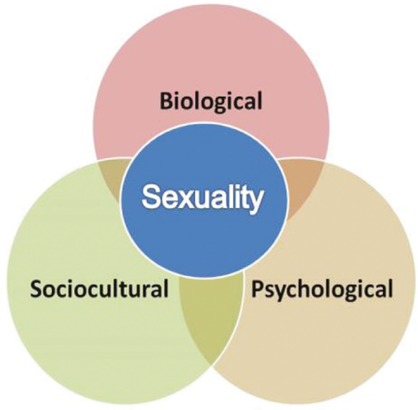
Sexual Orientation

Several studies revealed that in a state of psychosis, issues such as sexual orientation or gender become less defined. Sexual content of psychotic symptoms may or may not play a role. This could lead to gender confusion or experimenting with same-sex sexuality and intimacy. It is not uncommon that these feeling or actions lead to confusion or even shame afterwards. Notably, we were able to identify only one study focusing on lesbian, gay, and bisexual (LGB) people and psychosis. The findings suggest that LGB orientation experiences are associated with psychotic symptoms, most probably due to discrimination and minority stress.

Sexual Trauma

A significant amount of studies have shown that childhood (sexual) adversities are a risk factor in the development of psychosis.[9] Also, after the onset of psychosis, the risk of being (sexually) victimized increases.[10] The decreased ability to consent among people suffering from psychosis[11] may play a part in this. Thompson et al.[12] showed that a history of sexual trauma was related to the experience of psychotic symptoms containing sexual content. This 2-way interaction points to the significance of addressing trauma in psychosis. The authors assert that clinicians should take the content of psychotic experiences very

Figure 2. Biopsychosocial model and sexuality

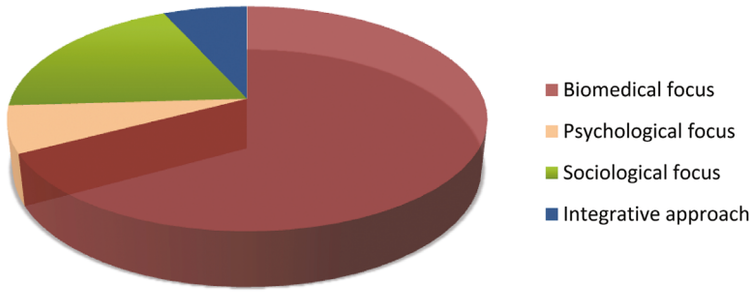


seriously in their work with patients. Even though there has long been caution with regard to the assessment and treatment of trauma in people with psychosis, recent studies show that it is both safe and effective to treat psychosis and comorbid post-traumatic stress disorder.[13] However, there remains a lack of studies that specifically address the impact of sexual trauma on the sexuality of adults living with psychosis.

Discussion

It is generally accepted by clinicians that sexuality should be approached from a biopsychosocial perspective (figure 2). From this viewpoint, it is recognized that biological, psychological, interpersonal, and sociocultural factors interact with each other in a dynamic system overtime, which may affect sexual function. In order to understand and address sexuality and related intimacy issues within the context of mental health care, all perspectives need to be taken into consideration. While reviewing the literature, the most noticeable finding is the relatively large representation of studies focusing on biological aspects of sexuality and intimacy such as psychotropic side effects and sexual risks like HIV and STIs (figure 3).

Figure 3. The focus of articles on sexuality and intimacy and psychosis



Practice and research focusing on psychosocial aspects of sexuality is highly needed in order to develop strategies to address the often reported unmet needs in the field of intimacy and sexuality among people with psychosis. By viewing a (potential) intimate relationship as a significant part of a person's environment, it becomes evident that this area of life should be taken into account when trying to facilitate recovery and enhancement of the position of people with psychosis in society. This has clear implications for policy, research, education, and practice developments. This review reveals the opportunities that exist for interprofessional collaborations where plans of care contain all perspectives, including the subjective experiences of service users. This holistic approach to recognizing and supporting intimacy and the expression of sexuality can not only enhance our knowledge and understanding of the individual needs and concerns but help support people in a more empowering, fulfilling, and recovery-orientated way.

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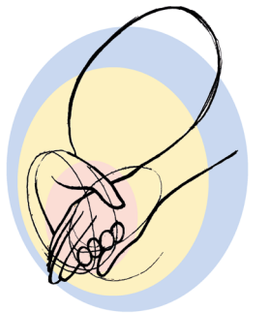


References

1. Nyer M, Kasckow J, Fellows I, et al. The relationship of marital status and clinical characteristics in middle-aged and older patients with schizophrenia and depressive symptoms. *Ann Clin Psychiatry*. 2010;22:172–179.
2. Van Os J, Kenis G, Rutten BPF. The environment and schizophrenia. *Nature*. 2010;468:203–212.
3. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med.* 2009;6:e1000097.
4. Walsh C, McCann E, Gilbody S, Hughes E. Promoting HIV and sexual safety behaviour in people with severe mental illness: a systematic review of behavioural interventions. *Int J Ment Health Nurs.* 2014;23:344–354.
5. de Boer MK, Castelein S, Wiersma D, et al. The facts about sexual (dys)function in schizophrenia: an overview of clinically relevant findings. *Schizophr Bull.* 2015;41:674–686.
6. Thornicroft G, Brohan E, Rose D, et al. Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey. *Lancet.* 2009;31:408–415.
7. Lasalvia A, Zoppei S, Bonetto C, et al. The role of experienced and anticipated discrimination in the lives of people with first episode psychosis. *Psychiatr Serv.* 2014;65:1034–1040.
8. Segalovich J, Doron A, Behrbalk P, et al. Internalization of stigma and self-esteem as it affects the capacity for intimacy among patients with schizophrenia. *Arch Psychiatr Nurs.* 2013;27:231–234.
9. Varese F, Smeets F, Drukker M. Childhood adversities increase the risk of psychosis: a meta-analysis of patient-control, prospective- and cross-sectional cohort studies. *Schizophr Bull.* 2012;38:661–671.
10. Bengtsson-Tops A, Ehliasson K. Victimization in individuals suffering from psychosis. J Psychiatr Ment Health Nurs. 2011;19:23–30.
11. Mandarelli G, Zangaro S, Raja M, et al. Competence to consent to sexual activity in bipolar disorder and schizophrenic spectrum disorders. *Arch Sex Behav.* 2012;41:507–515.
12. Thompson A, Nelson B, McNab C. Psychotic symptoms with sexual content in the "ultra high risk" for psychosis population: frequency and association with sexual trauma. *Psychiatry Res.* 2010;177:84–91.
13. Van den Berg D, de Bont PA, van der Vleugel BM, et al. Prolonged exposure vs eye movement desensitization and reprocessing vs waiting list for posttraumatic stress disorder in patients with a psychotic disorder; a randomized clinical trail. *JAMA Psychiatry.* 2015;27:259–267.

Sexuality and intimacy among people with serious mental illness: a qualitative systematic review

McCann, E., Donohue, G., de Jager, J., Nugter, A., Stewart, J., & Eustace (2019)

JBI Database System Rev Implement Rep, 17(1), 74-125

SEXUALITY AND INTIMACY AMONG PEOPLE WITH SERIOUS MENTAL ILLNESS: A QUALITATIVE SYSTEMATIC REVIEW

ABSTRACT

Objective: *The aim of this systematic review was to synthesize the best available qualitative evidence on the experiences and support needs of people with serious mental illness (SMI) regarding sexuality and intimacy within hospital and community settings. The objectives were to explore intimate relationship experiences of people with SMI, to uncover potential obstacles to the expression of sexuality and to present recommendations for mental health policy, education, research and practice.*

Introduction: *Mental health services worldwide have seen major transformations in recent years through deinstitutionalization programs and more enlightened ways of organizing and providing mental health care. However, in terms of social and emotional wellbeing, issues persist for people with SMI, particularly relating to intimacy and the expression of sexuality. This systematic review may assist service providers to determine ways that they may better support people in establishing and maintaining satisfying intimate relationships and the full expression of their sexuality.*

Inclusion criteria: *This review explored the intimacy and sexuality experiences, perceptions and concerns of people over the age of 18 years who were living with a SMI in hospital or community settings. This review considered studies that focused on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.*

Methods: *The databases MEDLINE, CINAHL, PsycINFO, Embase and Web of Science were utilised in the review. The search included studies published from 1995 up to and including February 6, 2018 and were limited to those in the English language. Each paper was assessed by two independent reviewers for methodological quality using the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research. Any disagreements that arose between the reviewers were resolved through discussion. Data extraction was conducted by two independent reviewers using the standardized qualitative data extraction tool*

from JBI. The qualitative research findings were pooled using JBI methodology. The JBI process of meta-aggregation was used to identify categories and synthesized findings.

Results: *Based on the thematic findings from the 21 studies, three synthesized findings were extracted from 10 categories and 83 findings: 1) the complexity of individual sexual experiences, 2) the clinical constructs of sexuality and 3) family and partner involvement.*

Conclusions: *Having fulfilling and satisfying sexual and relationship experiences is a fundamental human right that can enhance an individual's quality of life. Being aware of the potential stresses and challenges that having a SMI can have on a relationship and involving partners in the treatment, may help to promote intimacy and recovery. Practitioners can use these findings to guide future policy, education and developments in practice. Further research is required to develop and evaluate interventions that target the identified barriers and help people with SMI to fulfil their unmet sexuality and intimacy needs.*

ConQual Summary of Findings

Sexuality and intimacy issues among people with serious mental illness: a qualitative systematic review					
Bibliography: McCann E, Donohue G, de Jager J, Nugter A, Stewart J, Eustace-Cook J. Sexuality and intimacy among people with serious mental illness: a qualitative systematic review. JBI Database System Rev Implement Rep 2019; 17(1):74–125.					
Synthesized finding	**Type of research**	**Depend-ability**	**Credibility**	**ConQual score**	**Comments**
The complexity of individual sexual experiences Living with serious mental illness is a difficult and lifelong journey, beset with experiences often involving loss, trauma and victimization. In the midst of these multi-faceted challenges, the question of sexuality is one that is often neglected by mental health clinicians and by individuals themselves. For those individuals with a serious mental illness who identify outside of heteronormative relationships, this has led to what is described as a double stigma, with difficulties of alienation and identity. For others, the effects of self-stigma have acted as a barrier to intimacy, a difficulty in acceptance of self and feelings of inade-quacy.	Qualitative	High	Downgrade one level	Moderate	Downgraded one level as there was a mix of unequivocal and credible findings
The clinical constructs of sexuality The clinical constructs of sexuality include clinical attitudes, communication and environmental issues. The expression and experience of sexuality is highly influenced by the context it arises in. The setting of a mental health institution poses several challenges for both caregivers and consumers when it comes to the expression of sexuality, disclosures of (past) sexual experiences and the risks related to these issues.	Qualitative	High	Downgrade one level	Moderate	Downgraded one level as there was a mix of unequivocal and credible findings
Family and partner involvement Family and partner involvement is significant in terms of supporting the individual with SMI. The psychosocial needs of families are often unrecognised and the necessary supports are usually lacking.	Qualitative	High	Downgrade one level	Moderate	Downgraded one level as there was a mix of unequivocal and credible findings

The final synthesized findings were graded according to the ConQual approach for establishing confidence in the output of qualitative research synthesis and presented in the Summary of Findings.[46] The Summary of Findings includes the major elements of the review and details how the ConQual score was developed. Included in the table is the title, population, phenomena of interest and context for the specific review. Each synthesized finding from the review is presented along with the type of research informing it, a score for dependability, credibility, and the overall ConQual score. Despite low percentages noted for the collective responses to Q6 and Q7 (Table 1), at an individual level, all papers scored highly across other criteria and therefore the level "high" remains for Dependability on the ConQual Summary of Findings.

Introduction

Mental health services worldwide have seen major transformations in recent years through deintitutionalization programs and more enlightened ways of organizing and providing mental health care, particularly in relation to rights-based, empowering and service user-led policy initiatives.[1-4] However, in terms of social and emotional wellbeing, issues persist for people with serious mental illness (SMI), particularly related to intimacy and the expression of sexuality. The definition of SMI, with the widest consensus, is that of the US National Institute of Mental Health (NIMH) and is based on diagnosis, duration and disability. People who experience serious mental illness have conditions such as schizophrenia or bipolar disorder that can result in serious functional impairment which substantially interferes with or limits one or more major life activities.[5]
A recognised working definition of sexuality is:

> *"...a central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors."*[6(p.5)]

In terms of potential psychosocial supports, the area of human sexuality continues to present challenges to practitioners within the mental health professions.[7-8] Several studies have highlighted issues around unmet needs regarding intimate and sexual relationships among people diagnosed with SMI.[9-10] Where challenges in issues around sexuality and forming intimate relationships exist, some basic psychological needs may also remain unfulfilled.

A recent study has identified key issues related to the experience of sexuality in people with psychosis.[11] Some of the main concerns highlighted in the paper were around sexual needs, satisfaction and desires. Other issues concerned sexual risk and behaviour, sexual dysfunctions, stigma, sexual fantasies and sexual trauma. The study findings identified a noticeably large representation of evidence focusing on biological aspects of sexuality and intimacy such as psychotropic side-effects, sexual risks and sexually transmitted infections (STIs).[11] Practice and research focusing on psychosocial aspects of sexuality is therefore necessary to address the often unmet but reported needs regarding sexuality and intimacy in people with SMI.[12] In appreciating an intimate relationship as a fundamental part of a person's environment, it becomes increasingly evident that this area of life should not be ignored when trying to support recovery and enhancement of lives of people with

mental illness.[13] This has clear implications for policy, research, education and practice developments.

With the emergence of the recovery model in mental health, views on the possibility of recovery in people with SMI and ways of supporting people in the process are evolving.[14] The recovery ethos prioritizes the person instead of the condition and strives towards a satisfactory existence regardless of the presence of mental health issues. This approach was driven by service user movements and arose as a criticism of mental health care,which was seen as dominated by purely biomedical processes.[15-17] With this increasing focus on recovery oriented approaches, there is more emphasis on connecting care to the individual needs of people with SMI in different domains of living.[18] Despite these positive changes, some activities of living have received relatively little attention in mental health care. One of those domains is the expression of sexuality and intimacy and all that this entails. Sexuality, intimacy and relationships play amajor role in the lives of almost every human being. Since early childhood, people gravitate towards physical affection and intimacy. Sexuality and intimacy are therefore fundamental contributory elements of general wellbeing and quality of life.

However, sexuality and intimacy are not selfevident for everyone. About 15% of the general population is dissatisfied with his or her sex life and this percentage is significantly higher in people with mental health problems.[19] Several national and international studies have highlighted the significant gaps and unmet needs in intimate and sexual relationships especially among people with SMI.[9,11,20-22]

Significantly, the findings from one study revealed that more than two thirds of all people with a psychiatric disorder experienced sexual problems.[23] However, other researchers discovered this figure increases to 78% in people with depression.[24] Sexual problems also occur in people with post-traumatic stress disorders (PTSD)[25] and anxiety disorders.[26] However, the prevalence of sexual dysfunction among people with psychosis seems to be the highest as investigators concluded, in their research on people with schizophrenia, that 86–96% of the study population experienced sexual problems.[27] One other study found a figure of 64.1% among people who experience psychosis.[28] Even though some people report decreased needs in the field of sexuality and intimacy due to mental health problems, most people have the same requirements as the general population.[11,22] In terms of intimate relationships, people with SMI are more often single and/or divorced when compared to the general population.[29-33] In addition, partner relationships are often characterized by less intimacy and satisfaction within the relationship.[29-31] This is noteworthy, because research has shown that relationship status in people with SMI is correlated with wellbeing, quality of life and the development and course of psychiatric disorder.[34-37]

These studies have demonstrated the unmet needs that exist regarding sexuality and intimacy in people with SMI and highlight the requirement for more attention in clinical practice. While there has been some research on the biological aspects of sexuality, such as sexual health and psychotropic side-effects, studies on psychological and social

aspects of sexuality in people with SMI are underrepresented. Also, compared to sexuality, intimacy and relationships have received far less attention in research.[9,11,22] Within recovery-oriented care, attention to this area of life is growing and an overview of what is known so far is lacking or absent altogether. With the current review study, we aim to explore what is known about the needs and problems in the field of intimacy, sexuality and relationships among people with SMI and what factors might underlie individual reported unmet needs. Increased knowledge and awareness of sexuality and intimacy needs in people with SMI should help in bringing more attention to this important area of living, in order to promote recovery. Therefore, this review has the capacity to provide opportunities for multidisciplinary collaboration in developing shared insights and potential responses to the subjective experiences of people with SMI around sexuality and intimacy concerns. This holistic approach to recognizing and supporting intimacy and the expression of sexuality cannot only enhance our knowledge and understanding of the individual needs and concerns, but also help support people in a more empowering, fulfilling and recovery-oriented way.[13]

In order to address the research objectives, this systematic review of evidence generated by qualitative research was conducted. To confirm that no other systematic reviews existed about sexuality and intimacy experiences in relation to people with SMI, a preliminary exploration of the literature was conducted. A search of the Joanna Briggs Institute Database of Systematic Reviews and Implementations Reports, the Cochrane Library, PROSPERO, CINAHL, PubMed and Scopus databases did not find any current or planned systematic reviews on this topic. This current review was carried out in accordance with an a priori published protocol.[38]

Review question/objective

The aim of this systematic review was to synthesize the best available qualitative evidence on the experiences and support needs of people with SMI regarding sexuality and intimacy issues within hospital and community settings. The objectives of the present study were to:

I) Explore intimate relationship experiences of people with SMI.
II) Highlight specific issues related to sexuality that are important to people with SMI.
III) Uncover potential obstacles to the expression of sexuality.
IV) Present recommendations for mental health policy, education, research and practice.

Inclusion criteria

Participants

This qualitative review includes studies involving people aged over 18 years who have been diagnosed by a clinician with SMI of sufficient duration to meet diagnostic criteria specified within the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V)[39] or the 10th revision of the International Classification of Diseases (ICD-10).[40]

Years of living with SMI is not identified as a requirement for inclusion in this review once the diagnostic criteria, as stated above, have been met.

Phenomena of interest

This qualitative systematic review investigated intimacy and sexuality experiences, perceptions and concerns of people over the age of 18 years who are living with SMI. The review highlights pertinent issues and identifies specific needs in relation to sexuality and intimacy. Also, barriers to sexual expression have been elucidated.

Context

This review considers studies that have been conducted among people with SMI in mental health hospital or community settings.

Types of studies

This review considered studies that addressed intimacy and sexuality experiences of people living with a SMI. The focus was on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

Methods

Search strategy

The comprehensive search strategy involved a threephase process: i) a search of academic databases for published studies, ii) a search of sources of gray literature for unpublished studies, and iii) a hand search of reference lists for studies unidentified in the other two searches. Initial scoping searches using the database thesauri were run in MEDLINE, CINAHL, PsycINFO and Embase. These searches provided a list of synonyms using MeSH terms, CINAHL subject headings, PsycINFO descriptors and Emtree headings. This was then followed by an analysis of the keywords contained in the title and abstract, and of the index terms used to describe the articles retrieved during the search. A double strand search strategy was applied running the thesauri terms first and then keywords. These two searches were then combined using the OR operator. This method was repeated for each concept and at the end these four different concepts were combined together using AND: Concept 1 AND Concept 2 AND Concept 3 AND Concept 4 were combined to yield the results. This strategy was initially created within MEDLINE, and then adapted for all other databases searched using keywords and database-specific subject headings where applicable. The searches were conducted on 6th February 2018. All results were filtered for adults over 18 years of age as per the exclusion criteria. A date range of 1st January 1995 to 6th February 2018 was applied to coincide with the increasing emphasis and public discourse on recovery and related concepts involving people living with SMI.[41] The reviewers only included studies published in English. Five databases were selected for searching, MEDLINE (1965-), CINAHL Complete (1937-), PsycINFO (1990-), Embase

(1990-) and Web of Science (1945-). This database spectrum ensured wide coverage of the literature ranging from journal articles to conference proceedings and monographs. The search for unpublished or gray literature included ProQuest Dissertations and Theses, relevant key journals that report on conference proceedings, and the websites of relevant mental health organizations. The reference lists of all included studies were reviewed for additional relevant studies.

Listed below are four key concepts that were defined for searching and beneath each is a sampler of the thesauri terms searched. A fully mapped search strategy for each database is located in Appendix I.

I) Concept 1: Serious Mental Illness. MEDLINE: (MH "Personality Disorders+") OR (MH "Schizophrenia Spectrum and Other Psychotic Disorders+")OR (MH "Bipolar and Related Disorders+") OR (MH "Schizophrenia+" OR (MH "Psychotic Disorders+")

II) Concept 2: Sex or Intimacy. MEDLINE: (MH "Sexuality+") OR (MH "Sexual Behavior+") OR (MH "Paraphilic Disorders+")

III) Concept 3: Experiences. MEDLINE Keyword search only including experience OR experiences OR experienced OR view OR views OR viewpoint OR viewpoints OR perception . . .

IV) Concept 4: Study Type. MEDLINE: (MH "Empirical Research") OR (MH "Grounded Theory") OR (MH "Qualitative Research+") OR (MH "Hermeneutics") OR (MH "Focus Groups") OR (MH "Anthropology, Cultural+")

The subject librarian, involved in the review, carried out searches of academic databases and gray literature. The hand-search of reference lists of records that had been retrieved for inclusion eligibility was completed concurrently by two of the reviewers. Figure 1 contains a diagrammatic representation of the search strategy that is based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) method.[42] The final list of unique articles was then exported into an online systematic review program Covidence for screening.[43]

Assessment of methodological quality

After the removal of duplicates from the search, two reviewers scrutinised citation titles and abstracts using the defined inclusion and exclusion criteria. Qualitative papers selected for retrieval were assessed by two independent reviewers for methodological validity prior to inclusion in the review using the JBI Critical Appraisal Checklist for Qualitative Research[44]; a standardized critical appraisal instrument from the Joanna Briggs Institute System for the Unified Management, Assessment and Review of Information (JBI SUMARI).[45] Studies were excluded on the basis of not meeting the predefined eligibility criteria. Any disagreements that arose between the reviewers were resolved through discussion or with a third reviewer. The studies that remained were the final number included in this systematic review.

Data extraction

Qualitative data were extracted from the papers included in the review using the standardized data extraction tool from JBI SUMARI[45] by two independent reviewers. The data extracted included specific details about the country, phenomena of interest, participants, methods, methodology and the main results of each study. The extracted findings, and the accompanying illustrations from each paper, were evaluated for agreement and congruency by the primary and the secondary reviewers. Individual findings were appraised and could achieve one of three outcomes: unequivocal (well-illustrated and beyond reasonable doubt); credible (contains illustrations that may be challenged); or unsupported (findings not supported by data) (Appendix III).

Data synthesis

Qualitative research findings have been pooled, where possible, using JBI SUMARI with the metaaggregation approach.[45] This involved the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings and categorizing these findings on the basis of similarity in meaning. These categories have been subjected to a synthesis in order to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence based practice.

Results

Study Inclusion

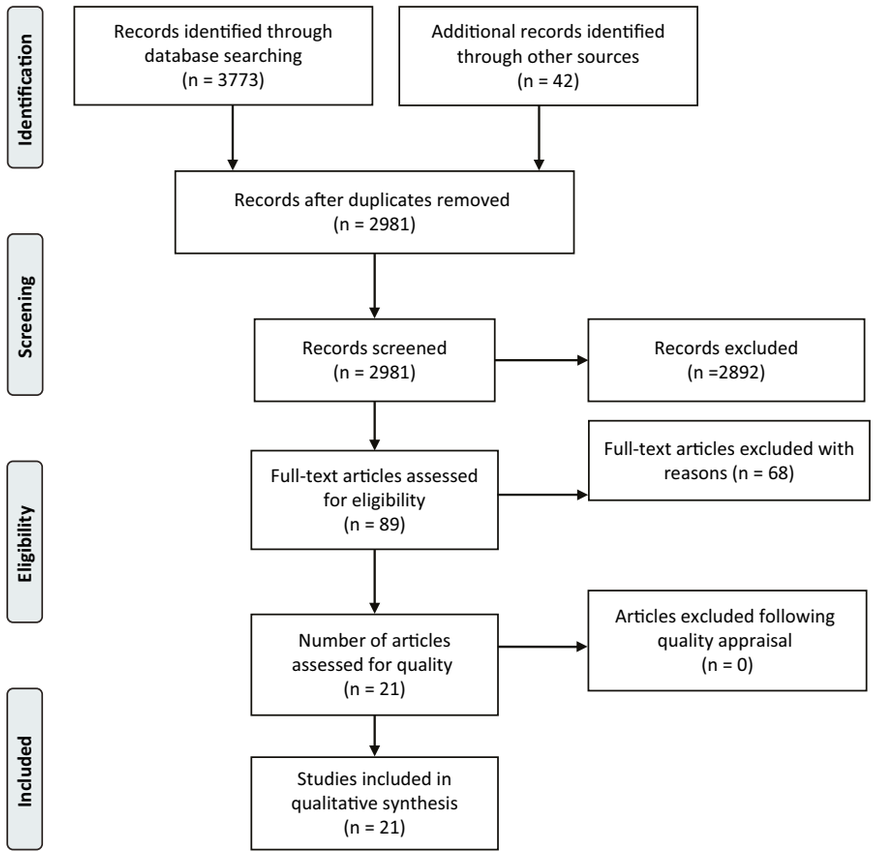
The comprehensive literature search returned 3773 records (Figure 1). A further 42 records were returned through searching the available gray literature. Following the removal of duplicates (n=834), using the inclusion criteria, two reviewers assessed the titles and abstracts of the remaining records (n=2981). A further 2892 records were excluded from the review. A total of 89 records were assessed for eligibility and 68 were excluded (Appendix V). Two reviewers appraised the remaining records (n=21) for methodological quality. None were excluded following quality appraisal. Finally, a total of 21 records published between 1995 and 2018 were included in the review.[22,47-66]

Methodological quality

Table 1 contains the quality appraisal of all studies. The results for each study ranged from a moderate score of six out of 10 (n=4) to a high score of seven and above out of 10 (n=17). Seven of the 10 quality appraisal questions achieved a high proportion of "yes" ratings; however, questions 1, 6 and 7 had a significantly lower proportion of "yes" ratings. For question 1, more than half of the studies (62%) contained details of the philosophical approach adopted or were unclear about their methodology. A total of 43% of the studies had a statement locating the researcher culturally or theoretically (question 6) and 43% had a statement indicating the influence of the researcher on the research (question 7). Despite

this, all key criteria were met across the 21 studies and therefore no study was excluded on the basis of this quality appraisal process.

Figure 1. PRISMA flowchart of the search and study selection process



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(6): e1000097.

Characteristics of included studies

The characteristics of the studies are provided in tabular form (Appendix II). A majority of the studies were published after 2010 (n=12) indicating a greater interest in the topic of intimacy, sexuality and mental health. The geographical locations and the number of studies conducted in each were: UK (n=5),[50,56,59,60,64] USA (n=4),[49,52,54,58] Australia (n=4),[47,48,61,63] Canada (n=2),[57,66] India (n=1),[51] Israel (n=1),[55] Netherlands (n=1),[22] New Zealand (n=1),[53] Slovenia (n=1)[65] and Sweden (n=1).[62] The methodologies used included qualitative description,[50-53,56,59,60,62,63] multiple case study,[47] single case study,[54,58] participatory action research,48 phenomenology[49,61,64,65] and grounded theory.[22,55,57,66] Sample sizes ranged from one to 146 participants. Most studies used individual interviews for data collection. Two used observation [47,54] and direct-therapist interactions.[58] One study used case notes[56] and another utilized focus groups.[53] The data analysis techniques used were thematic analysis,[48,50,52,53,56,61,62] content analysis, [51,59] case study analysis,[47,54,58] constant comparison analysis[54,55,57,66] and phenomenological analysis.[49,61,64,65]

Table 1. Methodological quality of included studies (n ¼ 21)

Reference	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Ashmore *et al.*[47]	U	Y	Y	Y	Y	N	Y	Y	Y	Y
Baker and Proctor[48]	Y	Y	Y	Y	Y	N	N	N	Y	Y
Ben-David *et al.*[49]	N	Y	Y	Y	Y	N	N	Y	Y	Y
Brown *et al.*[50]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Chandra *et al.*[51]	U	Y	Y	Y	Y	N	N	Y	Y	Y
Cogan[52]	Y	Y	Y	Y	Y	N	N	Y	U	Y
Davison and Huntington[53]	U	Y	Y	Y	Y	Y	Y	Y	Y	Y
de Jager *et al.*[22]	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Garett[54]	N	N	Y	U	Y	Y	Y	Y	Y	Y
Granek *et al.*[55]	N	Y	Y	Y	Y	U	N	N	Y	Y
Greenall and Jellico-Jones[56]	N	Y	Y	Y	Y	U	N	U	Y	Y
Kidd *et al.*[57]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Martz[58]	Y	N	Y	Y	Y	Y	Y	Y	N	Y
McCann[59]	N	Y	Y	Y	Y	U	N	Y	Y	Y
McCann[60]	U	Y	Y	Y	Y	N	N	Y	Y	Y
McCann and Clark[61]	N	Y	Y	Y	Y	U	Y	Y	Y	Y
Östman and Björk-man[62]	Y	Y	Y	Y	Y	U	N	Y	Y	Y
Quinn and Happell[63]	Y	Y	Y	Y	Y	Y	U	Y	Y	Y
Redmond *et al.*[64]	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Škodlar and Žunter Nagy[65]	N	Y	Y	Y	Y	U	N	Y	Y	Y
Volman and Landeen[66]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
% ‘‘yes’’ responses	48	90	100	95	100	38	38	86	90	100

N, no; U, unclear; Y, yes.
Y = yes, indicates a clear statement appears in the paper which directly answers the question.
N = no, indicates the question has been directly answered in the negative in the paper.
U = unclear, indicates there is no clear statement in the paper that answers the question or there is ambiguous information presented in the paper.
Critical appraisal questions for qualitative studies:
1. Is there congruity between the stated philosophical perspective and the research methodology?
2. Is there congruity between the research methodology and the research question or objectives?
3. Is there congruity between the research methodology and the methods used to collect data?
4. Is there congruity between the research methodology and the representation and analysis of data?
5. Is there congruity between the research methodology and the interpretation of results?
6. Is there a statement locating the researcher culturally or theoretically?
7. Is the influence of the researcher on the research, and vice- versa, addressed?
8. Are participants, and their voices, adequately represented?
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

All 21 studies included in the review addressed the views and opinions of people with SMI around intimacy and their sexual expression. The review objectives were considered fully to enable the construction of a meta-synthesis (Tables 2–4). The analysis yielded a total of 83 research findings, of which 37% (n=31) were assessed as unequivocal and 63% (n=52) as credible. See Appendix III for the findings from each study. The 83 findings were grouped into 10 categories that were aggregated into three synthesized findings. The first synthesized finding had four categories and 36 findings, 56% of which were unequivocal and 44% credible. The second synthesized finding had four categories and 38 findings, 18% of which were unequivocal and 82% credible. The third synthesised finding had two categories and nine findings, of which 56% were reported unequivocal and 44% credible. No findings received a rating of unsupported. The ConQual process was used to realise the level of confidence or trust that exists in the value and level of evidence of each synthesised finding (Summary of Findings). For synthesized finding 1 (the complexity of individual sexual experiences), the majority of the studies received four to five "yes" responses on the ConQual identified criteria for dependability; therefore, the level of confidence remained unchanged. The findings were a mix of unequivocal and equivocal (credible) ratings, thus necessitating the downgrading by an additional level, resulting in a ConQual score of moderate.

For synthesized finding 2 (the clinical constructs of sexuality), the majority of the studies also received four to five "yes" responses on the ConQual identified criteria for dependability; therefore, the level of confidence remained unchanged. The findings were a mix of unequivocal and equivocal (credible) ratings, thus necessitating the downgrading by an additional level, resulting in a ConQual score of moderate.

For synthesized finding 3 (family and partner supports), the majority of the studies also received four to five "yes" responses on the ConQual identified criteria for dependability; therefore, the level of confidence remained unchanged. The findings were a mix of unequivocal and equivocal (credible) ratings, thus necessitating the downgrading by an additional level, resulting in a ConQual score of moderate.

Synthesized finding 1: The complexity of individual sexual experiences

Living with SMI is a difficult and lifelong journey, beset with experiences often involving loss, trauma and victimization. In the midst of these multi-faceted challenges, the question of sexuality is one that is often neglected by mental health practitioners and sometimes by individuals themselves. For those individuals with SMI who identify outside of heteronormative relationships, this has led to what is described as a double stigma, with difficulties of alienation and identity. For others, the effects of self-stigma have acted as a barrier to intimacy, a difficulty in acceptance of self and feelings of inadequacy.

The emotional toll of this has led to experiences of 'abnormality' amongst this population; feelings of guilt and poor self-confidence for some, and for others, personal struggles in managing and maintaining close and intimate relationships. Whilst it is long established that supportive relationships with friends, family and community are beneficial to the mental health of all individuals, the experience of intimacy in this population contained personal narratives of loss, the dimensions of which are far reaching and include family, community and sexual intimacy. This synthesized finding was derived out of 36 findings which were divided into four categories (Table 2).

Table 2. Synthesized finding 1 – The complexity of individual sexual experiences

Findings	Categories	*Synthesized finding*
Emergence of stigma (U)	Stigma experiences	***The complexity of individual sexual experiences*** *Living with SMI is a difficult and lifelong journey, beset with experiences often involving loss, trauma and victimization. In the midst of these multi-faceted challenges, the question of sexuality is one that is often neglected by mental health clinicians and by individuals themselves. For those individuals with SMI who identify outside of heteronormative relationships, this has led to what is described as a double stigma, with difficulties of alienation and identity. For others, the effects of self-stigma have acted as a barrier to intimacy, a difficulty in acceptance of self and feelings of inadequacy.*
Self-stigma (C)		
Multiple sources of stigma (C)		
Double stigma (U)		
Effects of stigma (C)		
Self-stigma as barrier in the formation of intimacy (U)		
Mothers on trial: mental illness as stigma (C)		
The effects of heteronormativity (C)		
Struggling self-image, my sexuality and my illness, adjusting to change in sexual function, wanting intimacy, not feeling like a whole person (U)		
Illness as incompatible with sexuality (U)		
Relationships as problematic (C)	Making sense of individual sexual experiences	
Relationships as normalizing (C)		
Sexual fantasies, feelings of desire and satisfaction (C)		
Relationship needs and intimacy (C)		
Relationships outweigh sexuality (U)		
Uncertainties about one's capacity (U)		
Personal definitions of sexuality, searching for meaning, seeking satisfaction (U)		
Spirituality as important support (C)		
Social skills and deficits (C)		
Interaction between identities and mental illness (U)		
Effects of female socialization (C)		
Loss of children and parenthood (U)	Significance of loss	
Loss of intimate relationship (U)		
Loss of family (C)		
Loss of spouse or partner (U)		
Loss of friends (U)		
Loss of people in the community (U)		
Amputation: losing one's sexuality (U)		
Living with SMI challenging (U)	Emotional impact	
Feeling abnormal or "broken" (C)		
Going crazy (U)		
Anger or violence (C)		
Feelings of guilt, embarrassment and poor self-confidence during acute episode of psychosis (U)		
Personal trauma and struggle with relationships (U)		
Masturbation as stress relief (U)		
Alienation and despair with desire for relationships (C)		

Category 1.1: Stigma experiences

Despite increased consideration of the human rights of this population, people with mental illness continue to be stigmatized, leading to serious obstacles in the recovery trajectory for the individual.[22,51,54,60] Though mental illness stigma has been described as a contributor to social and sexual isolation, recent evidence suggests that it also may increase sexual risk behaviors.[57] Many lesbian, gay, bisexual, and transgender plus (LGBT+) people must confront stigma and prejudice based on their sexual orientation or gender identity, while also dealing with the societal bias against mental illness. The effects of this double stigma can be particularly harmful, especially when someone seeks treatment.[54,57]

"M returned to the concern of having 'a double stigma' because of her psychiatric diagnosis and transgender status. Because she had rarely discussed her psychiatric illness in previous sessions, this comment seemed almost incongruent with the trend of recent thoughts. M now denied psychosis, and focused on depressive symptoms, but rationalized these as the result of other people's behavior toward her."[54(p.134)])

"They had to call an ambulance for me. It was interesting because when I told the ambulance attendants about the Huntington's, they were very interested. But when they found out I have a mental illness, they stopped talking to me. I couldn't win no matter which way. If I go with Huntington's somebody might not know what it is and stop talking. If I go with mental illness, people back off. If I go with gay, people back off. It is like a triple-header. I couldn't win no matter which way."[57(p.25)]

"The word psychosis will not come out of my mouth. If I were in a happy relationship, perhaps I would tell her at some point. If she would be very easy to talk to, I would tell her," (Divorced, male, 42 years).[22(p.6)]

Category 1.2: Making sense of individual sexual experiences

Research on the sexuality of people with SMI most often focuses on dysfunction and the side-effects of medication.[22,50,59] When looking at the qualitative studies of this review, it was found that when asked, participants were happy to disclose both their desires for meaningful sexual expression alongside the uncertainty that long periods of isolation away from significant others may elicit.[22,59,62,64,66]

"I'd love to be in a relationship again. (...) I can hardly even imagine what it would be like. It seems like a dream. (...) If you're single for 10 years, then you're just really lonely. That's just what it is," (Single, male, 38 years).[22(p.4)]

"I'd really like to have children, but maybe it's too late now. We're trapped in this place. I'd like us both to live together in a flat in London.Could we have children? I don't know..."[(p.254)]

"The narratives of patients often included worries about being unable to lead a life in which healthy sexuality played a part. They wondered whether they still had the capacity for sexual activity and could give their partner satisfaction in a sexual relationship."[62(p.22)]

"I guess I get my strength from my friends and from the few members of my family who support me and love me... 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."[57(p.28)]

"The experience of schizophrenia affected the person's relationality, or how the person experienced relationships with others, including family members, friends, and mental health nurses. The data show that the embodiment of schizophrenia had a paradoxical effect on social relationships, sometimes eliciting support while at other times damaging relationships."[61(p.789)])

"I had become 'mental' at that time. I could not understand anything. I would go anywhere I liked and roam around. During that time many people have 'spoilt' me. Some would take me to the grove and would talk to me until it was dark and then would rape me and go away. They would get me eatables and take me to movies. Iused to feel very happy. These kinds of things happened many times. I do not even know who they were and what they did. I was very crazy about clothes, eatables, and movies. If anybody got me those I would go with them," 28-year old, bipolar disorder, mania with psychotic symptoms).[51(p.329)]

Category 1.3: Significance of loss

Narratives of loss were implicit across the findings of this review, although the dimensions of these loss experiences were multi-faceted and dependent on individual experiences.[48,50,53,57] Mental health problems alter existing relationships that can result in a lack of interest in sex and intimacy. On the other side, the stress of having a spouse with SMI can often be overwhelming and lead to relationship rupture. [22,52,55,60] This has far-reaching consequences, not just in maintaining healthy romantic relationships, but also in managing healthy relationships with family and the wider community.[48]

"I lost my husband. He dropped me off and said he didn't want anything to do with me... he couldn't take care of me anymore because of my mental illness, which means I lost

my whole life, everything."[48(p.98)]

"Sometimes my own mental illness caused a great deal of loss with the church when I started thinking that they're the devils in my house... I had religious delusions but the church couldn't see it as religious delusions."[48(p.98)]

"I would say this place has amputated my sexuality. Definitely, it's – it's not my home, it's not – it's not a free environment and... it's a – it's so anti-life. I just don't even think about sexuality in here and I grieve over that quite a lot. And... I try and cope with this place on its own terms, you know and whatever it has to offer me I will engage with. So and try to make it a reality, its own reality but I still can't feel human enough to be a sexual being in this environment."[50(p.250)]

Category 1.4: Emotional impact

Sexuality is an integral and crucial part of any individual's personal identity. When a person experiences SMI, the impact can be catastrophic and prolonged treatment can result in a further sense of alienation from both oneself and previous close relationships.[50,53,57,59,65] Mental health settings themselves can inadvertently place barriers in terms of an expression of these needs and, as a result, sexuality can be lost for individuals, with participants of this review expressing feelings of loneliness, guilt and despair in relation to this aspect of their identity.[53,57,63,65]

"One of the general characteristics of the sexual life of psychotic patients with other people is that it is absent for different reasons. The common denominator is difficulties in regulating closeness. Patients attribute to themselves and feel responsible for everything that they lack and cannot achieve. They feel inadequate both as sexual performers and partners as well as guilty for this inadequacy."[65(p.113)]

"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... I am still thinking that it [maintaining sobriety] is going to take me a lot of effort after 40 years of drinking. That was my best friend in the loneliness of knowing you are different from everybody else."[57(p.26)]

Synthesized finding 2: Clinical constructs of sexuality

The clinical constructs of sexuality include clinical attitudes, communication and environmental issues.

The expression and experience of sexuality is highly influenced by the context it arises in. The setting of a mental health institution poses several challenges for both caregivers and consumers when it comes to the expression of sexuality, disclosures of (past) sexual experiences and the risks related to these issues. This synthesized finding was derived out of 38 findings which were merged into four categories: safety, risk and vulnerability; mental health practitioners and therapeutic involvement; communication and disclosures; and the clinical setting (Table 3).

Table 3. Synthesized finding 2 – Clinical constructs of sexuality

Findings	Categories	Synthesized findings
Territorialization: Vulnerability/predation discourse (C)	Safety, risk and vulnerability	***The clinical constructs of sexuality*** *The clinical constructs of sexuality include clinical attitudes, communication and environmental issues. The expression and experience of sexuality is highly influenced by the context it arises in. The setting of a mental health institution poses several challenges for both caregivers and consumers when it comes to the expression of sexuality, disclosures of (past) sexual experiences and the risks related to these issues.*
Adult sexual abuse (C)		
Childhood sexual abuse (C)		
Impulsive sex acts can happen (C)		
Abuse within relationships (C)		
Safety is problematic for forensic group due to specific problems (C)		
Reactions to coercive sex (U)		
Female patients encouraged to take contraception as precaution (C)		
Screening for auto asphyxiation and safety procedures is important (C)		
Gender differences and vulnerability of youth present clinical high risk (U)		
Perpetrator of sexual abuse (C)		
Context of sexual abuse (C)		
Anger or violence (C)		
Psychotic drive (C)		
Sexual disinhibition (C)		
The attitude of mental health medical personnel (U)	Mental health practitioners and therapeutic involvement	
Exclusion and not asking about sexuality issues (C)		
Non-specificity of sexual disorders in psychotic patients (C)		
Managing the impact: regaining control, testing boundaries, perspective, opportunities and reclaiming a positive self-image (U)		
Erotic transference from client to therapist can occur (C)		
Importance of providing an understanding space (C)		
Difficulty understanding the transgender process (U)		
Auto-erotic asphyxiation occurs in women too and can be treated with exposure techniques (C)		
The assessment of sexual abuse by nurses as insufficient (C)		
Side effects of medication can be a barrier in sexual expression (C)		
Need to talk about support in sexual matters (C)	Communication and disclosure	
People with psychosis are willing and able to talk about their sexuality and it's safe to do so (U)		
Difficulties in establishing a stable sexual identity and questioning one's own sexual orientation (C)		
Lack of experience and resources (C)		
Delusional disclosures (C)		
Psychotic colouring of sexual abuse disclosure (C)		
Coming out as gay risky in hospital context (C)		
Need for social skills training for clients leaving hospital (C)	The clinical setting	
Male patients in hospital may have sex with other males without being gay (C)		
Privacy often lacking in mental health settings (C)		
Decline in sexual activity to do with being in hospital (C)		
Psychiatric service settings and challenges (C)		
Psychiatric service settings and positives (C)		

C, credible; U, unequivocal.

Category 2.1: Safety, risk and vulnerability

Clients expressed specific challenges, such as abuse in different situations including hospital and community settings.[22,52,56] Talking about and caring for safe and healthy sexual expression is difficult for all people. Different phenomena and barriers towards openness are presented and considered in the findings. It was found that impulsive sexual acts are not very frequent, but they make a strong impact.[47,50,51,63,64] Patients may inappropriately touch sexual organs of other patients or of the staff members, they can behave promiscuously, or can attempt sexual intercourse in public or covert places.[22,51,60,63]

"Sex is an organized act that two people come together and do – and they're going to do it wherever that is, you know, under a tree, at the end of a tunnel, they're still going to do it. Like, there's an old corridor. And there was a place where you hang your coats, where you can't see people when they looked down there. So I walked in and went to put my coat round there and they (two male patients) were having sex in the corner. . . and it's not the first time they'd done that actually, they'd done it somewhere else as well."[50 (p.248)]

"Three years ago I was inmy sister's house for a few days.My brother-in-law is not all right. He is very crazy about women. I think even my sister is aware of this, but she keeps quiet. She has two children and has to bring them up. She does not work and that is why I think she is scared. He had an eye on me also. But I never realized. One day I was alone at home. My brother-in-law came. That day he got an opportunity. He did not care, however much I requested. He raped me," (22 years old, psychosis). [51 (p.328)] *communication and disclosures; and the clinical setting (Table 3).*

"Case 8 followed some girls and then indecently assaulted another girl he had just met, after which he followed her home and waited for her outside. His explanation was he was looking for love and he felt that he loved his victim and 'she was nice'."[65(p.113)]

"There is always the risk of sexual assault, especially given the offending histories of our patients... Sometimes they might get involved above their capabilities and out of their comfort zone and be pressured into having sex."[63(p.671)]

"Like STDs. How do you explain this without getting your arse kicked? And if you ask for a condom, you're breaking the rules, so how do you explain that? You don't have access to condoms. Puts you at risk. They have condoms here, but you have to ask for them and then you're self-incriminating yourself because the next question is, 'What do you need that for?'

There is a condom machine but it is never full so you have to ask staff for them. It's a very awkward situation."[63(p.672)]

"Qualitative analysis suggested broad gender differences in emergent themes, with some overlap among youth. Themes among males were: feeling abnormal or 'broken', focus on 'going crazy', fantasy and escapism in video gaming, alienation and despair, but with desire for relationships. Themes among women were: psychotic illness in family members, personal trauma – more than half spontaneously brought up a history of trauma, including neglect, abuse, parental separation, and witnessing violence. There was also personal struggles with intimate relationships, personal development and selfesteem." [49(p.3-4)]

Category 2.2: Mental health practitioners and therapeutic involvement

For some, the onset of schizophrenia intensified social relationships but for others, a decline occurred.[52,54,55,61] Within the context of a romantic relationship, clients struggled with their sexuality in relation to being mentally ill.[59,62,63,66] Some participants blamed their medication, while others were affected by negative (sexual) experiences. Nevertheless, these topics are rarely discussed.[59] Proper education as well as assessment of sensitivity towards specific issues, such as transgender processes or autoerotic asphyxiation, appears to be lacking.[58,65] The first step in remedying the situation is to increase the awareness of mental health professionals in this regard, which is something that can be accomplished by more staff training in sexual matters and greater personal supervision of those providing supports and treatments.

"I think they feel uncomfortable talking in any, any depth about my sexuality. I don't think they've been trained to – I don't think that they, they have the insight. I'm sure we could have a very sensitive discussion with them about it, but for some reason, there's a barrier and I can't understand why."[50(p.246)]

"No one has ever asked me these questions earlier, so I have never told anyone. Now I feel OK and don't feel distressed about these experiences," (42 year old, obsessive-compulsive disorder). [51(p.329)]

"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." [(p.254)]

"In some cases an erotic transference from client towards his or her therapist occurs,

which can assume a form of erotic delusions."[65(p.113)]

"Psychotic people are so desperate for basic human relatedness and for hope that someone can relieve their misery that they are apt to be deferential and grateful to any therapist who does more than classify and medicate them. Understanding M, and not merely classifying her as a psychotic patient, had significant positive implications in her treatment." [54(p.135)]

"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. One participant also spoke about the impact of having a provider tell her that she was a lesbian herself... I felt it was nice that she did that. It made me feel less ashamed. It was because she is a nurse and she is gay and there is nothing wrong with that."[57(p.31)]

Category 2.3: Communication and disclosures

Communication about sexual matters is lacking in clinical practice and is rarely initiated by mental health professionals.[55,61] However, the evidence would suggest that most patients are very willing and able to do so. The fear of triggering unwanted responses appears unjust and it seems perfectly safe to talk about these issues within mental health care contexts. Based on the findings, talking about sexual issues and contemplating potential interventions are significant in terms of supports and psychosocial wellbeing. Responses to a variety of sexuality related disclosures are presented. Participants in existing studies appeared to respond well to the interviews. In fact, many seemed pleased to be asked about concerns regarding something as fundamental as sex and relationship issues.[47,59,65] There were no patient reports of distress or staff complaints about deleterious effects following interview sessions. No interview had to be prematurely terminated.

"We found that patients and partners do not regularly communicate with each other about issues related to their sexual relationship. However, some patients have said that they do speak with close friends and relatives about their sex life and their feelings of dysfunctionality." [62(p.22)]

"Patients with psychosis are willing, ready and even thankful if they are given the opportunity to talk about their sexuality. They have no problem discussing their wishes and fantasies, regardless whether they are heterosexual, homosexual or 'unusual', and their overt sexual activities, be it masturbatory or with others."[65(p.112)]

"Some people are made feel inadequate and this may be due to age and lack of experience. The thing is nobody ever said, you're single,what do you do about it? How do you go about being single? I mean obviously you talk to somebody these days off the road... they start walking away from you, get intimidated by you, you know. You get all... you feel upset."[64(p.163)]

"After spending two weeks in an acute inpatient unit in a psychotic state, Jay had been moved to sub-acute care, as she began to stabilize. Several days later, Jay returned to the unit after walking in the hospital grounds in a distressed state and told the nurses she had been 'raped by Santa Claus'. Staff assumed this was a regression of her psychosis, and initially dismissed her account. Following further investigation, eye witnesses reported seeing Jay with a grounds man who had a long white beard like Santa Claus. He was also recalled as wearing a red shirt that day. When confronted with this information, the grounds man admitted to having sex with Jay."[47(p.143)]

"This patient brought up that he might be gay and didn't want anyone else to know because he didn't want to be picked on, ridiculed, or raped... And then there is the issue of what happens if one of our guys are picked up on a gay beat? Imagine the headlines and imagine the implications for this place."[63(p.673)]

Category 2.4. The clinical setting

Being hospitalized is a significant life event. For some, the reason for hospitalization inhibits sexual needs temporarily. For others, sexuality remains an important aspect of life, throughout the admission and particularly for protracted stays.[49,50,56,61,66] There can be barriers and obstacles to the expression of sexuality such as a lack of privacy. Much depended on the type of setting and context. Some of the study participants were in a forensic unit and others were in supported accommodation in the community.[62,64] These, and other related topics are considered.

"Judging by the responses in some of the studies, a majority would like more opportunities to meet people and develop social skills away from the institution."[59(p.134)]

"Because of the environment, they have been indulging in homosexual activity. Which I possibly think is not the way they are orientated, but is due to the 'abnormal' environment... My understanding is that the guys who are gay aren't really gay. It's just that they can't get into bed with a woman. They get frustrated and turn gay because there are no women around... that's why a lot of them turn gay in prison. It's their only option."[63(p.674)]

"There is no privacy around here. There's not much chance to have sex. We're under the staff. Staff just come into the room, they don't bother to knock. I have no one to talk

to about this stuff and I get worried that I may harm her."[p.254]

"Sex relations had stopped for three-quarters of respondents since being hospitalized. When asked why sexual relations had stopped, the following reasons were given: illness of self (four); lost interest myself (four); lack of opportunity (five); no privacy (three); in hospital (six)."[59(p.135)]

Synthesized finding 3: Family and partner involvement

Family and partner involvement is significant in terms of supporting the individual with SMI. The psychosocial needs of families are often unrecognized and the necessary supports are usually lacking. This finding relates to family and partner experiences and support needs. Living with SMI presents a variety of stresses and challenges to both the person with the disorder and those who live with and care for them. This included partners who were learning to cope with the many challenges that the illness presented. In the last 20 years, the sociopolitical landscape in Europe has supported deinstitutionalisation, hospital closure programs and the locus of mental health care being situated in the community.As a result, this often necessitates families, including partners, facing the challenges and shouldering the burden involved in providing care and support to their family member. Families become a crucial element in fulfilling the person's health and social care requirements. Inevitably, families had become unpaid and unrecognized "silent" carers. In terms of sexual and relationship aspirations, studies have supported the idea that people with SMI are able to have satisfying and fulfilling intimate relationships. Despite the willingness and ability to be sexually active, challenges exist around establishing, sustaining and maintaining relationships. The necessary supports may include information and education, skills training, coping strategy enhancement and access to talking therapies. This synthesized finding was derived out of nine findings which were merged into two categories (Table 4).

Category 3.1: Family needs and supports

Families would often provide examples of the emotional and practical input that was givenunconditionally; "no matter what." However, the statutory supports available to families remained limited and this often led to increased anxiety, frustration and stress for family members.[48,52,55,59]

"Gender has been ignored in the treatment and support needs of people with SMI. Many family members, particularly mothers, had made significant sacrifices necessary to enable the provision of psychosocial supports to allow the person with SMI to lead a more satisfying, fulfilling and meaningful life. One mother felt services were failing her and her son stating that 'they are abusing my child emotionally. They planned on taking my kid away immediately after he was born without even discussing it with me'."[52(p.148)W]

Table 4. Synthesized finding 3 – Family and partner involvement

Findings	Categories	Synthesized finding
Family as sources of strength (U)	Family needs and supports	***Family and partner involvement*** *Family and partner involvement is significant in terms of supporting the individual with SMI. The psychosocial needs of families are often unrecognised and the necessary supports are usually lacking.*
Needs of mothers (C)		
The formation of relationships is challenging but important for most (U)	The experiences and needs of partners	
Difficulty accepting diagnosis (C)		
Emotional impact of SMI on spouses (U)		
SMI can lead to insecurities about family planning (U)		
Self-sacrifice (C)		
Caregiver burden (U)		
Personal evolution (C)		

"Mental health-related stigma was an obstacle to maintaining custody of children. Other issues included emotional abuse within the relationships, sexual abuse, locating information and supports around contraception, pregnancy and sexually transmitted infections." [51,52,62,63]

Category 3.2: The experiences and needs of partners

People with SMI can face challenges in the forming and maintaining relationships. However, people are willing and able to talk about intimacy experiences. There are higher rates of divorce and separation issues in people with SMI, two to three times more than in the general population.[48,53,55,60,61,63] The risk of suicide can be as high as 20%.[41] The formation and maintenance of intimate relationships was important to many participants and revealed in the studies included in this review.[52,62] People were able and willing to articulate their experiences, the strengths and the challenges they face and how they might cope with these. Research has shown the negative impact that SMI can have upon partners and potential distress and the strain on interpersonal and intimate relationships.[55]

"Spouses would try to 'stay on top' of possible relapses of their partner's condition. Some study participants described feeling 'resentful' and of being 'unappreciated' in the work they were doing. Difficulties were compounded if the partner with SMI had trouble accepting their diagnosis and treatments."[55(p.195)]

"Stigma associated with SMI was also an issue for some participants where people thought they may be unfairly judged and forced to only choose potential partners who had similar mental health experiences."[53(p.245)]

"One partner described the impact SMI can have upon their relationship...'I ask myself, is she escalating? I watch her carefully for a day or two until I find she's not, then I can relax again. How can you live with this? It is so scary'."[55(p.196)]

"Although many interpersonal challenges existed, there were some positive outcomes for the relationship. Partners noted that the bipolar disorder experiences strengthened their relationship by deepening their bond and increasing trust. For the spouses, trust had to do with the belief that their partner would remain stable and comply with treatment so that they would not have a recurrent episode. There was also evidence of increased empathy and compassion towards others through experiencing the challenges associated with the mental health condition. Spouses talked about developing resilience through facing adversity and appreciating new perspectives on 'what is important in life'."[55(p.194)]

Discussion

The purpose of conducting this systematic review was to synthesize the best available evidence regarding people with SMI and their sexuality and intimacy experiences. A comprehensive search of the literature produced 21 studies that met the inclusion criteria and addressed the aim and objectives of the systematic review. There was some international representation, with most studies conducted in the UK, USA and Australia that produced qualitative descriptive data through various appropriate designs. Following the appraisal process, all studies were included in the review as they addressed the review objectives highlighting sexual and relationship experiences, issues and concerns. The voice of participants and their views and opinions were imperative in informing and shaping the review.

The 21 included studies resulted in 83 unequivocal or credible findings that were grouped into 10 categories. Finally, three synthesized findings emerged from the data: 1) The complexity of individual sexual experiences, 2) Clinical constructs of sexuality, and 3) Family and partner involvement. The expression of sexuality and the drive to form fulfilling intimate relationships is a fundamental part of being human.[66] In terms of SMI and psychosocial aspects of recovery, holistic assessments of needs should include intimate relationships and address individual desires and wishes around forming and maintaining meaningful relationships.[67] However, challenges remain, as evidenced through this systematic review of the available literature.

Synthesized finding 1

The complexity of individualized experiences in relation to sexuality was a significant finding in relation to individuals with a diagnosis of SMI. When provided with an opportunity to express their thoughts on this topic, many individuals documented the stigma experiences

held both internally, in the formof self-stigma, and externally, through interactions with people in their communities. These experiences can present barriers and inhibit people from forming intimate or meaningful relationships.[68-70] People outside of heteronormative relationships can experience a double stigma that can often lead to an even heavier burden.[71] Given the already difficult experience of living with SMI, it is important for mental health practitioners to be aware of the impact of these stigma experiences on the individual and not to perpetuate them through their own internalised stigmatizing behaviours.

Synthesized finding 2

The question of sexual vulnerability and sexual coercion in the SMI group was identified in some of the reviewed studies.[22,47,51,56] These phenomena can take different forms and may be experienced in different contexts. For some, the identified events pose a lifelong barrier to their expression of sexuality. However, it is important to be aware that disclosures and perceptions of sexual experiences may be altered due to the person's state of mind.[71] In psychosis, sexuality may be experienced differently, which makes it important to listen carefully and for practitioners to ensure that they do not dismiss unclear or ambiguous expressions as purely psychotic or "delusional" experiences.[73] Potential barriers to the expression of sexuality for patients may be experienced because caregivers rarely enquire about sexuality and intimacy issues proactively. Therefore, important vulnerability and sometimes challenging issues remain hidden, which can lead to sexual risks. Issues of autonomy and responsibility can add complexity to the topic.[74] One of the most important outcomes is that several studies have shown people with serious mental health problems are willing and able to talk about sexuality and intimacy and that doing so is often constructive, informative and safe.[22,54,59-64]

Synthesized finding 3

Having fulfilling and satisfying sexual and relationship experiences is a fundamental human right that can enhance an individual's quality of life.[7-11] However, this review has indicated that, despite people with SMI possessing the will and desire to be intimate, potential obstacles exist.[35,36] The SMI experience can have a profound effect on family members, including partners and spouses.[60-62] Challenges remain around the supports and services available to significant people in the person's life. Being aware of the potential stresses and challenges to the relationship and involving partners in the treatment may help to promote intimacy and recovery.[1-4]

Strengths and limitations of the review

This review examined sexuality and intimacy issues for people who experience SMI. The review offers deep insights into the unique experiences of people with SMI and gives significant perspectives on the needs of individuals, partners and spouses. Because of the non-experimental design and explorative nature of most included studies in this review, the

exact nature of the relationship between the different concepts such as SMI and sexual expression cannot be established. Although this review offers extensive insights into issues regarding intimacy and sexual expression, further research is needed to explore the found topics in depth. Another opportunity exists to conduct research in different cultural contexts including non-English speaking countries.

Conclusions

This reviewhas identified a range of key concerns that exist in relation to the experiences and needs of people who have SMI regarding their sexual and relationship requirements. The findings fromthis review highlight areas requiring attention in terms of practice, education and future research developments.

Recommendations for practice

On the strength of the ConQual Summary of Findings, it is recommended and encouraged that policy makers in mental health settings make their policies on sexuality issues clear and explicit. These considerations should include issues such as privacy during admission; assessment of sexual risks, such as STIs or unwanted pregnancies; and the use of contraception.

These formalisations offer the preconditions to translate these policy implications to direct patient care:

1. Practitioners need to engage with people and routinely enquire about sexuality and intimacy issues. There should be an increased dialogue around “sensitive” issues. This may require them reflecting upon their own attitudes and beliefs around the topic. (Grade A)
2. Appropriate and adequate assessment and care planning should include sexuality and intimacy issues. (Grade A)
3. There needs to be a greater awareness and responsiveness of practitioners around sexual abuse issues, sexual risks and vulnerabilities. (Grade A)
4. There needs to be more availability of and access to talking therapies such as individual and couple counselling and psychosexual therapy. (Grade A)
5. There should be time dedicated to exploring thoughts, emotions and meaning around sexuality experiences including the implications of stigma, confidence and self-image. (Grade A)
6. Policies related to sexuality issues in healthcare settings need to be examined and reviewed. (Grade A)

Recommendations for education

Education and training have emerged as key concerns in developing knowledge and skills necessary to address issues in relation to the expression of intimacy and sexuality.

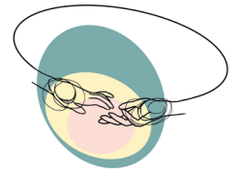
Specifically, these relate to psychosocial experiences, such as the impact of loss and isolation, discrimination and stigma, oppression and social exclusion. Educational input should highlight the sensitivity in dealing with specific issues, such as transgender experiences or autoerotic asphyxiation. The review has demonstrated that practitioners often have had limited previous educational and practice development opportunities.

I) The development of practitioner knowledge and skills that relate to the key issues highlighted in this review.
II) Inclusion of sexuality and intimacy issues within the undergraduate curriculum for all health and social care students.
III) Provision of sexual health education around family planning, contraception and safe sex strategies should be available for all stakeholders.
IV) Training for caregivers in asking about sexuality and (sexual) trauma and sexual health counselling.
V) There should be opportunities for skills training and educational sessions in the formation and maintenance of intimate relationships.
VI) Continuing professional development opportunities to include innovative teaching and learning approaches in order to build and develop confidence in addressing key sexuality issues and concerns.

Recommendations for research

This review highlights the need for a detailed focus on sexuality and intimacy issues among people with SMI in order to better understand their needs, effective supports, interventions and service responses. There is a significant opportunity to shift away from purely exploring sexuality and intimacy issues among people with SMI through the lens of perceived risk and vulnerability, towards developing and evaluating interventions that target the identified barriers and help people with SMI to fulfil their unmet needs. Due to the significant health and social care needs of people who experience SMI, there is an increased opportunity to research the effectiveness of supports, treatments and psychosocial interventions. Future research therefore, should address the following concerns:

I) Policy evaluation
II) Education and training evaluation
III) Sexuality and quality of life studies
IV) Intervention studies
V) Multi-centre national and international studies
VI) Service user and family involvement.



References

1. Australian Government. National Standards for Mental Health Services: National Mental Health Strategy Canberra: Commonwealth of Australia; 2010.
2. Department of Health and Children. A Vision for Change: Report of the Expert Group on Mental Health Policy. Dublin: Stationery Office; 2006.
3. Government of Scotland. Rights, Relationships and Recovery: The Report of the National Review of Mental Health Nursing in Scotland Edinburgh: Scottish Executive; 2006.
4. Mental Health Commission. A Recovery Approach within the Irish Mental Health Services. A Framework for Development. Dublin: Mental Health Commission; 2008.
5. Center for Behavioral Health Statistics and Quality. Key substance use and mental health indicators in the United States: Results from the 2015 National Survey on Drug Use and Health (HHS Publication No. SMA 16-4984, NSDUH Series H-51), 2016.
6. World Health Organization. Defining sexual health: Report of a technical consultation on sexual health, 28-31 January 2002 Geneva: World Health Organization; 2006.
7. McCann E. The expression of sexuality in people with psychosis: Breaking the taboos. *J Adv Nurs 2000;32*(1): 132–8.
8. Quinn C, Happell B. Consumer sexual relationships in a Forensic mental health hospital: Perceptions of nurses and consumers. *Int J Ment Health Nurs 2014;24*(2):121–9.
9. McCann E. The sexual and relationship needs of people who experience psychosis: quantitative findings of a UK study. *J Psychiatr Ment Health Nurs 2010;17*:295–303.
10. Gascoyne S, Hughes E, McCann E, Quinn C. The sexual health and relationship needs of people with severe mental illness. *J Psychiatr Ment Health Nurs 2016;23*(5):338–43.
11. de Jager J, McCann E. Psychosis as a barrier to the expression of sexuality and intimacy: An environmental risk? *Schizophr Bull 2017;43*(2):236–9.
12. McCann E, Sharek D. A survey of lesbian, gay, bisexual and transgender people's experiences of mental health services in Ireland. *Int J Ment Health Nurs 2014;23*(2):118–27.
13. Lavelle E. A Recovery Approach within the Irish Mental Health Services: A Framework of Development Dublin: Mental Health Commission; 2012.
14. Wilken JP. Understanding recovery from psychosis. A growing body of knowledge. *Journal of the Norwegian Psychological Association 2007;44*(5):658.
15. Frese FJ III, Knight EL, Saks E. Recovery from schizophrenia: With views of psychiatrists, psychologists, and others diagnosed with this disorder. *Schizophr Bull 2009;35*(2):370–80.
16. Davidson L, Drake RE, Schmutte T, Dinzeo T, Andres-Hyman R. Oil and water or oil and vinegar? Evidence-based medicine meets recovery. *Community Ment Health J 2009;45*(5):323–32.
17. Davidson L, Roe D. Recovery from versus recovery in serious mental illness: One strategy for lessening confusion plaguing recovery. *J Ment Health 2007;16*(4):459–70.
18. Slade M, Leese M, Cahill S, Thornicroft G, Kuipers E. Patientrated mental health needs and quality of life improvement. *BJPsych 2005;187*(3):256–61
19. Mulhall J, King R, Glina S, Hvidsten K. Importance of and satisfaction with sex among men and women worldwide: Results of the global better sex survey. *J Sex Med 2008;5*(4):788–95.
20. Kelly DL, Conley RR. Sexuality and schizophrenia: A review. *Schizophr Bull 2004;30*(4):767.
21. Werner S. Needs assessment of individuals with serious mental illness: Can it help in promoting recovery? *Community Ment Health J 2012;48*(5):568–73.
22. de Jager J, Cirakoglu B, Nugter A, van Os J. Intimacy and its barriers: A qualitative exploration of intimacy and related struggles among people diagnosed with psychosis. *Psychosis 2017;9*(4):301–9.
23. Drunen PR, van, Bijzitter GCR, Geerts E, van Beusekom IA. Sexual problems in psychiatric patients, a neglected subject. *Monthly Mental Health 2009;11*:998–1007.
24. Osvath P, Fekete S, Vörös V, Vitrai J. Sexual dysfunction among patients treated with antidepressants—a Hungarian retrospective study. *Eur Psychiatry 2003;18*(8):412–4.
25. Kotler M, Cohen H, Aizenberg D, Matar M, Loewenthal U, Kaplan Z, et al. Sexual dysfunction in male posttraumatic stress disorder patients. *Psychother Psychosom 2000;69*(6): 309–15.
26. Corretti G, Pierucci S, De Scisciolo M, Nisita C. Comorbidity between social phobia and premature ejaculation: Study on 242 males affected by sexual disorders. *Sex Marital Ther 2006;32*(2):183–7.
27. Macdonald S, Halliday J, MacEwan T, Sharkey V, Farrington S, Wall S, et al. Nithsdale Schizophrenia Surveys 24: sexual dysfunction: Case–control study. *BJPsych 2003;182*(1): 50–6.
28. Östman M. Low satisfaction with sex life among people with severe mental illness living in a community. *Psychiatry Res 2014;216*(3):340–5.
29. de Boer MK, Castelein S, Wiersma D, Schoevers RA, Knegtering H. The facts about sexual (dys) function in schizophrenia: an overview of clinically relevant findings. *Schizophr Bull 2015;41*(3):674–86.
30. Huguelet P, Mohr S, Miserez C, Castellano P, Lutz C, Boucherie M, et al. An exploration of sexual desire and sexual activities of women with psychosis. *Community Ment Health J 2015;51*(2):229–38.
31. Perry BL, Wright ER. The sexual partnerships of people with serious mental illness. *J Sex Res 2006;43*(2):174–81.
32. Tandon R, Nasrallah HA, Keshavan MS. Schizophrenia: Just the Facts 4. Clinical features and conceptualization. *Schizophr Res 2009;110*(1):1–23.
33. Thornicroft G, Tansella M, Becker T, Knapp M, Leese M, Schene A, et al. The personal impact of schizophrenia in Europe. *Schizophr Res 2004;69*(2):125–32.

34. Agerbo E, Byrne M, Eaton WW, Mortensen PB. Marital and labor market status in the long run in schizophrenia. *Arch Gen Psychiatry 2004;61*(1):28–33.
35. Hansson L. Determinants of quality of life in people with severe mental illness. *Acta Psychiatr Scand 2006;113*(s429):46–50.
36. Nyer M, Kasckow J, Fellows I, Lawrence EC, Golshan S, Solorzano E, et al. The relationship of marital status and clinical characteristics in middle-aged and older patients with schizophrenia and depressive symptoms. *Ann Clin Psychiatry 2010;22*(3):172–9.
37. Olfson M, Uttaro T, Carson WH, Tafesse E. Male sexual dysfunction and quality of life in schizophrenia. *J Clin Psychiatry 2005;66*(3):331–8.
38. McCann E, Donohue G, de Jager J, van Os J, Nugter A, Stewart J, et al. Sexuality and intimacy among people with serious mental illness in hospital and community settings: a qualitative systematic review protocol. *JBI Database System Rev Implement Rep 2018;16*(2):324–7.
39. DSM-V American Psychiatric Association. Diagnostic and statistical manual of mental disorders. Arlington: American Psychiatric Publishing; 2013.
40. World Health Organization. The ICD-10 classification of mental and behavioural disorders: clinical descriptions and diagnostic guidelines World Health Organization; 1992
41. Repper J, Perkins R. Social Inclusion and Recovery. A Model for Mental Health Practice. London: Bailliere Tindall; 2003.
42. Moher D, Shamseer L, Clarke M, Ghersi D, Liberati A, Petticrew M, et al. Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) 2015 statement. *Syst Rev 2015;4*(1):1.
43. Covidence [Computer program]. Version accessed 10 July 2017. Melbourne, Australia: Veritas Health Innovation. Available at www.covidence.org.
44. Lockwood C, Munn Z, Porritt K. Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. *Int J Evid Based Healthc 2015;13*(3):179–87.
45. Lockwood C, Porrit K, Munn Z, Rittenmeyer L, Salmond S, Bjerrum M, et al. Chapter 2: Systematic reviews of qualitative evidence. In: Aromataris E, Munn Z (Editors). Joanna Briggs Institute Reviewer's Manual. The Joanna Briggs Institute, 2017. Available from https://reviewersmanual.joannabriggs.org/.
46. Munn Z, Porritt K, Lockwood C, Aromataris E, Pearson A. Establishing confidence in the output of qualitative research synthesis: The ConQual approach. *BMC Med Res Methodol 2014;14*(108):2–7.
47. Ashmore T, Spangaro J, McNamara L. 'I was raped by Santa Claus': Responding to disclosures of sexual assault in mental health inpatient facilities. *Int J Ment Health Nurs 2015;24*(2):139–48.
48. Baker AE, Procter NG. 'You just lose the people you know': Relationship loss and mental illness. *Arch Psychiatr Nurs 2015;29*(2):96–101.

49. Ben-David S, Birnbaum ML, Eilenberg ME, DeVylder JE, Gill KE, Schienle J, et al. The subjective experience of youths at clinically high risk of psychosis: A qualitative study. *Psychiatr Serv 2014;65*(12):1499–501.
50. Brown SD, Reavey P, Kanyeredzi A, Batty R. Transformations of self and sexuality: Psychologically modified experiences in the context of forensic mental health. *Health 2014;18*(3):240–60.
51. Chandra PS, Deepthivarma S, Carey MP, Carey KB, Shalinianant MP. A cry from the darkness: women with severe mental illness in India reveal their experiences with sexual coercion. *Psychiatry 2003;66*(4):323–34.
52. Cogan JC. The consumer as expert: Women with serious mental illness and their relationship-based needs. *Psychiatr Rehabil J 1998;22*(2):142.
53. Davison J, Huntington A. "Out of sight": Sexuality and women with enduring mental illness. *Int J Ment Health Nurs 2010;19*(4):240–9.
54. Garrett NR. Treatment of a transgender client with schizophrenia in a public psychiatric milieu: A case study by a student therapist. *J Gay Lesbian Ment Health 2004;8*(3–4):127–41.
55. Granek L, Danan D, Bersudsky Y, Osher Y. Living with bipolar disorder: the impact on patients, spouses, and their marital relationship. *Bipolar Disord 2016;18*(2):192–9.
56. Greenall PV, Jellicoe-Jones L. Themes and risk of sexual violence among the mentally ill: Implications for understanding and treatment. *Sex Relation Ther 2007;22*(3):323–37.
57. Kidd SA, Veltman A, Gately C, Chan KJ, Cohen JN. Lesbian, gay, and transgender persons with severe mental illness: Negotiating wellness in the context of multiple sources of stigma. *Am J Psychiatr Rehabil 2011;14*(1):13–39.
58. Martz D. Behavioral treatment for a female engaging in autoerotic asphyxiation. *Clin Case Stud 2003;2*(3):236–42.
59. McCann E. The expression of sexuality in people with psychosis: breaking the taboos. *J Adv Nurs 2000;32*(1):132–8.
60. McCann E. Investigating mental health service user views regarding sexual and relationship needs. *J Psychiatr Ment Health Nurs 2010;17*(3):251–9.
61. McCann TV, Clark E. Embodiment of severe and enduring mental illness: Finding meaning in schizophrenia. *Issues Ment Health Nurs 2004;25*(8):783–98.
62. Östman M, Björkman AC. Schizophrenia and relationships: the effect of mental illness on sexuality. *Clin Schizophr Relat Psychoses 2013;7*(1):20–4.
63. Quinn C, Happell B. Exploring sexual risks in a forensic mental health hospital: Perspectives from patients and nurses. *Issues Ment Health Nurs 2015;36*(9):669–77.
64. Redmond C, Larkin M, Harrop C. The personal meaning of romantic relationships for young people with psychosis. *Clin Child Psychol 2010;15*(2):151–70.
65. Škodlar B,Žunter Nagy M. Sexuality and psychosis. *Psychiatr Danub 2009;21*(1):111–6.
66. Volman L, Landeen J. Uncovering the sexual self in people with schizophrenia. *J Psychiatr Ment Health Nurs 2007;14*(4):411–7.

67. Quinn C, Happell B. Talking about sexuality with consumers of mental health services. *Perspect Psychiatr Care 2013;49*(1):13–20.
68. Elkington KS, McKinnon K, Mann CG, Collins PY, Leu CS, Wainberg ML. Perceived mental illness stigma and HIV risk behaviors among adult psychiatric outpatients in Rio de Janeiro, Brazil. *Community Ment Health J 2010;46*(1): 56–64.
69. Incedere A, Küçük L. Sexual life and associated factors in psychiatric patients. *Sex Disabil 2017;35*(1):89–106.
70. Sarısoy G, Kaçar ÖF, Pazvantoğlu O, Korkmaz IZ, Öztürk A, Akkaya D, et al. Internalized stigma and intimate relations in bipolar and schizophrenic patients: a comparative study. *Compr Psychiatry 2013;54*(6):665–72.
71. Sansone RA, Sellbom M, Songer DA. A survey of same-sex sexual experiences among psychiatric inpatients with and without borderline personality symptomatology. *Prim Care Companion CNS Disord 2016;18*(2):22–36.
72. Bonfils KA, Firmin RL, Salyers MP, Wright ER. Sexuality and intimacy among people living with serious mental illnesses: Factors contributing to sexual activity. *Psychiatr Rehabil J 2015;38*(3):249.
73. de Boer MK, Castelein S, Wiersma D, Schoevers RA, Knegtering H. A systematic review of instruments to measure sexual functioning in patients using antipsychotics. *J Sex Res 2014;51*(4):383–9.
74. Pandor A, Kaltenthaler E, Higgins A, Lorimer K, Smith S, Wylie K, et al. Sexual health risk reduction interventions for people with severe mental illness: a systematic review. *BMC Public Health 2015;15*(1):138.

Appendix I: Search strategy

MEDLINE search strategy

Concept 1: Serious Mental Illness

MEDLINE: (MH “Personality Disorders+”) OR (MH “Schizophrenia Spectrum and Other Psychotic Disorders+”) OR (MH “Bipolar and Related Disorders+”) OR (MH “Schizophrenia+”) OR (MH “Psychotic Disorders+”)

Keywords: Schizophrenia OR Schizophrenic OR schizoaffective OR schizoid OR paranoidOR paranoia OR psychosis OR psychoses OR psychotic OR bi-polar OR bipolar OR manic OR mania OR manias OR “treatment resistant depression” OR Manic-Depressive OR “Manic Depressive” OR “Personality Disorder” OR “personality disorders” OR “serious mental illness”

Concept 2: Sexuality & Intimacy

MEDLINE: (MH ”Sexuality+“) OR (MH ”Sexual Behavior+“) OR (MH ”Paraphilic Disorders+“)

Keywords: sex_ OR sexual_ OR sexy_ OR sexuality_ OR ”Sexual Behavior“ OR ”Sexual Behaviour“ OR “Sexual Activities” OR “Sexual Activity” OR “Sex Behavior” OR “Sex Behaviour” OR “Oral Sex” OR “Sexual Orientation” OR “Sex Orientation” OR “Anal Sex” OR “sexual intercourse” OR coitus OR courtship OR masturbation OR intercourse OR intimacy OR intimate OR attraction OR attracted OR Bisexual_ OR Heterosexual_ OR Homosexual_ OR Transsexual_ OR Bi-sexual_ OR Hetero-sexual_ OR Homo-sexual_ OR Trans-sexual_ OR exhibitionism OR Fetishis_ OR Masochism_ OR “Sexual Masochism” OR Paedophil_ OR Pedophil_ OR Sadism OR Transvestism OR Voyeurism OR Paraphilias OR Paraphilia OR “Sex Deviations” OR “sex Deviation” or “deviant sex”

Concept 3: Experience

MEDLINE: keywords only

Keywords: experience OR experiences OR experienced OR view OR views OR viewpoint OR viewpoints OR perception OR perceptions OR perceive OR perceived OR attitude OR attitudes OR belief OR beliefs OR perspective OR perspectives OR opinion OR opinions OR concept OR concepts OR thought OR thoughts OR awareness OR value OR values

Concept 4: Study Type

MEDLINE: (MH ”Empirical Research“) OR (MH ”Grounded Theory“) OR (MH ”Qualitative Research+“) OR (MH ”Hermeneutics“) OR (MH ”Focus Groups“) OR (MH ”Anthropology, Cultural+“)

Keywords: “Empirical Research”OR“qualitative research”OR“Grounded Theory”ORHermeneuticsOR“focusgroups”OR“focusgroup”OR“observationalstudies”OR “observational study” OR “comparative study” OR ethnography OR phenomenology OR “action research” OR “feminist research” OR “narrative research” OR “narrative analysis” OR “descriptive study” OR “descriptive studies” OR “qualitative descriptive research” OR “exploratory study” OR “exploratory studies” OR “systematic review” OR “literature review” OR “qualitative study” OR “qualitative studies” OR “qualitative research design” OR “qualitative descriptive design” OR “qualitative research” OR “interpretative analysis” OR “case study” OR “case studies” OR survey OR “structured interview” OR “semi-structured interview” OR “unstructured interview” OR “open interview” OR “content analysis” OR “thematic analysis” OR “thematic coding” OR “open-ended interviews” OR “qualitative descriptive”

CINAHL search strategy

Concept 1: Serious Mental Illness

CINAHL: (MH ”Bipolar Disorder+“) OR (MH ”Schizophrenia+“) OR (MH ”Psychotic Disorders+“) OR (MH ”Personality Disorders+“)

Keywords: Schizophrenia OR Schizophrenic OR schizoaffective OR schizoid OR paranoidOR paranoia OR psychosis OR psychoses OR psychotic OR bi-polar OR bipolar OR manic OR mania OR manias OR “treatment resistant depression” OR Manic-Depressive OR “Manic Depressive” OR “Personality Disorder” OR “personality disorders” OR “serious mental illness”

Concept 2: Sexuality & Intimacy

CINAHL: (MH ”Psychosexual Disorders+“) OR (MH ”Sexuality+“) OR (MH ”Intimacy“)

Keywords: sex_ OR sexual_ OR sexy_ OR sexuality_ OR ”Sexual Behavior“ OR ”Sexual Behaviour“ OR “Sexual Activities” OR “Sexual Activity” OR “Sex Behavior” OR “Sex Behaviour” OR “Oral Sex” OR “Sexual Orientation” OR “Sex Orientation” OR “Anal Sex” OR “sexual intercourse” OR coitus OR courtship OR masturbation OR intercourse OR intimacy OR intimate OR attraction OR attracted OR Bisexual_ OR Heterosexual_ OR Homosexual_ OR Transsexual_ OR Bi-sexual_ OR Hetero-sexual_ OR Homo-sexual_ OR Trans-sexual_ OR exhibitionism OR Fetishis_ OR Masochism_ OR “Sexual Masochism” OR Paedophil_ OR Pedophil_ OR Sadism OR Transvestism OR Voyeurism OR Paraphilias OR Paraphilia OR “Sex Deviations” OR “sex Deviation” or “deviant sex”

Concept 3: Experience

CINAHL: keywords only

Keywords: experience OR experiences OR experienced OR view OR views OR viewpoint OR viewpoints OR perception OR perceptions OR perceive OR perceived OR attitude OR attitudes OR belief OR beliefs OR perspective OR perspectives OR opinion OR opinions OR concept OR concepts OR thought OR thoughts OR awareness OR value OR values

Concept 4: Study Type

CINAHL: (MH ”Focus Groups“) OR (MH ”Interviews+“) OR (MH ”Qualitative Studies+“) OR (MH ”Empirical Research“)

Keywords: “Empirical Research”OR“qualitative research”OR“Grounded Theory”ORHermeneuticsOR“focusgroups”OR“focusgroup”OR“observationalstudies”OR “observational study” OR “comparative study” OR ethnography OR phenomenology OR “action research” OR “feminist research” OR “narrative research” OR “narrative analysis” OR “descriptive study” OR “descriptive studies” OR “qualitative descriptive research” OR “exploratory study” OR “exploratory studies” OR “systematic review” OR “literature review” OR “qualitative study” OR “qualitative studies” OR “qualitative research design” OR “qualitative descriptive design” OR “qualitative research” OR “interpretative analysis” OR “case study” OR “case studies” OR survey OR “structured interview” OR “semi-structured interview” OR “unstructured interview” OR “open interview” OR “content analysis” OR “thematic analysis” OR “thematic coding” OR “open-ended interviews” OR “qualitative descriptive”

PsycINFO search strategy

Concept 1: Serious Mental Illness

PsycINFO: (DE ”Schizophrenia“) OR (DE ”Psychosis“) OR (DE ”Mania“) OR (DE ”Bipolar Disorder“) OR (DE ”Treatment Resistant Depression“) OR (DE ”Personality Disorders“)

Keywords: Schizophrenia OR Schizophrenic OR schizoaffective OR schizoid OR paranoidOR paranoia OR psychosis OR psychoses OR psychotic OR bi-polar OR bipolar OR manic OR mania OR manias OR “treatment resistant depression” OR Manic-Depressive OR “Manic Depressive” OR “Personality Disorder” OR “personality disorders” OR “serious mental illness”

Concept 2: Sexuality & Intimacy

PsycINFO: (DE ”Sexuality“ OR DE ”Intimacy“ OR DE ”Paraphilias“)

Keywords: sex_ OR sexual_ OR sexy_ OR sexuality_ OR ”Sexual Behavior“ OR ”Sexual Behaviour“ OR “Sexual Activities” OR “Sexual Activity” OR “Sex Behavior” OR “Sex Behaviour” OR “Oral Sex” OR “Sexual Orientation” OR “Sex Orientation” OR “Anal Sex” OR “sexual intercourse” OR coitus OR courtship OR masturbation OR intercourse OR intimacy OR intimate OR attraction OR attracted OR Bisexual_ OR Heterosexual_ OR Homosexual_ OR Transsexual_ OR Bi-sexual_ OR Hetero-sexual_ OR Homo-sexual_ OR Trans-sexual_ OR exhibitionism OR Fetishis_ OR Masochism_ OR “Sexual Masochism” OR Paedophil_ OR Pedophil_ OR Sadism OR Transvestism OR Voyeurism OR Paraphilias OR Paraphilia OR “Sex Deviations” OR “sex Deviation” or “deviant sex”

Concept 3: Experience

PsycINFO: keywords only

Keywords: experience OR experiences OR experienced OR view OR views OR viewpoint OR viewpoints OR perception OR perceptions OR perceive OR perceived OR attitude OR attitudes OR belief OR beliefs OR perspective OR perspectives OR opinion OR opinions OR concept OR concepts OR thought OR thoughts OR awareness OR value OR values

Concept 4: Study Type

PsycINFO: (DE ”Qualitative Research“ OR DE ”Empirical Methods“ OR DE ”Grounded Theory“ OR DE ”Interviews“ OR DE ”Observation Methods“) OR (DE ”Action Research“)

Keywords: “Empirical Research”OR“qualitative research”OR“Grounded Theory”ORHermeneuticsOR“focusgroups”OR“focusgroup”OR“observationalstudies”OR “observational study” OR “comparative study” OR ethnography OR phenomenology OR “action research” OR “feminist research” OR “narrative research” OR “narrative analysis” OR “descriptive study” OR “descriptive studies” OR “qualitative descriptive research” OR “exploratory study” OR “exploratory studies” OR “systematic review” OR “literature review” OR “qualitative study” OR “qualitative studies” OR “qualitative research design” OR “qualitative descriptive design” OR “qualitative research” OR “interpretative analysis” OR “case study” OR “case studies” OR survey OR “structured interview” OR “semi-structured interview” OR “unstructured interview” OR “open interview” OR “content analysis” OR “thematic analysis” OR “thematic coding” OR “open-ended interviews” OR “qualitative descriptive”

Embase search strategy

Concept 1: Serious Mental Illness

Emtree: ’schizophrenia’/exp OR ’psychosis’/exp OR ’personality disorder’/exp OR ’mania’/exp

Keywords: Schizophrenia OR Schizophrenic OR schizoaffective OR schizoid OR paranoidOR paranoia OR psychosis OR psychoses OR psychotic OR bi-polar OR bipolar OR manic OR mania OR manias OR “treatment resistant depression” OR Manic-Depressive OR “Manic Depressive” OR “Personality Disorder” OR “personality disorders” OR “serious mental illness”

Concept 2: Sexuality & Intimacy

Emtree: ’sexuality’/exp OR ’sex’/exp OR ’intimacy’/exp OR ’sexual behavior’/exp

Keywords: sex_ OR sexual_ OR sexy_ OR sexuality_ OR ”Sexual Behavior“ OR ”Sexual Behaviour“ OR “Sexual Activities” OR “Sexual Activity” OR “Sex Behavior” OR “Sex Behaviour” OR “Oral Sex” OR “Sexual Orientation” OR “Sex Orientation” OR “Anal Sex” OR “sexual intercourse” OR coitus OR courtship OR masturbation OR intercourse OR intimacy OR intimate OR attraction OR attracted OR Bisexual_ OR Heterosexual_ OR Homosexual_ OR Transsexual_ OR Bi-sexual_ OR Hetero-sexual_ OR Homo-sexual_ OR Trans-sexual_ OR exhibitionism OR Fetishis_ OR Masochism_ OR “Sexual Masochism” OR Paedophil_ OR Pedophil_ OR Sadism OR Transvestism OR Voyeurism OR Paraphilias OR Paraphilia OR “Sex Deviations” OR “sex Deviation” or “deviant sex”

Concept 3: Experience

Emtree: keywords only

Keywords: experience OR experiences OR experienced OR view OR views OR viewpoint OR viewpoints OR perception OR perceptions OR perceive OR perceived OR attitude OR attitudes OR belief OR beliefs OR perspective OR perspectives OR opinion OR opinions OR concept OR concepts OR thought OR thoughts OR awareness OR value OR values

Concept 4: Study Type

Emtree: ’qualitative research’/exp OR ’hermeneutics’/exp OR ’interview’/exp

Keywords: “Empirical Research”OR“qualitative research”OR“Grounded Theory”ORHermeneuticsOR“focusgroups”OR“focusgroup”OR“observationalstudies”OR “observational study” OR “comparative study” OR ethnography OR phenomenology OR “action research” OR “feminist research” OR “narrative research” OR “narrative analysis” OR “descriptive study” OR “descriptive studies” OR “qualitative descriptive research” OR “exploratory study” OR “exploratory studies” OR “systematic review” OR “literature review” OR “qualitative study” OR “qualitative studies” OR “qualitative research design” OR “qualitative descriptive design” OR “qualitative research” OR “interpretative analysis” OR “case study” OR “case studies” OR survey OR “structured interview” OR “semi-structured

interview” OR “unstructured interview” OR “open interview” OR “content analysis” OR “thematic analysis” OR “thematic coding” OR “open-ended interviews” OR “qualitative descriptive”

Web of Science search strategy (keyword only searches)

Concept 1: Serious Mental Illness

Keywords: Schizophrenia OR Schizophrenic OR schizoaffective OR schizoid OR paranoidOR paranoia OR psychosis OR psychoses OR psychotic OR bi-polar OR bipolar OR manic OR mania OR manias OR “treatment resistant depression” OR Manic-Depressive OR “Manic Depressive” OR “Personality Disorder” OR “personality disorders” OR “serious mental illness”

Concept 2: Sexuality & Intimacy

Keywords: sex_ OR sexual_ OR sexy_ OR sexuality_ OR ”Sexual Behavior“ OR ”Sexual Behaviour” OR “Sexual Activities” OR “Sexual Activity” OR “Sex Behavior” OR “Sex Behaviour” OR “Oral Sex” OR “Sexual Orientation” OR “Sex Orientation” OR “Anal Sex” OR “sexual intercourse” OR coitus OR courtship OR masturbation OR intercourse OR intimacy OR intimate OR attraction OR attracted OR Bisexual_ OR Heterosexual_ OR Homosexual_ OR Transsexual_ OR Bi-sexual_ OR Hetero-sexual_ OR Homo-sexual_ OR Trans-sexual_ OR exhibitionism OR Fetishis_ OR Masochism_ OR “Sexual Masochism” OR Paedophil_ OR Pedophil_ OR Sadism OR Transvestism OR Voyeurism OR Paraphilias OR Paraphilia OR “Sex Deviations” OR “sex Deviation” or “deviant sex”

Concept 3: Experience

Keywords: experience OR experiences OR experienced OR view OR views OR viewpoint OR viewpoints OR perception OR perceptions OR perceive OR perceived OR attitude OR attitudes OR belief OR beliefs OR perspective OR perspectives OR opinion OR opinions OR concept OR concepts OR thought OR thoughts OR awareness OR value OR values

Concept 4: Study Type

Keywords: “Empirical Research”OR“qualitative research”OR“Grounded Theory”ORHermeneuticsOR“focusgroups”OR“focusgroup”OR“observationalstudies”OR “observational study” OR “comparative study” OR ethnography OR phenomenology OR “action research” OR “feminist research” OR “narrative research” OR “narrative analysis” OR “descriptive study” OR “descriptive studies” OR “qualitative descriptive research” OR “exploratory study” OR “exploratory studies” OR “systematic review” OR “literature review” OR “qualitative study” OR “qualitative studies” OR “qualitative research design” OR “qualitative descriptive design” OR “qualitative research” OR “interpretative analysis” OR “case study” OR “case studies” OR survey OR “structured interview” OR “semi-structured

interview” OR “unstructured interview” OR “open interview” OR “content analysis” OR “thematic analysis” OR “thematic coding” OR “open-ended interviews” OR “qualitative descriptive”

Appendix II: Characteristics of included studies

Reference and country	Phenomena of interest	Participants	Methods	Method-ology	Main results
Ashmore *et al.* (2015)[47] Australia	Examine incidences of sexual assault on inpatient units	People with SMI (n = 5)	Observation and case notes Case study analysis	Case study	Model for disclosure were provided. Case studies demonstrating different disclosure scenarios. Therapeutic or investigative responses were given. The importance of effective communication and safety in responding to distress is elucidated. There needs to be more rigorous assessment and care planning. Review of policies required. Service capacity building and staff education and support discussed.
Baker and Proctor (2015)[48] Australia	Examine relationships, loss and mental illness	People with SMI (n = 16): female (n = 11), male (n = 5)	Semi structured interviews Thematic analysis	Participatory action research	Lost relationships were significant and impacted upon a person's illness trajectory. Participants viewed these losses as contributing to the onset of their illness including the loss of intimate relationships (partners, family, children or friends). The challenges of forming and maintaining intimate relationships are discussed. Practitioners need to be aware of the relevant factors that impact upon adequate and responsive care and supports.
Ben-David *et al.* (2014)[49] USA	Explore the experiences of at-risk youths, ethnically diverse males and females who were participants in a prodromal research program	Youth with SMI (n = 24): male (n-12), female (n = 12). Aged 16–27 years	Individual interviews Phenomenol-ogical analysis	Phenomen-ology	Emergent themes were largely different for males and females. Males described alienation and despair, feeling broken, and a fear of going "crazy." They desired relationships but instead they were alone, escaping into fantasy. They had a vague hopefulness that things might improve in the future, but no real plan for going forward. By contrast, the females described being in "the thick of things", managing relationships and building careers, while dealing with the sadness of ill family members and past trauma.
Brown *et al.* (2014)[50] UK	Examine the expression of sexuality in forensic mental health settings	Forensic mental health inpatients with SMI (n = 20): male (n = 15), female (n = 5). Aged 20–55 years	Semi structured interviews Thematic analysis	Qualitative description	Personal and sexual relationships were seen as problematic. The study revealed a transformation of people and their sexual identity. The emergent themes included: exclusion, territorialisation (strict regimes), and amputation (disconnection).
Chandra *et al.* (2003)[51] India	Explore sexual coercion in women with SMI on a mental health unit	Women with SMI (n = 146) screened for sexual coersion (n = 50)	Semi structured interviews Content analysis	Qualitative description	A total of 48% of participants reported their spouse as the perpetrator; 26% friend; and 20% uncle or cousin. Most coercion took place in the woman's home. Significantly, 60% had not told anyone and felt fearful, anxious and vulnerable. Their experiences remain invisible, hidden and unacknowledged. Further research is needed around vulnerability factors, help-seeking behaviors and supports.
Cogan (1998)[52] USA	Identify intimate relationship needs for women with SMI	Women with SMI (n = 25). Aged 18–65 years	Structured interviews Thematic analysis	Qualitative description	A majority of participants (80%) had emotional abuse needs, 56–68% had sexual abuse issues, 60% had sexual health needs (STIs, contraception, family planning). A significant number (77%) of mothers had child custody concerns. Stigma was an obstacle to keeping children. Staff were often reluctant to deal with sexual abuse issues.

(*Continued*)

Reference and country	Phenomena of interest	Participants	Methods	Method-ology	Main results
Davison and Huntington (2010)[53] New Zealand	Explore the sexuality experiences of women with SMI	Women with SMI (n = 8)	Individual interviews and focus group Thematic analysis	Qualitative description	Sexuality was seen as an important part of identity. There were challenges to expressing sexuality where participants were seen as "other" and invisible or hidden. Sexuality perceived as fundamental to care, supports and recovery. It is necessary to create cultures of support towards sexual expression in clinical practice. Sexuality is often controlled and influenced by systems and organisations such as the biomedicine, and psychiatry and societal responses that include stigma and heteronormativity.
de Jager *et al.* (2017)[22] Netherlands	Explore intimacy experiences among people with psychosis	People with diagnosis of psychosis (n = 28)	Semi structured interviews Constant comparison analysis	Grounded theory	Five factors emerged that impacted upon intimate relationships that were: medication side-effects, illness symptoms, stigma, sexual abuse and social skills. Health practitioners need to effectively engage with people around sexuality issues in order to establish pertinent psychosocial needs and to provide necessary interventions and supports.
Garrett (2004)[54] USA	Describe the treatment experiences of a transgender client with schizophrenia	MTF trans person aged 48 years diagnosed with schizophrenia	Observation, direct patient-therapist interactions Case study analysis	Case study	An individual case presentation that addresses the role of gender identity in the clinical treatment of a person identifying as transgender in provided. The main issues were around appropriate assessment and treatment opportunities in mental health settings. Many LGBT people may be resistant to "coming out" for fear of rejection, abandonment and being viewed as sexually deviant, which can have a detrimental effect on people accessing and using relevant support services.
Granek *et al.* (2016)[55] Israel	Explore the impact of bipolar disorder on individuals, spouses and intimate relationships	People with a diagnosis of bipolar disorder (n = 11). Spouses (n = 10)	Individual interviews Constant comparison analysis	Grounded theory	The impact of bipolar disorder on spouses included self-sacrifice, caregiving burden, the emotional impact and related challenges. The experiences of patients related to emotional issues, self-care responsibilities, and social struggles. The impact on the relationship included volatility, ambiguity and family planning issues. Given the high rates of divorce and relationship problems, relevant healthcare professionals can provide practical and emotional support to patients and spouses both individually and as couples.
Greenall and Jellicoe-Jones (2007)[56] UK	Explore the factors other than mental disorder relevant to sexual violence in mentally ill sex offenders	Men with a history of sexual offences and a diagnosis of schizophrenia (n = 11). Aged 23–72 years.	Case notes Content analysis	Qualitative description	Troubled childhoods, abuse in the home, unemployment issues and mental health problems were relevant factors in sexual violence. Sexual violence was driven by anger, psychosis, sexual disinhibition and paedophilia. Medication was used as the main treatment. There is a need to consider a range of psychosocial interventions in the treatment of sex offenders.
Kidd *et al.* (2011)[57] Canada	Examine LGBT people's experiences of stigma and connectedness	People with SMI (n = 11): lesbian (n = 6), gay men (n = 3), transwomen (n = 2)	Individual interviews Constant comparison analysis	Grounded theory	The study revealed the interactions between stigma and sexual and gender identity and the challenges people endure in mental health settings. Individual experiences of connection and community had positive effects on wellness and resilience. Mental health practitioners need access to knowledge and skills training to provide appropriate and responsive supports and care to this group.

(*Continued*)

Reference and country	Phenomena of interest	Participants	Methods	Method-ology	Main results
Martz (2003)[58] USA	Examine the treatment of a patient engaging in auto-asphyxiation	College student aged 22 years with SMI	Observation, direct patient-therapist interactions Case study analysis	Case study	The autoerotic asphyxiation was treated with the use of cognitive behavioural therapy. The study suggests that the described behavior succumbs to behavioral contingencies similar to any "normal" sexual behavior. Use of exposure techniques can be used to extinguish the power of such a taboo and forbidden behavior so as to render it impotent.
McCann (2000)[59] UK	Explore past and present sexual and relationship experiences; hopes for the future	Inpatients diagnosed with schizophrenia (n = 15): male (n = 7), female (n = 4)	Semi-structured interviews Content analysis	Qualitative description	The patients appeared to respond well to the interviews. Many seemed pleased to be asked about concerns regarding something as fundamental as sex and relationship issues. A significant number (eight) had no sexual relations at the present time. Just under half the respondents reported that they had enjoyed sexual relations before hospitalization. More than half reported having strong sexual feelings before admission to hospital. Just under half said they had sexual feelings at the present time. The reasons sexual activity stopped were: illness of self; lost interest myself; lack of opportunity; no privacy; or in hospital. A majority would like more opportunities to meet people and develop social skills away from the institution.
McCann and Clark (2004)[61] Australia	Examine how young people with schizophrenia experience their illness as an embodied phenomenon and find meaning in the illness.	Young adults with diagnosis of schizophrenia (n = 9): male (n = 5), female (n = 4)	Individual interviews Phenomenol-ogical analysis	Phenomenology	Three themes emerged from the data about how the participants embodied the experience of schizophrenia. - "Embodied temporality: illness seen as a catastrophic experience" illustrated how the illness affected the person's perception of present circumstances and future events. - "Embodied relationality: illness perceived as a mediator of social relationships" showed how the illness affected their relationship with others. - "Embodied treatment: medications side effects experienced as burdensome." This highlighted how the side effects of antipsychotic medications distorted the individual's perception of his or her body, and the individual's ability to engage in sexual relationships.
McCann (2010)[60] UK	Explore the sexuality experiences of people with psychosis living in the community	People with diagnosis of schizophrenia (n = 30): male (n = 15), female (n = 15)	Individual interviews Thematic analysis	Qualitative description	The findings illustrate a range of issues and concerns that are important to people with schizophrenia in the field of intimacy and sexuality. The respondents provided poignant accounts of their experiences and were willing and able to do so. The key themes that emerged were: stigma, sexual side effects of medications, family planning and sexual risks. Practitioners need to be more aware of sexuality needs and address pertinent issues

(*Continued*)

Reference and country	Phenomena of interest	Participants	Methods	Method-ology	Main results
Östman and Björkman (2013)[62] Sweden	Examine the effect of schizophrenia on intimacy and sexuality experiences	People with a diagnosis of schizophrenia (n = 5): female (n = 3), male (n = 2). Partners (n = 3)	Individual interviews Thematic analysis	Qualitative description	People with schizophrenia diagnosis were willing and able to discuss intimacy and sexuality issues. Main areas for concern were: intimacy in the relationship; uncertainties about capacity; sexual fantasies, desire and sexual satisfaction; and communication and psychosexual supports. Practitioners need to provide opportunities for people to discuss relevant sex and relationship concerns that may guide the development of responsive and appropriate interventions and supports. Need further research to evaluate potential treatments and therapeutic interventions.
Quinn and Happell (2015)[63] Australia	Explore sexual risks and the views of patients and nurses	Forensic patients with SMI (n = 10): male (n = 6), female (n = 4). Aged 25–48 years. Nurses (n = 12)	Individual interviews Thematic analysis	Qualitative description	Sexual risk was a major theme arising from the interviews. Subthemes from nurse participants included sexual safety, sexual vulnerability, unplanned pregnancies, and male sexuality issues. Subthemes from patients included risks associated with sexual activity, access to information and sexual health care, unplanned pregnancies, vulnerability, and male sexuality issues. Information and assistance were considered by patients to be less than satisfactory in improving their knowledge or in providing the support they considered important to reduce sexual risks.
Redmond *et al.* (2010)[64] UK	Explore the meaning of romantic relationships for youth with psychosis	Youth with diagnosis of psychosis (n = 8)	Semi-structured interviews Interpretative phenomenol-ogical analysis	Phenomenology	Five key themes around relationships emerged from the study: illness as a barrier; relationships as positive; relationships as "high risk"; developing trust and confidence; and lack of experience and resources. Strategies for addressing the challenges and barriers are presented and discussed. Practitioners are in a good position to support young people in their intimate relationships. Interventions may include programs that incorporate education and skills training around dating experiences. Supported employment schemes and continuing education can increase access to financial resources and to expanding social networks.
Škodlar and Žunter Nagy (2009)[65] Slovenia	Examine sexuality experiences among people with psychosis psychodynamically	Unclear	Multiple discussions and case reports Phenomenol-ogical analysis	Phenomenology	Patients with psychosis are willing, ready and even thankful if given the opportunity to talk about their sexuality experiences. Participants would rarely bring up the topic spontaneously. Sexual disorders, except for the sexual dysfunctions accompanying neuroleptic treatment, are not specific by their frequency or form. Sexual activity is often limited. Masturbation was seen as a replacement for sexual activity and as a means of reducing tension and anxiety. Impulsive sexual acts were not very frequent, but they can have as strong impact. In some cases an erotic transference from client towards his or her therapist occurs, which can assume a form of erotic delusions.

(*Continued*)

Reference and country	Phenomena of interest	Participants	Methods	Method-ology	Main results
Volman and Landeen (2007)[66] Canada	Examine how people with schizophrenia perceive and experience their sexuality	People with a diagnosis of schizophrenia (n = 10): male (n = 5); female (n = 5)	Individual interviews Constant comparison analysis	Grounded theory	People may integrate sexuality into a sense of self. Some people were able to maintain satisfying sexual relationships and to construct their own meaning of sexuality and articulate key issues and concerns. Implications for effective recovery are presented and "opening the door" to discussions of sexuality. There is a need to integrate sexuality and intimacy into holistic care programs through rigorous psychosocial assessments and recovery plans. There needs to be a full evaluation of the interventions and the processes involved.

LGBT, lesbian, gay. bisexual, transgender; MTF, male to female; SMI, serious mental illness.

Ashmore T, Spangaro J, McNamara L. 'I was raped by Santa Claus': Responding to disclosures of sexual assault in mental health inpatient facilities. Int J Ment Health Nurs. 2015; 24(2):139–48.[47]	
Finding	*Psychotic coloring of sexual abuse disclosure (C)*
Illustration	After spending 2 weeks in an acute inpatient unit in a psychotic state, Jay had been moved to subacute care, as she began to stabilize. Several days later, Jay returned to the unit after walking in the hospital grounds in a distressed state and told the nurses she had been "raped by Santa Claus". Staff assumed this was a regression of her psychosis, and initially dismissed her account. Following further investigation, eye witnesses reported seeing Jay with a groundsman who had a long white beard like Santa Claus. He was also recalled as wearing a red shirt that day. When confronted with this information, the groundsman admitted to having sex with Jay. (p.143)
Finding	*Delusional disclosures (C)*
Illustration	Cecily, 84 years old, was admitted to a general hospital after falling and breaking her hip. Following surgery, she reported that she had been abducted from her hospital bed and raped by men wearing masks. An investigation of staff, patients and visitors present in the unit at the time was undertaken to ensure there were no times that abuse might have occurred. Clinicians spoke with Cecily about her fears and implemented actions to increase her sense of safety. Having excluded the possibility that sexual violence had occurred at that time, and taking into account age, prior mental state, and other manifested symptoms, post-general anaesthetic dementia was diagnosed. (p.143)
Baker AE, Procter NG. 'You Just Lose the People You Know': Relationship Loss and Mental Illness. Arch Psychiatr Nurs. 2015; 29(2):96–101.[48]	
Finding	*Loss of intimate relationship (U)*
Illustration	…to do with loss of husband, marriage…everything I'd worked for…that all coincides with my illness because that was the cause of it.... (p.98)
Finding	*Loss of spouse or partner (U)*
Illustration	I lost my husband. He dropped me off and said he didn't want anything to do with me…..he couldn't take care of me anymore because of my mental illness, which means I lost my whole hoke, everything. (p.98)
Finding	*Loss of children and parenthood (U)*
Illustration	…I lost him through death…but I lost a bit of time and freedom I had with him because I was put in a mother and baby home because people…didn't think I could care for him. (p.98)
Finding	*Loss of family (C)*
Illustration	I lost my sister-in-law's respect. She… couldn't handle the fact that I'd been in a psychiatric hospital… that nearly killed me… my sister-in-law's attitude. (p.98)
Finding	*Loss of friends (C)*

Illustration	Not only were they not. . .coming and seeing me, I stopped going and seeing them because I felt so depressed. (p.98)
Finding	*Loss of people in the community (C)*
Illustration	Sometimes my own mental illness caused a great deal of . . .loss with the church when I started thinking that they're the devils in my house. . .I had religious delusions but the church couldn't see it as religious delusions. (p.98)
Ben-David S, Birnbaum ML, Eilenberg ME, DeVylder JE, Gill KE, Schienle J, Azimov N, Lukens EP, Davidson L, Corcoran CM. The subjective experience of youths at clinically high risk of psychosis: a qualitative study. Psychiatr Serv. 2014; 65(12):1499–501.[49]	
Finding	*Gender differences and vulnerability of youth present clinical high risk (U)*
Illustration	Themes among males were: feeling abnormal or "broken", focus on "going crazy", fantasy and escapism in video gaming, alienation and despair, but with desire for relationships. Themes among women were: psychotic illness in family members, personal trauma - more than half spontaneously brought up a history of trauma, including neglect, abuse, parental separation, and witnessing violence, struggle with intimate relationships, career and personal development.
Brown SD, Reavey P, Kanyeredzi A, Batty R. Transformations of self and sexuality: psychologically modified experiences in the context of forensic mental health. Health. 2014;18(3):240–60.[50]	
Finding	*Exclusion and not asking about sexuality issues (C)*
Illustration	"I think they feel uncomfortable talking in any, any depth about my sexuality. I don't think they've been trained to – I don't think that they, they have the erm.. the insight. I'm sure we could have a very sensitive discussion with them about it, but for some reason, there's a barrier and I can't understand why" (p.246)
Finding	*Territorialisation: Vulnerability and predation discourse (C)*
Illustration	"Sex is an organised act that two people come together and do – and they're going to do it wherever that is, you know, under a tree, at the end of a tunnel, they're still going to do it. Like, there's an old corridor. And there was a place where you hang your coats, where you can't see people when they looked down there. So I walked in and went to put my coat round there and they (two male patients) were having sex in the corner . . . and it's not the first time they'd done that actually, they'd done it somewhere else as well". (p.248)
Finding	*Amputation: losing one's sexuality (C)*
Illustration	"I would say this place has amputated my sexuality. Definitely, it's – it's not my home, it's not – it's not a free environment and . . . it's a – it's so anti-life. I just don't even think about sexuality in here and I grieve over that quite a lot. And . . . I try and cope with this place on its own terms, you know and whatever it has to offer me I will engage with. So and try to make it a reality, its own reality but I still can't feel human enough to be a sexual being in this environment". (p.250)
Chandra PS, Deepthivarma S, Carey MP, Carey KB, Shalinianant MP. A cry from the darkness: women with severe mental illness in India reveal their experiences with sexual coercion. Psychiatry. 2003; 66(4):323–34.[51]	

Finding	*Adult sexual abuse (C)*
Illustration	"Three years ago I was in my sister's house for a few days. My brother-in-law is not all right. He is very crazy about women. I think even my sister is aware of this, but she keeps quiet. She bas two children and bas to bring them up. She does not work and that is why I think she is scared. He bad an eye on me also. But I never realized. One day I was alone at home. My brother-in-law came. That day be got an opportunity. He did not care, however much I requested. He raped me." (22-year-old, psychosis) (p.328)
Finding	*Childhood sexual abuse (C)*
Illustration	"When I was 8 to 9 years old, my cousin came to our house. He was an adult at that time. He came behind me to a room where I went. It was dark there. He tried to grab me from behind. I just pushed him away and ran away from there. I found it bad, be was doing it with sexual feelings ... another incident I remember was when I was 4 to 5 years old, and a boy in the neighborhood used to come to my house. He was 10 to 12 years old. One day be said 'bold my penis and you will feel better.' I did not know what to do. I just held it and then left it and ran away." (42-year-old, obsessive-compulsive disorder) (p.328)
Finding	*Perpetrator of sexual abuse (C)*
Illustration	"Even in my mother's house my elder brother beat me up, asking me why I came here leaving my husband. I have bruises all over my body. Even when I was a kid be would bit me and sometimes when no one was there at home be would do thing like touching my breasts, vagina and make me touch his genitals and so on. I did not know anything at that time. I was scared of him. Hence I would keep quiet." (20-year-old, severe depression) (p.328)
Finding	*Context of sexual abuse (C)*
Illustration	"I bad become 'mental' at that time. I could not understand anything. I would go anywhere I liked and roam around. During that time many people have 'spoilt' me. Some would take me to the grove and would talk to me until it was dark and then would rape me and go away. They would get me eatables and take me to movies. I used to feel very happy. These kinds of things happened many times. I do not even know who they were and what they did. I was very crazy about clothes, eatables, and movies. If anybody got me those I would go with them." (28-year-old, bipolar disorder, mania with psychotic symptoms) (p.329)
Finding	*Reactions to coercive sex (U)*
Illustration	"My husband is a very strict man. I have to listen to him. Whenever be wants [sex], I have to agree, otherwise be will beat me up. I am scared that be may go to other women. What to do? Men can do anything. We women will have to do what they say. That is our fate. Sometimes I would cry and other times I would get angry. Now I have got used to all this." (30-year-old, bipolar, disorder with mania and psychotic symptoms) (p.329)
Cogan JC. The consumer as expert: Women with serious mental illness and their relationship-based needs. Psychiatr Rehabil J. 1998; 22(2):142.[52]	
Finding	*Abuse within relationships* (C)

Illustration	"I have been threatened by men, but because they don't live with me I can't get a restraining order or relief from abuse. So they can basically do what they want." (p.147)
Finding	*Sex related issues (C)*
Illustration	"A lot of lesbian women are there [at a community mental health social club]. There's a lot of homophobia among the other clients and some of the staff." (p.147)
Finding	*Needs of mothers (U)*
Illustration	"Dealing with SRS [Social Rehabilitation Services] and the lies they tell you. My son is in SRS custody. My son's father threatened to kill me and my son. They turned it around and said that I threatened to kill him. They are abusing my child emotionally. They planned on taking my kid away immediately after he was born without even discussing it with me". (p.148)
Finding	*Mental illness as stigma: mothers on trial (C)*
Illustration	"If you are labeled mentally ill you can't take care of your kid. My son is not thriving in any foster home. He's lost weight. SRS has put a restraining order on me. I can't see my kid. I'm in legal stuff. I'm on my third judge and fifth lawyer. I need my son back. I am smart enough to know if I could take care of my son. If I couldn't I would put him up for adoption. I know how to take care of kids". (p.148)
Davison J, Huntington A. "Out of sight": Sexuality and women with enduring mental illness. Int J Ment Health Nurs. 2010; 19(4):240–9.[53]	
Finding	*The effects of female socialization (C)*
Illustration	"Well, one of my biggest stumbling blocks was feeling like I always needed permission, permission to be a woman, and not validating myself, not feeling good about myself, to have a say. .. and feeling threatened. I always felt threatened that something was going to happen to me, I was gonna get the bash, or something like that". (p.244)
Finding	*The effects of stigma (C)*
Illustration	"I kind of had like a rule for myself that it wasn't something that I'd just tell anyone, but it wasn't a secret either. I felt when beginning a relationship, it was really important really early on to let the person know, and when I didn't feel they were going to run away because of it" (p.245)
Finding	*The effects of heteronormativity (C)*
Illustration	"Some of us we actually hid it, our sexual orientation, by trying to conform to what society wanted, by trying to be seen as having a partner of the opposite gender". (p.245)
de Jager J, Cirakoglu B, Nugter A, van Os J. Intimacy and its barriers: A qualitative exploration of intimacy and related struggles among people diagnosed with psychosis. Psychosis. 2017 Jun 1:1–9.[22]	
Finding	*Relationship needs & intimacy (C)*
Illustration	"I'd love to be in a relationship again. (…) I can hardly even imagine what it would be like. It seems like a dream. (…) If you're single for 10 years, then you're just really lonely. That's just what it is". (Single, male, 38 years) (p.4)
Finding	*Self-stigma (C)*

Illustration	"The word psychosis will not come out of my mouth. If I were in a happy relationship, perhaps I would tell her at some point. If she would be very easy to talk to, I would tell her" (Divorced, male, 42 years). (p.6)
Finding	*Social skills and deficits (C)*
Illustration	"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." (Single, female, 34 years) (p.6)
Finding	*Sexual abuse (C)*
Illustration	"I have been divorced for 28 years from my first husband but I have lain in bed with fear for 23 years." (Married, female, 57 years). (p.6)
Garrett NR. Treatment of a transgender client with schizophrenia in a public psychiatric milieu: A case study by a student therapist. J Gay Lesbian Ment Health. 2004; 8(3–4):127–41.[54]	
Finding	*Double stigma (U)*
Illustration	M returned to the concern of having "a double stigma" because of her psychiatric diagnosis and transgender status. Because she had rarely discussed her psychiatric illness in previous sessions, this comment seemed almost incongruent with the trend of recent thoughts. M now denied psychosis, and focused on depressive symptoms, but rationalized these as the result of other people's behavior toward her. (p.134)
Finding	*Importance of providing an understanding space (C)*
Illustration	"Psychotic people are so desperate for basic human relatedness and for hope that someone can relieve their misery that they are apt to be deferential and grateful to any therapist who does more than classify and medicate them." Understanding M, and not merely classifying her as a psychotic patient, had significant positive implications in her treatment". (p.135)
Finding	*Difficulty understanding the transgender process (U)*
Illustration	Possibly the most difficult area in M's treatment was understanding her identification as a male-to-female transgender person. Her understanding appeared concrete and immature, incomplete in some meaningful way. p137 When the therapist's anxiety regarding the disparity between M's transgender and mental illness concerns was confronted, a primary goal of treatment emerged. M wanted to be understood by others, and this appeared to be a projection of her need to understand herself. (p.137)
Granek L, Danan D, Bersudsky Y, Osher Y. Living with bipolar disorder: the impact on patients, spouses, and their marital relationship. Bipolar Disord. 2016; 18(2):192–9.[55]	
Finding	*Emotional impact of SMI on spouses (U)*

Illustration	Throughout the interviews, both partners described dealing with symptoms of the disorder such as aggressiveness, impulsivity, compromised memory, psychotic incidents, personality changes, and severe episodes of depression and mania that included extreme hyperactivity and intense feelings of sorrow, sadness, and anxiety. (p.193). "I have to have my antennae out. And most of the time everything is fine... but every once in a while, I ask myself, is she escalating? And I watch her carefully for a day or two until I find that she's not, and then I relax again'. 'How can you live with this? It's so scary. You don't want to live like this... when he was hospitalized, I saw people here who are elders and you think to yourself, it's scary, very scary". (p.196)
Finding	*Self-sacrifice (U)*
Illustration	For spouses, sacrifices included giving up on having more children because of the patient's inability to participate fully in child raising; being chronically sleep deprived; giving up on their own pleasures in life (i.e. going out with friends, having hobbies, going to movies or dancing); and feeling as if they had no time or energy to think about themselves, or their own needs and wishes. (p.194)
Finding	*Caregiver burden (U)*
Illustration	Spouses described responsibilities that sometimes included the 'full-time job' of caring for the patient (i.e., medical appointments, ensuring treatment compliance, caring for the patient while hospitalized, etc.), occasionally being the sole financial provider in a context where medical care added expenses, and taking full responsibility for care of the house and children. Spouses reported other impacts including helplessness to assist the patient in the face of bipolar disorder; loneliness in coping with the effects of the disorder; embarrassment and shame at the partner's condition; anxiety and hypervigilance that the patient would relapse (p.194)
Finding	*Personal evolution (C)*
Illustration	Spouses described positive impacts including increased empathy and compassion towards others, a sense of resilience in dealing with life's hardships, and a sense of perspective on what is important in life. (p194)
Finding	*Difficulty accepting diagnosis (U)*
Illustration	Spouses described the difficulty of the patient in accepting the diagnosis and the subsequent changes that come with the condition, including treatment compliance and lifestyle changes to prevent relapses. (p194)
Greenall PV, Jellicoe-Jones L. Themes and risk of sexual violence among the mentally ill: implications for understanding and treatment. Sex Relation Ther. 2007; 22(3):323–37.[56]	
Finding	*Anger or violence (C)*
Illustration	"Case 2 was hearing voices and thought the radio was talking to him. He was angry, irritable and hostile, and spoke of violent intentions towards others. He could not remember sexually assaulting two girls on public transport, but recalls drinking heavily beforehand." (p.329)
Finding	*Psychotic drive (C)*

Illustration	"Case 7 sat in a car armed with knives waiting for a particular type of woman to rape and murder. He has been acting like this for several weeks. This behaviour was apparently driven by voices in his head that instructed him to find rape and kill a woman. The thought of this excited him and had become incorporated into his sexual fantasies." (p.330)
Finding	*Sexual disinhibition (C)*
Illustration	"Case 8 followed some girls and then indecently assaulted another girl he had just met, after which he followed her home and waited for her outside. His explanation was he was looking for love and he felt that he loved his victim and she was nice." (p.330)
Finding	*Childhood sexual abuse (C)*
Illustration	"Case 11 indecently assaulted three children over several years. These assaults were reportedly related to periods of depression, low self-esteem and self-pity, deviant sexual fantasies of grooming and being alone with children, plus powerful rationalization that his actions would not harm his victims." (p.331)
Kidd SA, Veltman A, Gately C, Chan KJ, Cohen JN. Lesbian, gay, and transgender persons with severe mental illness: Negotiating wellness in the context of multiple sources of stigma. Am J Psychiatr Rehabil. 2011; 14(1):13–39.[57]	
Finding	*The emergence of stigma (U)*
Illustration	"People started to make fun of me. I started to get beat up sometimes...I think that people knew I was gay before I really knew myself."(p.23)
Finding	*Multiple sources of stigma (C)*
Illustration	"They had to call an ambulance for me. It was interesting because when I told the ambulance attendants about the Huntington's, they were very interested. But when they found out I have a mental illness, they stopped talking to me. I couldn't win no matter which way. If I go with Huntington's somebody might not know what it is and stop talking. If I go with mental illness, people back off. If I go with gay, people back off. It is like a triple-header. I couldn't win no matter which way". (p.25)
Finding	*Interactions between identities and mental illness (U)*
Illustration	"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... I am still thinking that it [maintaining sobriety] is going to take me a lot of effort after 40 years of drinking. That was my best friend in the loneliness of knowing you are different from everybody else". (p.26)
Finding	*Family as sources of strength (U)*
Illustration	"I guess I get my strength from my friends and from the few members of my family who support me and love me." "I am lucky to have a relationship with my dad...I I know a lot of people with mental illness who don't have that kind of family connection, never mind being gay." (p.28)
Finding	*Psychiatric service settings and challenges (C)*

Illustration	"When you go into the unit you're already sick enough, you wouldn't be going into a unit if you weren't. You don't want to have to educate everybody...you're probably suicidal, you probably wish you were dead, and then you have to explain yourself all over again". (p.29)
Finding	*Psychiatric service settings and positives (C)*
Illustration	"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." One participant also spoke about the impact of having a provider tell her that she was a lesbian herself. "I felt it was nice that she did that. It made me feel less ashamed. It was because she is a nurse and she is gay and there is nothing wrong with that." (p.31)
Martz D. Behavioral treatment for a female engaging in autoerotic asphyxiation. Clin Case Stud. 2003; 2(3):236–42.[58]	
Finding	*Autoerotic asphyxiation occurs in women too and can be treated with exposure techniques (C)*
Illustration	"This case study presents a 22-year-old college female with comorbid depression and avoidant personality disorder complaining of the use of autoerotic asphyxiation during masturbation." (p.236) "After the 10 exposure sessions, Sue reported that the fantasy was diminished during masturbation and consequently she had ceased use of asphyxiation." "It suggests that this behavior succumbs to behavioral contingencies much like any normal sexual behavior. Use of an exposure technique can be used to extinguish the power of such a taboo and forbidden behavior so as to render it impotent." (p.240)
Finding	*Screening for auto asphyxiation and safety procedures (C)*
Illustration	"Due to the life-threatening nature of this behavior, psychotherapists should regularly screen for this practice in their clients. Furthermore, if a client is performing such a behavior, the therapist should ensure that he/she has designed the ligature in a failsafe manner until the behavior is extinguished." (p.241)
McCann E. The expression of sexuality in people with psychosis: breaking the taboos. J Adv Nurs. 2000; 32(1):132–8.[59]	
Finding	*Need for social skills training for clients leaving hospital (C)*
Illustration	"Judging by the responses, a majority would like more opportunities to meet people and develop social skills away from the institution". (p.135)
Finding	*Decline in sexual activity to do with being in hospital (C)*
Illustration	Sex relations had stopped for three-quarters of respondents since being hospitalized. When asked why sexual relations had stopped, the following reasons were given: illness of self (four); lost interest myself (four); lack of opportunity (five); no privacy (three); in hospital (six). (p.135)
McCann E. The sexual and relationship needs of people who experience psychosis: quantitative findings of a UK study. J Psychiatr Ment Health Nurs 2010; 17:295–303.[9]	
Finding	*People are able and willing to talk about intimacy (U)*

Illustration	"Nevertheless, all of the participants were able to articulate their views of intimacy and mentioned aspects such as love, closeness and caring". (p.253)
Finding	*The formation of relationships is challenging but important for most (U)*
Illustration	"Of the 30 participants, only one respondent said he had never been in a relationship. Three men and nine women were currently in a relationship. People were able to expand on their experiences and some of the challenges they face in forming and maintaining relationships. (p.253)
Finding	*Privacy often lacking in mental health settings (C)*
Illustration	"There is no privacy around here. There's not much chance to have sex. We're under the staff. Staff just come into the room, they don't bother to knock. I have no one to talk to about this stuff and I get worried that I may harm her."
Finding	*Self-stigma is a barrier in the formation of intimacy (C)*
Illustration	"I am reluctant [to approach women] because I'm afraid they all know that I am not well. I am very reluctant to go next to my own Kurdish people because of the shame I feel." (p.254)
Finding	*SMI can lead to insecurities about family planning (U)*
Illustration	"I'd really like to have children, but maybe it's too late now. We're trapped in this place. I'd like us both to live together in a flat in London. Could we have children? I don't know" (p.254)
Finding	*Sexual side effects of medication can be a barrier in sexual expression (C)*
Illustration	"It sometimes stopped me from having sex because I cannot relax to do sexual movements. I get stiffness in my arms and legs. Slowness too, and it does something to the muscles, I was like with myself the other day and couldn't make it hard, like a few days ago like I could swear it can stop you sex life completely." (p.254)
McCann TV, Clark E. Embodiment of severe and enduring mental illness: Finding meaning in schizophrenia. Issues Ment Health Nurs. 2004; 25(8):783–98.[61]	
Finding	Living with SMI challenging (U)
Illustration	"For many participants, schizophrenia was a devastating experience that made the future even more unpredictable. They felt alarmed because they could see no future beyond their immediate illness experience." (p.788)
Finding	*Feelings of guilt, embarrassment and poor self-confidence during acute episode of psychosis (U)*
Illustration	For example, Martin limited his social activities because of his embarrassment about the illness: "When it was my friend's 21st birthday party last Saturday…I had to tell him I couldn't go." (p.788)
Finding	*Relationships as problematic (C)*
Illustration	"The data show that the embodiment of schizophrenia had a paradoxical effect on social relationships, sometimes eliciting support while at other times damaging relationships." (p.789)

Finding	*Spirituality as an important support (C)*
Illustration	"Spirituality provided a means of support in striving to cope with the experience of schizophrenia." (p.789)
Östman M, Björkman AC. Schizophrenia and relationships: the effect of mental illness on sexuality. Clin Schizophr Relat Psychoses. 2013; 7(1):20–4.[62]	
Finding	*Relationships outweigh sexuality (U)*
Illustration	The patients' narratives told of bad or non-existent sexual relationships, with some patients and partners having experienced no sexual intercourse at all. Some reported no sexual activity in their relationship for 8 months, 2 years, and even 7 years. Both patients and partners indicated that they had had a much healthier sex life before the onset of the illness. Some patients related with delight how they had experienced sexuality earlier and actively partook in it. (p.22)
Finding	*Uncertainties about one's capacity (U)*
Illustration	The narratives of patients often included worries about being unable to lead a life in which healthy sexuality played a part. They wondered whether they still had the capacity for sexual activity and could give their partner satisfaction in a sexual relationship. (p.22)
Finding	*Sexual fantasies, feelings of desire and satisfaction (C)*
Illustration	The patients we interviewed experienced a failure to achieve satisfaction during sexual intercourse. Some longed for the ability to achieve orgasm. Others claimed that they were incapable of feeling anything at all: neither desire nor satisfaction, whether they were aroused or not. One patient, who had been sexually abused as a child, told of how those experiences had impacted her thoughts and behavior, leaving her with feelings of inappropriateness, dirtiness, and embarrassment about sexual matters. (p.22)
Finding	*Need to talk about support in sexual matters (C)*
Illustration	We found that patients and partners do not regularly communicate with each other about issues related to their sexual relationship. However, patients have said that they do speak with close friends and relatives about their sex life and their feelings of dysfunctionality (p.23)
Finding	*The attitude of mental health medical personnel (U)*
Illustration	The first step in remedying the situation is to increase the awareness of mental health professionals in this regard, something that can be accomplished by more staff training in sexual matters and greater personal supervision of those providing treatment. (p.23)
Quinn C, Happell B. Exploring sexual risks in a forensic mental health hospital: Perspectives from patients and nurses. Issues Ment Health Nurs. 2015; 36(9):669–77.[63]	
Finding	*Sexual safety problematic for forensic group due to specific problems (C)*

Illustration	"There is always the risk of sexual assault, especially given the offending histories of our patients.. .. Sometimes they might get involved above their capabilities and out of their comfort zone and be pressured into having sex" (p. 671) "Some patients need protecting, some are sick you know" (p.673) "I know some blokes will force themselves on some of the females. I've heard that blokes stand over the girls and I've heard that male patients give the female patients money for sex" (p.674)
Finding	*The assessment of sexual abuse by nurses is insufficient (C)*
Illustration	It's possible that the abuser might be so dominant that the victim might be too afraid to identify the abuse out of fear from the abuser or lack of belief from staff. Distrust from staff occurs, and so why would you identify abuse occurring if you're simply not heard. We have a lot of female patients here who have trauma histories and we don't want to open old wounds because they are too frightened to speak out and say I really didn't want that to happen. So that's something we do not do. (p. 672)
Finding	*Female patients encouraged to take contraception as precaution (C)*
Illustration	"If someone was to become pregnant, the whole trauma of having a child, childbirth, the whole aspect of this would just be totally unmanageable.. . We get them to see the GP and we start them on the pill. They don't have any choice in it. It's for the best" (p.672) "Physically and chemically it would be a major concern because genetically two people with schizophrenia having a baby together there is a very high probability that that baby is going to have schizophrenia" (p.673)
Finding	*Male patients in hospital may have sex with other males without being gay (C)*
Illustration	"Because of the environment, they have been indulging in homosexual activity. Which I possibly think is not the way they are orientated, but is due to the abnormal environment "(p.672) "My understanding is that the guys who are gay aren't really gay. It's just that they can't get into bed with a woman. They get frustrated and turn gay because there are no women around. .. that's why a lot of them turn gay in prison. It's their only option" (p.674).
Finding	*Coming out as gay risky in hospital context (C)*
Illustration	"This patient brought up that he might be gay, and didn't want anyone else to know because he didn't want to be picked on, ridiculed, or raped". (p. 673) "And then there is the issue of what happens if one of our guys are picked up on a gay beat? Imagine the headlines and imagine the implications for this place" (p.673).
Redmond C, Larkin M, Harrop C. The personal meaning of romantic relationships for young people with psychosis. Clin Child Psychol Psychiatry. 2010; 15(2):151–70.[64]	
Finding	*Illness as incompatible with sexuality (U)*
Illustration	"It's really difficult as a mentally ill person to actually meet people who I feel/ 'cos mental illness is … don't know if this is right but a lot of people my age haven't had any kind of … so I feel quite isolated in that respect" (p.158)
Finding	*Relationships as normalizing (C)*

Illustration	"I think they'd be pleased for me 'cos I found someone … I'm not just hiding behind my mental health problems … I'm getting on with life and doing things just like any other young woman" (p159)
Finding	*Lack of experience and resources (C)*
Illustration	"The thing is nobody ever said, you're single, how do you? What do you do about it? How do you go about being/ I mean obviously you talk to somebody these days off the road … they start walking away from you, get intimidated by you, you know....You get all … you feel upset" (Ali) (p163)
Škodlar B, Žunter Nagy M. Sexuality and psychosis. Psychiatr Danub. 2009; 21(1):111–6.[65]	
Finding	*People with psychosis are willing and able to talk about their sexuality and it's safe to do so*
Illustration	"Patients with psychosis are willing, ready and even thankful if they are given the opportunity to talk about their sexuality. They have no problem discussing their wishes and fantasies, regardless whether they are heterosexual, homosexual or unusual, and their overt sexual activities, be it masturbatory or with others" (p.112)
Finding	*Non-specificity of sexual disorders in psychotic patients (C)*
Illustration	"Sexual disorders, except for the sexual dysfunctions accompanying neuroleptic treatment, are not specific by their frequency or forms." "However as already stated their frequency does not exceed the frequency of sexual problems of other patients" (p.112)
Finding	*Difficulties in establishing a stable sexual identity and questioning one's own sexual orientation (C)*
Illustration	"They feel themselves as being changeable in behavior, speech and gesture through associating with different people. They can feel also empty of a sense of self or inner hold and they cannot assume a firm stance about anything. So, in the same way sexual attraction and sexual identity are at stake as well. Patients can feel attracted to both sexes or even to people of different age-groups, and they can be confused in this respect" (p.112)
Finding	*Feelings of guilt (C)*
Illustration	"One of the general characteristics of the sexual life of psychotic patients with other people is that it is absent for different reasons. The common denominator is difficulties in regulating closeness." "Patients attribute to themselves and feel responsible for everything which they lack and cannot achieve. They feel inadequate both as sexual performers and partners as well as guilty for this inadequacy" (p.113)
Finding	*Masturbation as stress relief (C)*
Illustration	"Masturbation may represent a central sexual activity of a patient as it serves as a replacement for sexual activity with another and as a means of reducing tension and anxiety" (p.113)
Finding	*Erotic transference from client to therapist can occur (C)*
Illustration	In some cases an erotic transference from client towards his or her therapist occurs, which can assume a form of erotic delusions" (p.113)

Finding	*Impulsive sex acts can happen (C)*
Illustration	"Impulsive sexual acts are not very frequent, but they make a strong impact. Patients can grab sexual organs of other patients or of the staff members, they can behave promiscuously, or can enter sexual intercourse in public or not hidden places" (p.113)
Volman L, Landeen J. Uncovering the sexual self in people with schizophrenia. J Psychiatr Ment Health Nurs. 2007; 14(4):411–7.[66]	
Finding	*Personal definitions, seeking satisfaction, searching for meaning (U)*
Illustration	"It's all about relationships- loving relationships, companionship, and trust". (p.413)
Finding	*My sexuality and my Illness; struggling self-image, adjusting to changes in sexual function, wanting intimacy, not feeling like a whole person (U)*
Illustration	"He tells me that he loves me, and that I'm a good person. [He also tells me] that I am beautiful and that I have a good soul. My friends tell me that too. It makes me feel alright, but the voices tell me different" (p.414)
Finding	*Managing the impact; regaining control, testing boundaries, perspective, opportunities and reclaiming a positive self-image (U)*
Illustration	"[The illness affected my sexuality] in a negative way, of course. But it takes faith to have the full experience of life even if you have something working against you. You can live with things that are negative and somehow those negative things work out eventually" (p.415)

C, credible; GP, general practitioner; SRS, Social Rehabilitation Services; U, unequivocal.

Appendix IV: JBI definitions of levels of credibility

Unequivocal (U): findings accompanied by an illustration that is beyond reasonable doubt and therefore not open to challenge.

Credible (C): findings accompanied by an illustration lacking clear association with it and therefore open to challenge.

Unsupported (Un): findings not supported by data. (JBI, 2014, p.40)[46]

Appendix V: Excluded studies and reasons for their exclusion

The following studies did not meet the predefined inclusion criteria and were excluded from the final review.

à Campo J, Nijman H, Merckelbach HL, Evers C. Psychiatric comorbidity of gender identity disorders: a survey among Dutch psychiatrists. Am J Psychiatry. 2003; 160(7):1332–6.
Reason for exclusion: Ineligible study design

Acunã MJ, Martı´n JC, Graciani M, Cruces A, Gotor F. A comparative study of the sexual function of institutionalized patients with schizophrenia. J Sex Med. 2010; 7(10):3414-23.
Reason for exclusion: Ineligible study design

Aizenberg D, Zemishlany Z, Dorfman-Etrog P, Weizman A. Sexual dysfunction in male schizophrenic patients. J Clin Psychiatry. 1995; 56(4):137-141.
Reason for exclusion: Non-retrievable

Allen DJ. The role of personality and defense mechanisms in the adjustment to a homosexual identity. J Homosex. 2002; 42(2):45-62.
Reason for exclusion: Ineligible patient population

Amoo G. Zoophilic recidivism in schizophrenia: a case report. Afr J Psychiatry. 2012;15(4):223-225
Reason for exclusion: Ineligible study design

Apantaku-Olajide T, Gibbons P, Higgins A. Drug-induced sexual dysfunction and mental health patients' attitude to psychotropic medications. Sex Relation Ther. 2011; 26(2):145-55.
Reason for exclusion: Ineligible study design

Azariah S, Coverdale J. How sexual health clinics address the needs of patients with major mental disorders: an Australasian survey. Venereology. 2001;14(3):105.
Reason for exclusion: Ineligible study design

Bai YM, Huang Y, Lin CC, Chen JY. Emerging homosexual conduct during hospitalization among chronic schizophrenia patients. Acta Psychiatr Scand. 2000; 102(5):350-353.
Reason for exclusion: Ineligible study design

Biaggo M, Roades LA, Staffelbach D, Cardinali J, Duffy R. Clinical evaluations: Impact of

sexual orientation, gender, and gender role. J Appl Soc Psychol. 2000; 30(8):1657-1669.
Reason for exclusion: Ineligible phenomena

Bitzer J, Platano G, Tschudin S, Alder J. Education: Sexual Counseling for Women in the Context of Physical Diseases—A Teaching Model for Physicians. J Sex Med. 2007; 4(1):29-37.
Reason for exclusion: Ineligible phenomena

Black DW, Kehrberg LL, Flumerfelt DL, Schlosser SS. Characteristics of 36 subjects reporting compulsive sexual behavior. Am J Psychiatry. 1997; 154(2):243.
Reason for exclusion: Ineligible patient population

Bonfils KA, Firmin RL, Salyers MP, Wright ER. Sexuality and intimacy among people living with serious mental illnesses: Factors contributing to sexual activity. Psychiatr Rehabil J. 2015; 38(3):249.
Reason for exclusion: Ineligible study design

Bouchard S, Godbout N, Sabourin S. Sexual attitudes and activities in women with borderline personality disorder involved in romantic relationships. J Sex Marital Ther. 2009; 35(2):106-21.
Reason for exclusion: Ineligible study design

Boyda D, McFeeters D, Shevlin M. Intimate partner violence, sexual abuse, and the mediating role of loneliness on psychosis. Psychosis. 2015; 7(1):1-3.
Reason for exclusion: Ineligible study design

Brotto LA, Knudson G, Inskip J, Rhodes K, Erskine Y. Asexuality: A mixed-methods approach. Arch Sex Behav. 2010; 39(3):599-618.
Reason for exclusion: Ineligible study design

Brown A, Lubman DI, Paxton S. Sexual risk behaviour in young people with first episode psychosis. Early Interv Psychiatry. 2010; 4(3):234-42.
Reason for exclusion: Ineligible phenomena

Brown AP, Lubman DI, Paxton SJ. Psychosocial risk factors for inconsistent condom use in young people with first episode psychosis. Community Ment Health J. 2011; 47(6):679-87.
Reason for exclusion: Ineligible study design

Brown A, Lubman DI, Paxton SJ. Reducing sexually-transmitted infection risk in young people with firstepisode psychosis. Int J Ment Health Nurs. 2011; 20(1):12-20.

Reason for exclusion: Ineligible study design

Chanen A, Jovev M, Betts J, Nyathi Y, Smith A, Pitts M, Stabolidis A, Thompson K. The sexual health and relationships of young people with borderline personality pathology. Early Interv Psychiatry 2016; 10:83-83.
Reason for exclusion: Ineligible study design

Coverdale JH, Turbott SH, Roberts H. Family planning needs and STD risk behaviours of female psychiatric out-patients. BJ Psychiatry. 1997;171(1):69-72.
Reason for exclusion: Ineligible study design

Coverdale JH, Turbott SH. Risk behaviors for sexually transmitted infections among men with mental disorders. Psychiatr Serv. 2000; 51(2):234-8.
Reason for exclusion: Ineligible study design

Cummings SM, Cassie KM. Perceptions of biopsychosocial services needs among older adults with severe mental illness: Met and unmet needs. Health Soc Work. 2008;33(2):133-43.
Reason for exclusion: Ineligible patient population

Dardennes R, Al Anbar N, Rouillon F. Episodic sexual addiction in a depressed woman treated with Cyproterone Acetate. J Clin Psychopharmacol. 2013; 33(2):274-6.
Reason for exclusion: Ineligible phenomena

de Boer MK, Castelein S, Wiersma D, Schoevers RA, Knegtering H. A systematic review of instruments to measure sexual functioning in patients using antipsychotics. J Sex Res. 2014; 51(4):383-9.
Reason for exclusion: Ineligible study design

Dein KE, Williams PS, Volkonskaia I, Kanyeredzi A, Reavey P, Leavey G. Examining professionals' perspectives on sexuality for service users of a forensic psychiatry unit. Int J of Law Psychiatry. 2016; 44:15-23.
Reason for exclusion: Ineligible patient population

De Luca M, Chenivesse P. Psychosis and Fetishist relationships: a case study. Evolution Psychiatrique. 2003; 68(4):551-62.
Reason for exclusion: Ineligible language

Dickerson FB, Brown CH, Kreyenbuhl J, Goldberg RW, Fang LJ, Dixon LB. Sexual and reproductive behaviors among persons with mental illness. Psychiatr Serv. 2004;

55(11):1299-301.
Reason for exclusion: Ineligible study design

Elkington KS, McKinnon K, Mann CG, Collins PY, Leu CS, Wainberg ML. Perceived mental illness stigma and HIV risk behaviors among adult psychiatric outpatients in Rio de Janeiro, Brazil. Community Ment Health J. 2010; 46(1):56-64.
Reason for exclusion: Ineligible study design

Eklund M, O¨ stman M. Belonging and doing: important factors for satisfaction with sexual relations as perceived by people with persistent mental illness. Int J Soc Psychiatry. 2010; 56(4):336-47.
Reason for exclusion: Ineligible study design

Fuoco M, Cox L, Kinahan T. Penile amputation and successful reattachment and the role of winter shunt in postoperative viability: A case report and literature review. Can Urol Assoc J. 2015; 9(5-6):E297.
Reason for exclusion: Ineligible phenomena

Gonzalez-Torres MA, Salazar MA, Inchausti L, Ibañez B, Pastor J, Gonzalez G, Carvajal MJ, Fernandez- Rivas A, Madrazo A, Ruiz E, Basterreche E. Lifetime sexual behavior of psychiatric inpatients. J Sex Med. 2010; 7(9):3045-56.
Reason for exclusion: Ineligible study design

Goodman LA, Rosenberg SD, Mueser KT, Drake RE. Physical and sexual assault history in women with serious mental illness: prevalence, correlates, treatment, and future research directions. Schizophr Bull. 1997; 23(4):685.
Reason for exclusion: Ineligible study design

Granstein J, Strimbu K, Francois D, Kahn DA. An Unusual Case of Erotomania and Delusional Misidentification Syndrome. J Psychiatr Pract. 2015;21(4):306-12.
Reason for exclusion: Ineligible phenomena

Hariri AG, Karadag F, Gurol DT, Aksoy UM, Tezcan AE. Sexual problems in a sample of the Turkish psychiatric population. Compr psychiatry. 2009; 50(4):353-60.
Reason for exclusion: Ineligible study design

Harley EW, Boardman J, Craig T. Sexual problems in schizophrenia: prevalence and characteristics. A cross sectional survey. Soc Psychiatry Psychiatr Epidemiol. 2010;45(7):759-66.
Reason for exclusion: Ineligible study design

Higgins A, Barker P, Begley CM. Iatrogenic sexual dysfunction and the protective withholding of information: in whose best interest? J Psychiatr Ment Health Nurs. 2006; 13(4):437-46.
Reason for exclusion: Ineligible patient population

Hui CL, Poon VW, Ko WT, Miao HY, Chang WC, Lee EH, Chan SK, Lin J, Chen EY. Risk factors for antipsychotic medication non-adherence behaviors and attitudes in adult-onset psychosis. Schizophr Res. 2016; 174(1):144-9.
Reason for exclusion: Ineligible study design

Incedere A, Küçük L. Sexual life and associated factors in psychiatric patients. Sex Disabil. 2017; 35(1):89-106.
Reason for exclusion: Ineligible study design

Jensen HM, Poulsen HD. Auto-vampirism in schizophrenia. Nord J Psychiatry. 2002; 56(1):47-8.
Reason for exclusion: Ineligible phenomena

Kalichman SC, Benotsch E, Rompa D, Gore-Felton C, Austin J, Luke W, DiFonzo K, Buckles J, Kyomugisha F, Simpson D. Unwanted sexual experiences and sexual risks in gay and bisexual men: Associations among revictimization, substance use, and psychiatric symptoms. J Sex Res. 2001; 38(1):1-9.
Reason for exclusion: Ineligible study design

Kalichman SC, Gore-Felton C, Benotsch E, Cage M, Rompa D. Trauma symptoms, sexual behaviors, and substance abuse: correlates of childhood sexual abuse and HIV risks among men who have sex with men. J Child Sex Abus. 2004; 13(1):1-5.
Reason for exclusion: Ineligible study design

Kaltenthaler E, Pandor A, Wong R. The effectiveness of sexual health interventions for people with severe mental illness: a systematic review. Health Technol Assess. 2014;18(1):1-74.
Reason for exclusion: Ineligible study design

King C, Feldman J, Waithaka Y, Aban I, Hu J, Zhang S, Hook III E, Bachmann LH. Sexual risk behaviors and sexually transmitted infection prevalence in an outpatient psychiatry clinic. J Sex Transm Dis. 2008; 35(10):877-82.
Reason for exclusion: Ineligible phenomena

Krasucki C, Kemp R, David A. A case study of female genital self-mutilation in schizophrenia. Psychol Psychother. 1995; 68(2):179-86.
Reason for exclusion: Ineligible phenomena

Lam D, Donaldson C, Brown Y, Malliaris Y. Burden and marital and sexual satisfaction in the partners of bipolar patients. Bipolar Disord. 2005; 7(5):431-40.
Reason for exclusion: Ineligible study design

Loue S. Ethical issues in a study of bipolar disorder and HIV risk among African-American men who have sex with men: case study in the ethics of mental health research. Journal Nerv Ment Dis. 2012; 200(3):236-41.
Reason for exclusion: Ineligible phenomena

Martin L, Perlman CM, Hirdes JP. Social relationships and activities among married psychiatric inpatients with sexual difficulties. J Sex Marital Ther. 2011; 37(4):307-22.
Reason for exclusion: Ineligible phenomena

Mansour-Musova H, Weiss P. Sexual Abuse and Rape Experiences in Female Schizophrenic Patients. Ceska Slov Psychiatr. 2007; 102(4):179.
Reason for exclusion: Ineligible study design

Mansour-Musova H, Weiss P. Sexual orientation and homosexual experiences in female schizophrenic patients. Ceska Slov Psychiatr. 2007;102(3):127.
Reason for exclusion: Ineligible study design

Meade CS, Sikkema KJ. Psychiatric and psychosocial correlates of sexual risk behavior among adults with severe mental illness. Community Ment Health J. 2007; 43(2):153-69.
Reason for exclusion: Ineligible study design

Miller LJ, Finnerty M. Family planning knowledge, attitudes and practices in women with schizophrenic spectrum disorders. J Psychosom Obstet Gynaecol 1998; 19(4):210-7.
Reason for exclusion: Ineligible study design

Nagaraj AK, Pai NB, Rao S. A comparative study of sexual dysfunction involving risperidone, quetiapine, and olanzapine. Ind J Psychiatry. 2009; 51(4):265.
Reason for exclusion: Ineligible study design

Nnaji RN, Friedman T. Sexual dysfunction and schizophrenia: psychiatrists' attitudes and training needs. Psychiatr. 2008; 32(6):208-10.
Reason for exclusion: Ineligible patient population

Olfson M, Uttaro T, Carson WH, Tafesse E. Male sexual dysfunction and quality of life in schizophrenia. J Clin Psychiatry. 2005; 66(3):331
Reason for exclusion: Ineligible study design

Ozcan NK, Boyacıoğlu NE, Enginkaya S, Dinc¸ H, Bilgin H. Reproductive health in women with serious mental illnesses. J Clin Nurs. 2014; 23(9-10):1283-91.
Reason for exclusion: Ineligible study design

Pandor A, Kaltenthaler E, Higgins A, Lorimer K, Smith S, Wylie K, Wong R. Sexual health risk reduction interventions for people with severe mental illness: a systematic review. BMC Public Health. 2015; 15(1):138.
Reason for exclusion: Ineligible study design

Quinn C, Browne G. Sexuality of people living with a mental illness: a collaborative challenge for mental health nurses. Int J Ment Health Nurs. 2009; 18(3):195-203.
Reason for exclusion: Ineligible patient population

Quinn C, Happell B. Getting BETTER: Breaking the ice and warming to the inclusion of sexuality in mental health nursing care. Int J Ment Health Nurs. 2012; 21(2):154-62.
Reason for exclusion: Ineligible patient population

Raja M, Azzoni A. Sexual behavior and sexual problems among patients with severe chronic psychoses. Eur Psychiatry. 2003; 18(2):70-6.
Reason for exclusion: Ineligible study design

Sansone RA, Chu JW, Wiederman MW. Sexual behaviour and borderline personality disorder among female psychiatric inpatients. Int J Psychiatry Clin Prac. 2011; 15(1):69-73.
Reason for exclusion: Ineligible study design

Sansone RA, Sellbom M, Songer DA. A survey of same-sex sexual experiences among psychiatric inpatients with and without borderline personality symptomatology. Prim Care Companion CNS Disord. 2016;18(2): 22-36.
Reason for exclusion: Ineligible study design

Sarısoy G, Kaçar ÖF, Pazvantoğlu O, Korkmaz IZ, Öztürk A, Akkaya D, Yılmaz S, Böke Ö, Sahin AR. Internalized stigma and intimate relations in bipolar and schizophrenic patients: a comparative study. Compr Psychiatry. 2013; 54(6):665-672.
Reason for exclusion: Ineligible study design

Segalovich J, Doron A, Behrbalk P, Kurs R, Romem P. Internalization of stigma and self-esteem as it affects the capacity for intimacy among patients with schizophrenia. Arch Psychiatr Nurs. 2013; 27(5):231-4.
Reason for exclusion: Ineligible study design

Selby EA, Braithwaite SR, Joiner Jr TE, Fincham FD. Features of borderline personality disorder, perceived childhood emotional invalidation, and dysfunction within current romantic relationships. J Fam Psychol. 2008; 22(6):885.
Reason for exclusion: Ineligible study design

Singh D, Berkman A, Bresnahan M. Seroprevalence and HIV-associated factors among adults with severe mental illness: a vulnerable population. SAMJ: S Afr Med J. 2009; 99(7):523-7.
Reason for exclusion: Ineligible study design

Tharoor H, Anandhalakshmi Kaliappan SG. Sexual dysfunctions in schizophrenia: Professionals and patients perspectives. Ind J Psychiatry. 2015; 57(1):85.
Reason for exclusion: Ineligible study design

Werner S. Needs assessment of individuals with serious mental illness: Can it help in promoting recovery? Community Ment Health J. 2012; 48(5):568-73.
Reason for exclusion: Ineligible study design

Westheide J, Helmstaedter C, Elger C, Cooper-Mahkorn D, Sträter B, Maier W, Kühn KU. Sexuality in male psychiatric inpatients. A descriptive comparison of psychiatric patients, patients with epilepsy and healthy volunteers. Pharmacopsychiatry. 2007; 40(5):183-90.
Reason for exclusion: Ineligible study design

Young adult with psychotic disorders have problems related to sexuality, intimacy and relationships. An explanatory study based on focus groups

de Jager, J., Wolters, H.A., Pijnenborg, G.H. (2016)
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YOUNG ADULT WITH PSYCHOTIC DISORDERS HAVE PROBLEMS RELATED TO SEXUALITY, INTIMACY AND RELATIONSHIPS. AN EXPLANATORY STUDY BASED ON FOCUS GROUPS

ABSTRACT

Background: *Research has shown that young adults with psychotic disorders frequently have problems relating to sexuality, intimacy and relationships. Such problems are often neglected in clinical practice.*

Aim: *To perform a study that explores, on the basis of focus groups, how issues such as sexuality, intimacy and relationships can be addressed as part of the treatment of adolescents suffering from a psychotic disorder.*

Method: *We created eight focus groups consisting of clients attending the department of psychotic disorders and caregivers who worked there. The meetings of each focus group were fully transcribed and analysed by means of Nvivo.*

Results: *Clients indicated they wanted to address the topics of sexuality, intimacy and relationships in a group setting. They expressed the wish to have mixed gender groups and decided that in the group discussions the main focus should be on the exchange of personal experiences.*

Conclusion: *In our view, it is desirable that psychiatry pays more attention to the subject of sexuality. By providing the opportunity to discuss experiences, problems, feelings and insecurities in a gender mixed group setting and a low-threshold environment, the care for young adults with psychosis can be optimized.*

About 20% of the Dutch population struggles with sexual problems such as pain during intercourse or erectile dysfunctioning (Kedde e.a. 2006). For people with a mental disorder, this percentage is 67% (Drunen e.a., 2009). The percentage of sexual dysfunctioning is the highest among people with a psychotic disorder, about 86-96% (Macdonals e.a. 2003).

Medication is often an evil-doer: the use antipsychotics leads in 30 till 60% of the cases to sexual problems in which loss of libido, erectile dysfunction of lubrication problems and orgasm difficulties are the most often reported (Knegtering e.a. 2007). Side effects on sexual functioning often lead to non-adherence of medication (Perkins 2002). Also, psychological factors such as a lack of knowledge and information, low self-esteem, cognitive problems such as weakened motivation may lead to omission of contraceptive use. This may cause

STD's and unwanted pregnancies (Abernethy e.a. 1974; Cournos e.a. 1994).

It appears a challenge for youth with a psychotic disorder to engage in desired interaction and to hold off undesired interactions (Verhulst & Schneidman 1981).

Besides that, schizophrenia usually manifests in adolescence, a phase in which sexuality usually evolves. Partially due to this fact, the manifestation of psychosis may complicate the evolution of a person's sexuality.

The discussed literature underlines the importance of attention for sexuality, intimacy and relationships within mental health care settings. Yet, the topic is often ignored by caregivers, even if the caregiver is aware of existing problems (Katz 2005b; Krebs 2006; Shell 2007). Caregivers usually only engage in conversations on sexuality when initiated by clients, which hardly happens (Fortier e.a. 2003; Guthrie 1999; McCann 2003; Quinn & Browne 2009; Shield e.a. 2005). This leads to the following research question: In what way should caregivers pay attention to sexuality, intimacy and relationships within the care for young adults with psychotic disorders?

Method

We answer the research question by conduction qualitative research using focus groups among young adults with a psychotic disorder and professionals providing care to this group. Focus groups consist of a series of planned discussions with the aim of finding out the perceptions of the target group in a safe environment (Krueger & Casey 2014). The core of focus groups as a method is the reciprocal interaction of the participants.

In total 17 clients and 15 professionals participated in the study (see table 1). Participants were recruited in a center for young adults with first psychosis, part of mental health center GGZ Drenthe and a center for psychosis, part of the University center of Psychiatry (UCP).

Inclusion criteria were a psychotic disorder, and an age between 16 and 35. Exclusion criteria were an estimated IQ < 70, problems that complicate normal functioning in a group setting such as aggression, as judged by the clinician. The aim was to include a minimum of 3 and a maximum of 8 participants per focus group. The focus groups for clients were male of female only in order to enhance safety and openness. The professionals that were approached to participate were all clinicians working for the department for early psychosis of GGZ Drenthe.

Procedure

The medical ethical committee of the University medical Centre Groningen approved the study. Clients that met the inclusion criteria were invited to participate by their clinician and if they were willing, contacted by the researchers. The researchers directly contacted the professionals. Prior to the focus groups, all participants were briefed on the aim of the study and asked to fill in an informed consent. The focus group meetings were led by an

Table 1. Overview of participants

Group	N	Description	Gender	Mean age	Rage	SD
Clients I	2	CEP GGZ Drenthe	Female	27	25-28	2.25
Clients II	4	CEP GGZ Drenthe	Male	22	19-29	4.69
Clients III	5	CEP GGZ Drenthe	Male	31	27-35	4.35
Clients IV	3	CEP GGZ Drenthe	Female	28	27-30	2.08
Clients V	3	UCP -UMCG	Male	28	23-33	3.93
Professionals I	8	Psychologist, psychology assistents	Male(40%) Female (60%)	34	24-52	9.29
Professionals II	4	Psychiatrists	Female (50%) Male (50%)	49	30-62	13.78
Professionals III	3	Art- and psychomotor therapists	Female (60%) Male (30%)	38	36-42	3.21

CEP: Centre for early psychosis – GGZ Drenthe

UCP-UMCG: clinic for early psychosis, part of university centre of psychiatry – Groningen

experienced moderator and video recorded.

A funnel approach was used during the meetings, which entails that a meeting starts broadly and globally to create a general brainstorm (Hennink e.a. 2010). As the meeting progresses, more structure and guiding will be provided in order to gather information on the specific topics formulated on the in advance prepared topic list. During the meetings, a script was used in which a fixed introduction, the topic, core questions and a fixed ending were provided.

Data analysis

The moderator made notes of observations such as specific interactions and the intensity of showed emotions. These were used as a tool during the interpretation and analyses of the data. The recorder meetings were all fully transcribed. The analyses were carried out by a stepwise coding procedure (Krueger & Casey 2014; Morgan & Krueger 1997) using Nvivo software.

Results

The importance of sexuality and related topics

All clients underlined the importance of paying attention to sexuality, intimacy and relationships within the context of their treatment. Most clients (76%) pointed out that sexual issues are currently not a topic that is talked about. Being the one to raise the topic

is for most clients way to scary. Only one participant said that he thought himself able to raise the topic. An illustrative quote was:

"I believe it is important to talk about this, since it really is an issue. Being mentally ill raises many questions and I don't know how to find answers right now."

Also, all the participating professionals underlined the importance of the topic. 73% thought it important to 'open the door towards a need or question'; 66% found 'providing education and acknowledging a clients problems' important reasons to raise the topic of sexuality, intimacy and relationships. Decreasing the risk of non-compliance to medication was for 44% a reason to raise the topic, just as decreasing sexual risk behaviors. An illustrative quote was:

"You just see the need for intimacy and relationships and struggle of not being able to get this".

Time was said to be most important reason for the current lack of attention. Some admitted to find the topic difficult to bring up in conversations with clients.

What the conversation should be about

Clients expressed feelings of insecurity and a perceived lack of skills in contact with peers (88%). The felt need for relationships and intimacy was nevertheless strong.

"I would like to have a girlfriend, but I think the social part would be hard for me. I really don't know how to go about this. I don't have any experience in this".

As many young adults share experiences with sexuality and intimacy with each other, young adults with SMI express that they hardly even talk about these topics among each other. There appeared to be uncertainty among the participants about the role that being sick played in contact with others (83%). An illustrative statement was:

"I prefer a partner from outside of psychiatry, someone that is stable. That is actually what I need. But yeah, is that realistic? Does a healthy person want to be with someone like me? I often wonder."

Self-stigma, inferiority and uncertainty due to the psychotic vulnerability is an issue that all clients appeared to experience. 78% said they would like to discuss these experiences and issues with peers. Difficulties in feeling your own limits, guarding these limits and using the social skills to effectively communicating these limits was mentioned as an important issue by more than half of the female participants. For male participants however, this did not seem important. Information about the role of medication was important to both men

and women (60%). It was unanimously stated that currently, insufficient attention is paid to this topic.

The focus groups with healthcare professionals showed that all healthcare professionals found the biological aspects of sexuality most urgent. 83% found attention for engaging in social contacts and relationships important.

How to shape the conversation?

The most important conditions that were mentioned: voluntary participation and a safe atmosphere. 78% of clients would like to see meetings in a mixed group context because this enables the sharing of experiences and offers the opportunity to learn from each other. Problems that are directly related to one's own sexual functioning should be raised and addressed in the individual context. The healthcare professionals appeared more cautious about whether or not to address sexuality and intimacy in a group context. 50% thought the group context to be to unsafe for discussing such themes.

Discussion

Attention to sexuality should undeniably play a role in the current recovery oriented treatment of young adults with a psychotic vulnerability. In clinical practice, this appears not to be the case. It is well possible that caregivers are too careful: half of the healthcare professionals indicated that talking about sexuality and intimacy within a group setting would be to unsettling, while clients indicate that they actually wish to share experiences concerning sexuality and intimacy in a group context.

However, topics directly related to one's own sexual functioning, such as a sexual function disorder, should be addressed within individual context. Caregivers must actively inquire about these topics. The fear of having insufficient knowledge about sexuality and intimacy raises a threshold among caregivers. This study however suggests that substantive knowledge is not required: the largest need among clients lies in the exchange of experiences with peers in a safe environment. Group dynamic skills of caregivers might be of more importance than substantive knowledge about sexuality, intimacy and relationships.

Limitations

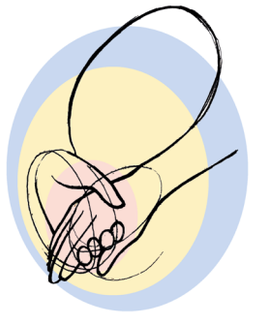
Due to the relatively small sample, there is a risk of insufficient generalizability toward the entire target group. Also, due to the voluntary participation, a selection bias may have occurred. It may be more burdensome to participate for clients who experience personal issues of insecurities concerning the research theme, which may refrain then from entering the study. This could lead to underreporting of issues. On the other one could argue that overreporting could also occur as people who experience uncertainties or problems related to the research issue might feel more urged to participate.

The results show that young adults with psychosis would like to address issues such

as; how to enter in and maintain relationships and how to deal with being mentally vulnerable in the context of romantic relationships, in a mixed group setting. As focus groups are a group setting as well, issues of a more personal nature may have become overshadowed. Taking this into account, future research should repeat the current study by using in depth interviews. Also, data triangulation may enhance the reliability of findings.

Clinical implications

The results of this study provide tools for the implementation of attention for sexuality, intimacy and relationships in the context of mental health services. Mixed group meetings with voluntary participation, focused on the sharing of experiences, may meet an existing need for care. In these meetings, a facilitators' group dynamic skills, may be of more importance than actual extensive knowledge on sexuality and intimacy.



References

Abernethy V, Grunebaum H, CloughL, Hunt B, Groover B. Family planning during psychiatric hospitalization. *Am J Orthopsychiatry 1974*; 46: 154-62.

Cournos F, Guido JR, Coomaraswamy S, et al: Sexual activity and risk of HIV infection among patients with schizophrenia. *Am J Psychiatry 1994*; 151: 228-32.

Fortier P, Mottard JP, Trudel Q, Even S. Study of sexuality-related characteristics in young adults with schizophrenia treated with novel neuroleptics and in a comparison group of young adults. *Schizophr Bull 2003*; 29: 559-72.

Guthrie C. Nurses' perceptions of sexuality relating to patient care. *J Clin Nurs 1999*; 8: 313-21.

Hennink M, Hutter I, Baley A. *Qualitative research methods.* Londen: Sage; 2010.

Katz A. Sexually speaking. Do ask, do tell. Why do so many nurses avoid the topic of sexuality? *Am J Nurs 2005*; 105: 66-8.

Kedde H, Haas S de. Problemen met het seksueel functioneren. In: Bakker F, Vanwesenbeek I, red. *Seksuele gezondheid in Nederland.* Delft: Eburon; 2006.

Knegtering H, Bruggeman R, Castelein S, Wiersma D. Antipsychotica en seksueel functioneren bij mensen met psychosen. *Tijdschr Psychiatr 2007*; 49: 733-42.

Krebs L. What should I say? Talking with patients about sexuality. *Clin J Oncol Nurs 2006*; 10: 313-5.

Krueger RA, Casey MA. *Focus groups: a practical guide for applied research.* 5e ed. Thousand Oaks: Sage; 2014.

Labor N, Medeiros D, Carlson E, Pullo N, Seehaus M, Peake K, e.a. Adolescents' need to talk about sex and sexuality in an urban mental health setting. *Social Work in Mental Health 2008*; 3: 135-3.

McCann E. Exploring sexual and relationship possibilities for people with psychosis – a review of the literature. *J Psychiatr Ment Health Nurs 2003*; 10: 640-9.

Morgan DL, Krueger RA. *The focus groups kit.* Londen: Sage; 1997.

Perkins DO. Predictors of noncompliance in patients with schizophrenia. *J Clin Psychiatry 2002*; 63: 1121-8.

Quinn C, Browne G. The sexuality of people living with a mental illness: A collaborative challenge for mental health nurses. *Int J Ment Health Nurs 2009*; 18: 195-203.

Shell JA. Including sexuality in your nursing practice. *Nurs Clin North Am 2007*; 42: 685-96.

Shield H, Fairbrother G, Obmann H. Sexual health knowledge and risk behaviour in young people with first episode psychosis. *Int J Ment Health Nurs 2005*; 14: 149-54.

Verhulst J, Schneidman B. Schizophrenia and sexual functioning. *Hosp Community Psychiatry 1981*; 32: 259-62.

Sexual Expression and It's Determinants, in People Diagnosed with Psychotic Disorders

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SEXUAL EXPRESSION AND IT'S DETERMINANTS, IN PEOPLE DIAGNOSED WITH PSYCHOTIC DISORDERS

ABSTRACT

This qualitative study aims to explore the difficulties people with a psychotic disorder have in sexual expression, and associated determinants. Twenty-eight semi-structured interviews were conducted and analyzed using the Grounded Theory method. Almost all participants experienced unfulfilled needs in sexual expression. These unfulfilled needs were associated with a range of factors, including antipsychotic medication, psychotic symptoms, sexual abuse, social skills and stigma, all of which may converge on a pathway involving (sexual) self-esteem. Further research is required to better understand the role of self-esteem in relation to sexual needs and expression in people with psychotic disorders.

INTRODUCTION

In surveys, around 15% of the general population indicates dissatisfaction with his or her sex life (Mulhall et al. 2008). This percentage is as high as 64% in people with a mental disorder diagnosed in the realm of psychosis (Östman 2014). Despite the fact that 83% experiences sexual feelings, people with a psychotic disorder often report not being able to express their sexuality (Peitl et al. 2009; McCann 2010). Sexual expression describes the way a person experiences sexuality and communicates sexuality with others. Expressing sexuality includes three factors: sexual behavior, sexual communication and sexual identity (Harvey et al. 2004).

Sexual expression plays an important role in self-definition, as expressing sexuality can confirm the sense of being a man or woman, which is important for self-esteem and identity (Volman and Landeen 2007). It is influenced by biological, psychological and social factors (Denman 2004). Therefore, a bio-psycho-social approach may shed more light on the difficulties people diagnosed with a psychotic disorder face in the field of sexuality and their sexual expression. Patients who have had psychotic symptoms often suffer from deficit symptoms. These symptoms as well as the use of antipsychotic drugs have impact on their sexual expression. Lack of motivation or desire, arousal and orgasm are common problems (Harley et al. 2010; Van Sant et al. 2012). Sexual dysfunctions caused by the side-effects of medication play an important role in the observed high rates of non-adherence among

people diagnosed with a psychotic disorder (Malik et al. 2010). Further, the body image is often perceived negatively by weight gain as a side-effect of antipsychotic drugs (Volman and Landeen 2007; Östman and Björkman 2013).

Usually, the onset of a psychosis occurs in adolescence or young adulthood, a phase during which sexuality and psychosocial skills also develop (Whisman et al. 2014). A psychotic episode may lead to a later onset or absence of sexual experience, less knowledge and fewer skills to develop sexual roles and to connect to others in a sexual fashion (Volman and Landeen 2007). Fears and doubts about sexual orientation (Skodlar and Nagy 2009), low sexual confidence and feelings of sexual incompetence may develop (Peitl et al. 2009; Kelly and Conley 2004).

Social factors concern the limitations in social skills and social insight that people with a psychotic disorder may experience (Peitl et al. 2009; Savla et al. 2013). Several studies show that this may impede the ability to start or maintain sexual relations (Pinkham et al. 2007; Lysaker et al. 2007; Van Sant et al. 2012). Östman and Björkman (2013) indicate that patients and partners hardly communicate about issues related to their sexual relationship. Earlier literature shows that stigma is also an important social barrier to expressing sexuality (McCann 2003; Cook 2000) and may become an obstacle in forming relationships because of fear of rejection (de Jager et al. 2017; Wright et al. 2007).

Although the literature indicates several biological, psychological and social factors that affect sexual expression, a focus on biological factors dominates (Jager and McCann 2017). Research into the subjective sexual experiences, problems and needs of people with psychotic disorders is scarce. De Jager and McCann (2017) stated that practice and research focusing on psychosocial aspects of sexuality is required in order to develop strategies that address unmet needs in the field of intimacy and sexuality among people with a psychotic disorder. The aim of this study is 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.

Method

A qualitative study was conducted and the Grounded Theory (Glaser and Strauss 1967) was used to analyze the data. Grounded Theory is a systematic methodology involving the construction of theory through methodic gathering and analysis of data. During the revision of the data, repeated ideas, concepts or elements become apparent, and are tagged with codes. As more data is collected, and re-reviewed, codes can be grouped into concepts, and then into categories. Data collection was carried out parallel to data analysis until saturation was reached and new research data did not provide any new information (Baarda et al. 2005; Charmaz 2006). Participants were recruited from community mental health teams specialized in flexible assertive community treatment (FACT). The participants

were (a) currently diagnosed by their clinician with a psychotic disorder (including a DSM-IV diagnosis of schizophrenia, schizoaffective disorder, schizophreniform disorder, and psychotic disorder NOS), (b) ranged in age from 18 to 65 years and (c) had to be capable to provide written informed consent. People were excluded when their clinician determined (a) a florid psychotic state, which significantly affected their mental competence to consent, and/or (b) an IQ below 70. When a formal IQ assessment was missing, the IQ's were estimated based on educational levels.

Participants were recruited by convenience sampling and received no reward for their participation. Data was collected by semi-structured, in-depth interviews lasting approximately 1–2 h, conducted by two researchers. The interview contained 43 open-end questions about the patient's sexual expression, his or her existing (unfulfilled) needs regarding sexual expression and related problems. Significant observations of emotions and nonverbal behaviors during the interviews were included. Follow-up was facilitated when needed.

The interviews were audio recorded and transcribed verbatim. The data was coded in Atlas.ti software (Muhr 1991) (Version 1.6.0) and analyzed in three stages (Boeije 2005). During the first stage, open coding, fragments of transcripts of the interviews and observations were coded and organized in themes. The second stage, axial coding, focused on fragments and codes that were relevant to the research question in order to outline and unravel relationships surrounding the themes. The third stage, selective coding was applied until saturation was reached (Boeije 2005).

In order to ensure internal reliability, two other researchers independently coded one-third of the transcripts of the interviews. These coded transcripts were compared and differences were discussed in order to reach consensus and achieve comparable results.

Compliance with Ethical Standards

The Institutional Review Board of the Noord-Holland-Noord mental health care organization approved the study. Participants gave verbal and written informed consent and were all mentally competent to give consent, as indicated by their clinician. There was no conflict of interest.

Results

Participants

Thirty-two people with a psychotic disorder were recruited. After an extensive briefing session, four people declined, for reason of current mental health problems (n = 2) or the research topic being too intimate (n = 2). Twenty-eight participants, aged 22 to 62 years (mean = 42 years, SD = 10.2), participated (Table 1). Throughout the result section, quotes of the participants will be used to illustrate the findings.

Table 1. Demographic characteristics

	Male ($n=19$) n (%)[a]	Female ($n=9$) n (%)[a]	Total (N=28) N (%)[a]
Age			
18–29	3 (16)	1 (11)	4 (14)
30–39	4 (21)	1 (11)	5 (18)
40–49	10 (53)	3 (33)	13 (64)
50 or older	2 (11)	4 (44)	6 (21)
Sexual identity			
Heterosexual	18 (95)	7 (78)	25 (89)
Bisexual	0 (0)	2 (22)	2 (7)
Homosexual	1 (5)	0 (0)	1 (4)
Marital status			
Married or cohabitating	3 (16)	3 (33)	6 (21)
In a relationship, not cohabitating	3 (16)	1 (11)	5 (18)
Divorced/single/widowed	13 (68)	5 (56)	17 (61)

[a]Totals may exceed 100% due to rounding

Sexual Needs

Almost all participants described sexuality as a natural, basic need and an important aspect of life (79%). Participants defined sexuality as the satisfaction of sexual needs as well as a way of expressing and receiving intimacy and love. Three-quarters of the participants felt that sexuality is only meaningful in a romantic relationship that involves love and intimacy. 82% reported unmet needs in their sexual expression. “You learn to deal with it. Sure. But I miss it. Yes, you can also visit a prostitute, but that’s not what I’m looking for. I guess I have to wait for a relationship. But how do I do that?” (Male, 46 years). Some participants (11%) had little or no need for sexual expression, which was mainly due to side-effects from medication.

Factors That Affect Sexual Expression

We identified the following factors and sub-factors that appeared to affect sexual expression:

Direct (Side) Effects of Antipsychotics

Half of the participants indicated that the use of medication seriously affected the need for and perception of sexuality. Apart from the effects on libido, 21% of the men had trouble in erectile functioning and 26% reported problems with ejaculation.“I could not reach an orgasm. I cannot explain how frustrating that is ...” (male, 41 years). Two women reported lubrication problems. The sexual dysfunctions participants mentioned interfered

with intercourse and masturbation, but also led to lower sexual self-esteem and shame about sexual dysfunction. “I have been laughed at because I could not get an erection. That’s not pleasant” (male, 53 years). These problems often resulted in the avoidance of intimacy and sexuality.

Indirect Effects of Antipsychotics

Flattened affect, cognitive problems, increased salvation, fatigue and weight gain were reported side-effects that affected sexual self-esteem, making participants more hesitant towards engaging in sexual contact; “Well, you’ve become fat. (...) You feel unattractive” (male, 41 years). These side-effects also limited sexual communication with partners and the capacity for engaging in (sexual) contact with potential partners: “I felt numb. Sometimes, when I went out, I sat with people who had a conversation and I could not follow. It all went too fast” (Female, 33 years). Direct Effects of Psychotic Symptoms The need for sexual expression may change during a psychotic episode. Some participants (14%) experienced less or no sexual feelings at all during their psychosis. A third (32%) noticed an increase in sexual feelings. For some (18%), this was combined with less awareness of personal limits and a decreased ability to communicate needs, desires and boundaries, which made them vulnerable towards sexual risk-taking. In some participants, the increase in sexual feelings and risk-taking could be traced back to psychotic symptoms with sexual content (7%).

Apart from changes in libido and sexual communication, having a psychotic episode appeared to have an effect on sexual identity. A number of participants explained that they lost contact with reality during a psychotic episode, and in that state they experienced an unstable self-image, and doubts and anxiety about sexual orientation (18%) and gender identity (7%). “I fancy women, …, but …I mean, if you are psychotic then sometimes… you just don’t know anymore” (female, 33 years). For some, doubts about sexual orientation led to experimenting with sexuality during a psychotic episode with someone of the other sex than they were previously attracted to. Afterwards, some of the participants experienced shame and confusion over these feelings and behaviors, as well as lingering doubts.

Indirect Effects of Psychotic Symptoms

Some participants experienced feelings of shame about their behavior during a psychotic episode (18%). They explained how they had to rebuild their identities and everyday life before they could express themselves again sexually. “Feelings of guilt of course, about how you’ve behaved. (...) We had to sit down and regain trust and respect for each other (...). (...) and yes well, questions like: who am I really? Where am I going?” (Female, 45 years). Some participants (11%) avoided sexual expression in order to protect their mental stability. Falling in love, sexual intercourse, rejection and relationship problems were seen as a possible cause of psychotic decompensation. “I just try not to fall in love anymore, it is too much” (female, 33 years). For others, the experience of psychosis and overcoming the struggles meant growing as a person and a sexual being.

Sexual Trauma

More than half of the participants had experienced sexual trauma in the past, varying from sexual assault to multiple rapes. All indicated an effect on their sexuality. “Well if you went through something like that, you just do not have much self-respect anymore” (female, 29 years). At least half of the participants who had been sexually abused, never or hardly ever told others. “I’ve been sexually abused by my father in the past. (...) I never told anyone. And, uh, it’s only when my father deceased, that I told my husband. (...) And that has had its effect on our sexual relationship. Yes, these are quite difficult things” (Female, 53 years). Especially guilt and shame about sexual abuse appeared to act as barriers in communicating these experiences. Some of the participants explained that the experience of guilt and shame was due in part to ‘forbidden’ positive feelings about sexual acts during the abuse.

Participants explained how, during sexual activity in the present, memories of the sexual trauma were activated, causing their bodies to ‘lock down’. They expressed how hard it is to endure, let alone enjoy, being touched intimately. In some participants, these experiences increased doubts about whether they “were worthwhile”, which made it more difficult to feel (sexually) confident.

In some participants (14%), sexual trauma seemed to be related to doubts about sexual orientation (14%). Two male participants who had been sexually abused and experienced sexual problems explained how they found a way to deal with these issues by taking on the dominant role within sadomasochistic (SM) sex “(...) Within SM I feel confident, then it just goes better” (male, 53 years). The dominant role seemed to compensate for feelings of inferiority due to dysfunctions. In this way, SM appeared to allow them to gain positive experiences, which helped rebuild sexual confidence.

Social Skills

Among half of the participants, difficulties in social skills were mainly reflected in impairments in social cognition (46%). This may lead to misunderstandings and decreased (sexual) communication among partners (32%) and to reduced access to sexual partners among unmarried participants (46%). “I can’t do it..... Basically I’m avoiding it all. And if I somehow have to go and meet people, I have no idea what’s interesting or which subject that person likes to talk about. Nerve wrecking” (...) (male, 42 years). Three quarters of unmarried participants did not know how to make contact in order to achieve a (sexual) relationship (77%). “If you haven’t had a relationship for a long time, you don’t know how to approach a woman” (male, 46 years). More than a third of the participants was using the internet to connect with other men and women (39%). Participants explained that the physical distance tended to decrease performance anxiety.

Stigma

More than two-thirds of the participants experienced public stigma because of their psychotic disorder (68%). In addition, more than a third of the participants had faced rejection from friends and intimate (sexual) contacts after a psychotic episode or after the disclosure of their psychosis susceptibility. Fearing negative reactions to the disclosure of a psychotic disorder, the majority of the participants refrained from disclosing at all (54%). In more than half (61%) of the participants, internalization of stigma occurred: “I find it difficult to engage in a relationship because I am afraid no one would want me, all those problems... (...) Then I think to myself; what do I have to offer?” (Female, 31 years). “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” (female, 57 years). Due to reduced confidence, many participants refrained from engaging in any relationship, causing 29% of the participants to not being in a sexual relationship for over 7 years.

Discussion

This qualitative study examined the unmet needs and problems in sexual expression in people diagnosed with a psychotic disorder. Contrary to common belief, sexuality and sexual expression were perceived as important and basic needs. The data showed that sexual expression remained mostly unfulfilled among participants and that the unmet needs are due to a variety of barriers including a high prevalence of sexual dysfunction. These findings are consistent with earlier studies (McCann 2010; Östman and Björkman 2013; Peitl et al. 2009; Huguelet et al. 2015; Östman 2014; Fan et al. 2007). Other problems reported by the participants included: low frequency of sexual activity (mainly intercourse), difficulties in sexual communication (especially explicit communication about sexual feelings, needs and limits), and instability in sexual identity. A combination of biological, psychological and social factors influenced these barriers in sexual expression.

Antipsychotics had direct impact on sexual expression, but participants also experienced indirect effects, like feelings of shame and low (sexual) self-confidence, which led to problems in physical intimacy. Previous research suggests that sexual dysfunction reduces (sexual) self-confidence, while low (sexual) self-confidence in turn can worsen sexual dysfunction (Raja and Azzoni 2003; Baggaley 2008; McCabe et al. 2010). Additional changes in appearance and shame about sexual dysfunction could cause altered experience of pleasure related to sex and intimacy or lead to outright avoidance of sexuality and intimacy. Earlier studies reported similar results (Higgins et al. 2005).

Like previous research (Skodlar and Nagy 2009; Rajkumar 2014), in the current study, some participants experienced an unstable sense of self and identity during a psychotic episode associated with changes in sexual desire, sexual activity and identity. Afterwards, these changes often led to shame about these behaviors, thoughts and feelings, which

affected self-esteem and sexual expression in a negative fashion (Skodlar and Nagy 2009). Attention to the experience and expression of sexuality during a psychotic episode appears important in order to reduce the impact of these (afterwards possibly seen as negative) experiences on the self. An open discussion in which psycho-education, normalization and a sincere interest are combined would be required.

Sexual trauma also affected (sexual) self-image and self confidence. Even though the participants reporting sexual trauma experienced no flashbacks or other symptoms related to sexual trauma in daily life, expressing sexuality was problematic for some. Sexual contact in the present could evoke memories of abuse in the past, causing the body to respond involuntarily, causing it to 'lock-down'. This suggests that the absence of symptoms of PTSD does not mean there is no effect of the trauma on the sexual expression in the present. In the process of clinical diagnosis and treatment of trauma-related complaints, sexual functioning in the present should not be overlooked. Fear, guilt and shame led participants to refrain from talking about trauma with partners or professionals. This suggests it is essential that clinicians always actively inquire about (sexual) trauma and it's effect on sexual functioning.

Another finding was related to coping with problems in sexual expression. Some participants found a way to deal with dysfunctions in sexual expression by taking a dominant role in SM, thus compensating feelings of inferiority. This finding may suggest that regaining self-confidence and possibly even dominance can help overcome sexual barriers. Research on this topic is scarce, although Wismeijer and Assen (2013) also found an association between SM (dominance) and reduced uncertainty about sexual dysfunction.

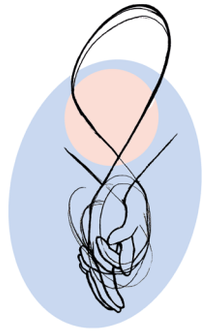
Difficulties in estimating the meaning of social cognition were associated with problems in sexual expression in a number of participants. This result resonates with findings linking alterations in 'theory of mind' and social cognition to psychotic disorder (Savla et al. 2013).

In the current study, experiencing stigma also appeared associated with reduced sexual confidence. This corresponds to what was found elsewhere (Segalovich et al. 2013; McCann 2010). Some participants seemed to internalize stigma, perceiving themselves as 'unsuitable' as a (sexual) partner due to their vulnerability, sometimes even leading to sexual isolation, as noted in previous research (de Jager et.al. 2017; Wright and Gayman 2005; Wright et al. 2007; Brohan et al. 2013; Smith and Herlihy 2011).

The results of the current study suggest that a combination of the above-mentioned bio-psychosocial factors interfere with the sexual expression of people diagnosed with a psychotic disorder. A possible unifying factor in the frequent presence of insecurity and shame is low (sexual) selfconfidence. Previous research suggests that uncertainty and shame are manifestations of lower (sexual) self-confidence (Jacoby 1996; Leary et al. 1995) and that people with psychosis experience a significantly lower (sexual) self-esteem than the general population, decreasing the ability to build intimacy with others, thus making it less likely to enter into a sexual relationship (Peitl et al. 2009; Cook 2000). Conversely, low (sexual) self-confidence seems to increase the inhibiting effect of these factors. It may be that the unmet need for sexual expression is explained by a combination of bio-psychosocial factors, in which low self-esteem plays a central role.

The current study has several limitations that affect the external validity. First, no comparisons were made with people with other diagnoses or with the normal population. Therefore, it is unknown to what extent some of the results are specifically associated with psychotic disorders. Second, the method of selection of participants could reduce the generalizability of the results. Thirdly, there are limitations in the representativeness of the sample. Although the composition of men and women in the sample is in accordance with the composition of the actual population in mental health care, the sample consisted of a large number of male participants in the same age group.

Due to the explorative nature of this study, further research is required to test the hypotheses as generated about the possible association between (sexual) confidence and the observed bio-psycho-social factors. Possible gender differences should also be addressed. The current results underline the importance of incorporating (problems in) sexual expression in mental health care practice and offers insight into which factors can be of importance. In clinical practice; just like regaining a social life or a paid job can be a component of a treatment plan, if chosen by a client, regaining sexual expression can be as well. Also, it's important for caregivers to keep in mind, that even if a (sexual) problem can't be fixed, it is still important to offer the possibility to talk about it.



References

Baarda, D. B., Goede de, M. P. M., & Teunissen, J. (2005). *Basisboek kwalitatief onderzoek. Handleiding voor het opzetten en uitvoeren van kwalitatief onderzoek.* Groningen: Wolters Noordhoff.

Baggaley, M. (2008). Sexual dysfunction in schizophrenia: focus on recent evidence. *Human Psychopharmacology, 23*(3), 201–209.

Boeije, H. R. (2005). *Analyseren in kwalitatief onderzoek: Denken en doen.* Amsterdam: Boom Onderwijs.

Brohan, E., Clement, S., Rose, D., Sartorius, N., Slade, M., & Thornicroft, G. (2013). Development and psychometric evaluation of the discrimination and stigma scale (DISC). *Psychiatry Research, 208*(1), 33–40.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative research*. London: Sage.

Cook, J. A. (2000). Sexuality and people with psychiatric disabilities. *Sexuality Disability, 18*(3), 195–206.

de Jager, J., Ciragoglu, B., Nugter, A., & van Os, J. (2017). Intimacy and its barriers: A qualitative exploration of intimacy and related struggles among people diagnosed with psychosis. *Psychosis, 9*(4), 301–309.

de Jager, J., & McCann, E. (2017). Psychosis as a barrier to the expression of sexuality and intimacy: An environmental risk? *Schizophrenia Bulletin, 43*(2), 236–239.

Denman, C. (2004). *Sexuality: A biopsychosocial approach.* London: Sage.

Fan, X., Henderson, D. C., Chiang, E., et al. (2007). Sexual functioning, psychopathology and quality of life in patients with schizophrenia. *Schizophrenia Research, 94*(1), 119–127.

Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research.* New York: Aldine.

Harley, E. W. Y., Boardman, J., & Craig, T. (2010). Sexual problems in schizophrenia: prevalence and characteristics: A cross sectional survey. *Social Psychiatry and Epidemiology, 45*(7), 759–766.

Harvey, J. H., Wenzel, A., & Sprecher, S. (2004). *The handbook of sexuality in close relationships.* Mahwah, NJ: Lawrence

Erlbaum. Higgins, A., Barker, P., & Begley, C. M. (2005). Neuroleptic medication and sexuality: The forgotten aspect of education and care. *Journal of Psychiatric and Mental Health Nursing, 12*(4), 439–446.

Huguelet, P., Mohr, S., Miserez, C., et al. (2015). An exploration of sexual desire and sexual activities of women with psychosis. *Community Mental Health Journal, 51*(2), 229–238.

Jacoby, M. (1996). *Shame and the origins of self-esteem: A Jungian approach.* Londen: Routledge.

Kelly, D. L., & Conley, R. R. (2004). Sexuality and schizophrenia: A review. *Schizophrenia Bulletin, 30*(4), 767–779.

Leary, M. R., Tambor, E. S., Terdal, S. K., & Downs, D. L. (1995). Self-esteem as an interpersonal monitor. *Journal of Personality and Social Psychology, 68*(3), 518–530.

Lysaker, P. H., Davis, L. W., Warman, D. M., Strasburger, A., & Beattie, N. (2007). Stigma, social function and symptoms in schizophrenia and schizoaffective disorder: Associations across 6 months. *Psychiatry Research, 149*(1), 89–95.

Malik, P., Kemmler, G., Hummer, M., Riecher-Roessler, A., Kahn, R. S., & Fleischhacker, W. W. (2010). Sexual dysfunction in first-episode schizophrenia patients: Results from European first episode schizophrenia trial. *Journal of Clinical Psychopharmacology, 31*(3), 274–280.

McCabe, M., Althof, S. E., Assalian, P., et al. (2010). Psychological and interpersonal dimensions of sexual function and dysfunction. *The Journal of Sexual Medicine, 7*(1–2), 327–336.

McCann, E. (2003). Exploring sexual and relationship possibilities for people with psychosis—A review of the literature. *Journal of Psychiatric and Mental Health Nursing, 10*(6), 640–649.

McCann, E. (2010). The sexual and relationship needs of people who experience psychosis: quantitative findings of a UK study. *Journal of Psychiatric and Mental Health Nursing, 17*(4), 295–303.

Muhr, T. (1991). ATLAS/ti—A prototype for the support of text interpretation. *Qualitative Sociology, 14*(4), 349–371.

Mulhall, J., King, R., Glina, S., & Hvidsten, K. (2008). Importance of and satisfaction with sex among men and women worldwide: Results of the global better sex survey. *The Journal of Sexual Medicine, 5*(4), 788–795.

Östman, M. (2014). Low satisfaction with sex life among people with severe mental illness living in a community. *Psychiatry Research, 216*(3), 340–345.

Östman, M., & Björkman, A. C. (2013). Schizophrenia and relationships: The effect of mental illness on sexuality. *Clinical Schizophrenia & Related Psychoses, 7*(1), 20–24.

Peitl, M. V., Rubesa, G., Peitl, V., Ljubicic, D., & Pavlovic, E. (2009). Aspects of sexual self-perception in schizophrenic patients. *European Journal of Psychiatry, 23*(1), 37–46.

Pinkham, A. E., Penn, D. L., Perkins, D. O., Graham, K. A., & Siegel, M. (2007). Emotion perception and social skill over the course of psychosis: A comparison of individuals "at-risk" for psychosis and individuals with early and chronic schizophrenia spectrum illness. *Cognitive Neuropsychiatry, 12*(3), 198–212.

Raja, M., & Azzoni, A. (2003). Sexual behaviour and sexual problems among patients with severe chronic psychoses. *European Psychiatry, 18*(2), 70–76.

Rajkumar, R. P. (2014). Gender identity disorder and schizophrenia: neurodevelopmental disorders with common causal mechanisms? *Schizophrenia Research and*

Treatment, 2014, 463757.

Savla, G. N., Vella, L., Armstrong, C. C., Penn, D. L., & Twamley, E. W. (2013). Deficits in domains of social cognition in schizophrenia: A meta-analysis of the empirical evidence. *Schizophrenia Bulletin, 39*(5), 979–992.

Segalovich, J., Doron, A., Behrbalk, P., Kurs, R., & Romem, P. (2013). Internalization of stigma and self-esteem as it affects the capacity for intimacy among patients with schizophrenia. *Archives of Psychiatric Nursing, 27*(5), 231–234.

Skodlar, B., & Nagy, M. Z. (2009). Sexuality and psychosis. *Psychiatria Danubina, 21*(1), 111–116.

Smith, S., & Herlihy, D. (2011). Sexuality in psychosis: Dysfunction, risk and mental capacity. *Advances in Psychiatric Treatment, 17*(4), 275–282.

Van Sant, S. P., Ahmed, A. O., & Buckley, P. F. (2012). Schizophrenia, sexuality, and recovery. *J Ethics Ment Health, 7*(1), 1–5.

Volman, L., & Landeen, J. (2007). Uncovering the sexual self in people with schizophrenia. *Journal of Psychiatric and Mental Health Nursing, 14*(4), 411–417.

Whisman, M. A., Johnson, D. P., Li, A., & Robustelli, B. L. (2014). Intimate relationship involvement, intimate relationship quality, and psychiatric disorders in adolescents. *Journal of Family Psychology, 28*(6), 908.

Wismeijer, A. A., & Assen, M. A. (2013). Psychological characteristics of BDSM practitioners. *The Journal of Sexual Medicine, 10*(8), 1943–1952.

Wright, D. E., Perry, B. L., & Foote-Ardah, C. E. (2007). Stigma andthe sexual isolation of people with serious mental illness. *Social Problems, 54*(1), 78–98.

Wright, E. R., & Gayman, M. (2005). Sexual networks and HIV risk of people with severe mental illness in institutional and community based care. *AIDS and Behavior, 9*(3), 341–353.

6

Intimacy and its barriers: A qualitative exploration of intimacy and related struggles among people diagnosed with psychosis

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INTIMACY AND ITS BARRIERS: A QUALITATIVE EXPLORATION OF INTIMACY AND RELATED STRUGGLES AMONG PEOPLE DIAGNOSED WITH PSYCHOSIS

Abstract

Previous studies indicate that intimate relationships and sexual expression are common unmet needs amongst people with psychosis. Research has mainly focused on sexuality and sexual dysfunction and little is known about the effects of psychosis on intimacy and intimate relationships. This study aimed to explore which problems participants encounter in establishing intimacy and maintaining intimate relationships, from the perspective of interpersonal process model of intimacy. Twenty-eight participants with a psychotic disorder receiving flexible assertive community treatment were interviewed about their needs and experiences with intimate relationships, using a semi-structured interview. The interviews were transcribed and coded using Grounded Theory methodology. Five overarching categories in relation to problems in establishing and maintaining intimate relationships emerged: side effects of medication, mental symptoms, stigma and selfstigma, sexual abuse, and lack of social skills and experience. Loss of selfesteem was an overarching central theme common to all five categories.

Introduction

An intimate relationship is conceptualized by Reis and Shaver (1988) as an interpersonal process in which two partners express and share their feelings, thoughts and experiences, both verbally and non-verbally, in order to learn more about themselves and each other. Two important concepts in the formation of these intimate relationships are self-disclosure and responsiveness of the partner. Selfdisclosure is the verbal and non-verbal communication of information about oneself (Prager & Roberts, 2004; Reis & Shaver, 1988). Responsiveness refers to the reaction of a partner to the disclosed feelings, thoughts and needs (Laurenceau, Barrett, & Pietromonaco, 1998; Reis & Shaver, 1988). Ideally, a partner will respond with understanding, care and validation (Reis & Shaver, 1988). Eventually, “under certain conditions, repeated interactions characterized by this process develop into an intimate relationship” (Reis & Shaver, 1988, p. 388).

Unfortunately, how to establish and maintain intimate relationships is not self-evident for everyone. If someone fails to form intimate relationships, some basic psychological needs may remain unfulfilled and in times of stress there may be no significant other to turn to. This can lead to social isolation, loneliness, fear and sadness (Baumeister & Leary, 1995; Mellor, Stokes, Firth, Hayashi, & Cummins, 2008). Research has shown that engaging in intimate relationships is harder for many people diagnosed with a psychotic disorder. Several studies have highlighted the often unmet needs in intimate and sexual relationships among people diagnosed with schizophrenia and related psychotic disorders (de Jager, Wolters, & Pijnenborg, 2016; Kelly & Conley, 2004; Werner, 2012). Furthermore, single marital status has been associated with low quality of life and is associated with a poorer prognosis in people with psychosis (Agerbo, Byrne, Eaton, & Mortensen, 2004; Nyer et al., 2010). Several studies identified factors that might influence these unmet needs such as (self)stigma and sexual dysfunction (Östman & Björkman, 2013; Wright, Wright, Perry, & Foote-Ardah, 2007).

The current study approaches intimacy from a recovery prospective. The recovery model assumes that people diagnosed with a mental disorder can recover and live a meaningful life. Within a recovery approach, sexuality and intimacy may be seen as fundamental and personal expressions of humanity that have implications for self-determination, social inclusion and reclaiming a meaningful life. To facilitate the recovery process of people suffering from mental disorders and to maximize the quality of life, it is important to find out what issues people are struggling with when it comes to intimacy and relationships.

Nevertheless, to date, it has been insufficiently explored how and why having a psychotic disorder may hamper the process of establishing and maintaining intimate relationships. Also, while there has been research on sexuality and sexual health, intimacy has received far less attention (de Jager & McCann, 2017). The question remains why the (physical and emotional) intimacy needs of a large group of people remain unfulfilled. Therefore, the primary aim of the study is to explore what problems people diagnosed with a psychotic disorder experience in the field of intimacy and relationships, and what factors underlie these problems. As a basis for our exploration, we use the interpersonal process model of self-disclosure and responsiveness (Reis & Shaver, 1988). This model has often been used to identify problems related to intimacy amongst a variety of patient groups but has never been used to explore intimacy-related problems amongst people diagnosed with a psychotic disorder.

Method

Design

A qualitative study was conducted. Grounded Theory methodology, developed by Glaser and Strauss (1967), was used to test and further develop a theory regarding problems in establishing and maintaining intimate relationships among people with a psychotic disorder. The Grounded Theory approach strives to develop a theory arising from the research data. In line with the Grounded Theory approach, data collection was conducted parallel to data analysis. The data collection was terminated when a substantive point of saturation was reached, that is: when no new information could be obtained by further data collection (Charmaz, 2006).

Participants

We recruited people who were diagnosed with a psychotic disorder (including a clinical DSM-IV diagnosis of schizophrenia, schizoaffective disorder, schizophreniform disorder, delusional disorder or psychotic disorder NOS) who were willing to share their needs, experiences and difficulties in engaging and forming intimate relationships. Participants were recruited from four community mental health teams specializing in flexible assertive community treatment (FACT). Participants had to meet the following criteria: (a) had experienced at least one psychotic episode, and (b) was between 18 and 65 years of age. Participants had to be able to understand the study information and procedures and give informed consent. Exclusion criteria were a florid psychotic state and an estimated IQ of less than 70.

Procedure

The study was conducted with the approval of the Institutional Review Board of Noord-Holland-Noord mental health services. Participation was voluntary and no compensation was offered. A non-selective sample from the mental health service information base, consisting of patients of FACT teams, was drawn. In order to enhance representativeness of the sample, clinicians were asked to approach each person that met the inclusion criteria for participation. This resulted in the participation of people with and without sexual or intimacy problems. Potential participants were then contacted by their clinician and asked if they would be willing to participate in the study. Participants were also recruited through flyers at the four community mental health centers. Those who were willing to participate in the study were able to contact the researchers directly. The clinician of each participant was asked to sign a form in which it was stated that the participant met the inclusion criteria and had the capacity to provide informed consent. All participants signed an informed consent form. Data was collected with semi-structured interviews, lasting approximately 1–2 h, conducted by two researchers, one leading the interview and the other making notes of significant events. With the permission of the participants, audio recordings of the interview were made. After each interview, participants were asked if the interview brought up any negative emotions or memories. If so, clinical follow-up was offered and facilitated as required.

Analysis

All sound recordings were transcribed verbatim in a word processing program and

Table 1. Demographic and clinical characteristics

	Male	Female	Total
	(*n* = 19)	(*n* = 9)	(*n* = 28)
	n (%)	*n* (%)	*n* (%)
Age			
18–29	3 (16)	1 (11)	4 (14)
30–39	4 (21)	1 (11)	5 (18)
40–49	10 (53)	3 (33)	13 (64)
50 or older	2 (11)	4 (44)	6 (21)
Sexual identity			
Heterosexual	18 (95)	7 (78)	25 (89)
Bisexual	0 (0)	2 (22)	2 (7)
Homosexual	1 (5)	0 (0)	1 (4)
Marital status			
Married or cohabitating	3 (16)	3 (33)	6 (21)
In a relationship, not cohabitating	3 (16)	1 (11)	5 (18)
Divorced/single/widowed	13 (68)	5 (56)	17 (61)

identifiable personal information was removed. Emotions and striking nonverbal behaviors were described in the text fragments. The software program Atlas.ti was used to further process, code and analyze the data. The analysis followed the three stages of Grounded Theory. The first phase consisted of open coding, in which transcriptions were read sentence by sentence to identify themes or categories. In this phase, codes were assigned to fragments regardless of the hypothesized relevance to the research question (Corbin & Strauss, 1990). In the second phase, axial coding was performed, which involved a critical appraisal of the assigned codes and a shift of attention to fragments that were relevant to the research question. At the end of the axial coding, the formation of a theory by creating main and subcategories began (Corbin & Strauss, 1990). In the last phase, the phase of selective coding, the core category was established and relationships between the different categories were determined (Corbin & Strauss, 1990). In order to establish inter-coder reliability and agreement (Campbell, Quincy, Osserman, & Pedersen, 2013), one third of the interviews were coded independently by two additional assessors and differences were discussed in order to achieve comparable results.

Results

Thirty two people with a psychotic disorder were recruited. After an extensive briefing session, four people declined, because of current mental health problems (n = 2) or the research topic being too intimate (n = 2). Twenty-eight participants, aged 22–62 years (mean = 42 years, SD = 10.22), participated (Table 1).

The coding process resulted in five factors that are of influence in establishing and maintaining intimate relationships: side effects of medication, symptoms of mental disorder, (self)stigma, sexual abuse and lack of social skills and experience. These factors will be discussed in the light of the interpersonal process model. We start with a description of the extent to which interviewees reported a need for intimacy.

Relationship needs & intimacy

Emotional and physical “closeness to another person” was the most frequently stated definition of intimacy among the interviewees. The emotional side of intimacy was often seen as a precondition for physical intimacy. Only in a loving relationship was sexuality considered as meaningful and intimate.The absence of a partner was for the majority of interviewees (n = 17, 61%) reason for dissatisfaction with the level of intimacy in their lives. Being single and the associated feeling of loneliness was considered as hard to endure (n = 8, 42%).

“I’d love to be in a relationship again. (…) I can hardly even imagine what it would be like. It seems like a dream. (…) If you’re single for 10 years, then you’re just really lonely. That’s just what it is” (Single, male, 38 years).

An intimate relationship can have both negative and positive effects on mental well-being. On the one hand, a partner can be an important source of support in difficult times and act as a protective factor for mental problems. In this case, the partner provides a certain degree of strength, peace and support during periods of instability as well as being an important confidant, especially when there is no openness about mental problems with others. Six interviewees found that having a relationship led to a reduction of mental distress or helped motivating them to seek help in times of trouble. Two interviewees indicated that the monitoring of mental distress through a second pair of eyes can be an advantage.

“She is the rock that I lean on. She drags me through hard times and won’t leave me hanging. I can really talk to her. That is such an amazing feeling” (Married, male, 42 years).

On the other hand, symptoms may exacerbate as a consequence of falling in love or tension within a current relationship. Several people (n = 7, 25%) had experienced that love, relationship problems or a broken heart can trigger the onset of symptoms. For this reason, partner characteristics as “quiet” and “stable” were seen as desirable.

“I once had a boyfriend who wasn’t mentally healthy himself (…) You pull each other into areas of madness. I need someone that can pull me out of it” (Single, female, 34 years).

Categories 1 and 2: symptoms and side effects of medication

Symptoms and side effects of medication are discussed together as the mental problems and side effects that affect intimacy largely overlapped, making it impossible

to differentiate between the two. Almost half of the respondents (n = 12, 43%) reported a significant difference in their ability to make contact with others, before and after the exacerbation of symptoms. As some interviewees explained: in a psychotic episode some people tend to isolate themselves and become more self-absorbed, having little or no contact with the outside world. They indicated that connecting to others "used to be easier". Especially taking the initiative to approach people and starting a spontaneous conversation became more difficult. Symptoms such as ideas of reference, anxiety, depression, cognitive problems, fatigue and hallucinations were an obstacle in initiating and engaging in contact. These symptoms appear to interact negatively with both self-disclosure and responsivity towards others.

Also, symptoms or side effects cannot always be hidden. When people try to navigate through life while experiencing symptoms and/or using medication with side effects, involuntary self-disclosure may arise as a result. The potential visibility of the symptoms or side effects of medication such as trembling or sweating was an additional stressor in social situations. This often led to a fear of being judged or stigmatized as "crazy" or "disabled" by others. The (fear of) involuntary self-disclosure and the related risk of stigmatization appeared to have a strong effect on self-esteem. It strongly decreased the likelihood of engaging in social contact, which seemed especially the case when side effects of medication also impacted sexual functioning.

More than half of the interviewees (n = 16, 57%) experienced, currently or in the past, sexual side effects such as impotence, erectile dysfunction, increase and decrease in sexual desire, disruption of ejaculation or orgasm. Particularly in men, sexual problems were linked to self-esteem and confidence. In some, anxiety or tension due to sexual problems led to avoidance of contact and of self-disclosure (n = 4), as self-protection against potential rejection.

"It's not just because of the medication that you can't get an erection, it is also because of performance anxiety. 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" (Single, male, 53 years).

Five interviewees noted the exact opposite. Experiencing symptoms, overcoming these symptoms, combined with lessons learned from therapy, helped them to be more open, sociable and trustful towards others, leading to an increase in both self-disclosure and responsivity.

When interviewees had a partner, symptoms of psychotic disorder such as flattened affect, social withdrawal and delusions influenced their perception of intimacy. The problems that occurred seemed related mostly to distance and closeness to the partner. A psychotic episode in itself is a shocking experience for partners. In a state of confusion, some behaved or expressed themselves in a way that was considered offensive to the partner. Interviewees indicated that partners should take time to process these events. Both needed to rediscover each other and rebuild their trust over time. It is not self-evident that the physical intimacy between partners recovers automatically.

"Before, I was intimate with my wife but after I was too insecure and confused. I didn't know how to touch her anymore. In fact, I can understand that she started seeing someone else, since I really wasn't there" (Divorced, male, 62 years).

As the next quote illustrates, the emergence of psychosis can seriously affect mental well-being of the partner.

"He just really wanted to help me. Imagine seeing someone you love slip away and not being able to help. It was very hard for him. At a certain point he became very depressed. I felt, and still feel extremely guilty about it" (Single, female, 34 years).

On the one hand, both partners having mental problems was considered advantageous because it creates mutual understanding and acceptance. This lowered the threshold to self-disclosure. Sometimes, having a partner who knows what it is like to have a mental disorder resulted in higher responsivity and perceived responsivity on both sides, increasing the intimacy amongst partners. Nevertheless, for some interviewees, the exact opposite was true. If both partners are struggling, they might end up taking up too much space in the relationship, compromising each other's existence as a partner. As a consequence, heightened levels of self-disclosure, both voluntary and involuntary, secondary to symptoms, appeared to lead to a reduction in perceived responsivity, decreasing equivalency and intimacy at the same time.

"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" (Single, male, 42 years).

Overall, there was little room for sexuality during a psychotic episode. However, some people experienced an increase in sexual desire and/or sexual contact. Some of these had been pleasant, some were retrospectively described as "strange" or "weird". These experiences seemed not in line with the usual sexual self-image and were accompanied by remorse and/or shame. After a psychotic episode, shame about one's own behavior can be the cause of avoidance in social contact and lead to (further) isolation.

Category 3: (self-)stigma

Almost all interviewees had experienced prejudice due to their mental vulnerabilities. For some, these prejudices resulted in loss of social contacts. A male interviewee said

that both friendly and intimate relationships were terminated by others after disclosing his psychiatric background.

"I notice that people are afraid to approach me because of my mental illness, so they avoid me. I notice that they walk away from me and that isn't easy" (Single, male, 45 years).

It became clear that people who had been stigmatized were more reluctant to enter into contact and struggled with trust. A male interviewee explained how he had "built a wall" around him in order to keep others away, out of the fear of being rejected or abandoned again. Only when there was a basis of trust, were people willing to be open about their mental illness. In other words, people were willing to self-disclose, when they expected appropriate responsivity.

"The word psychosis will not come out of my mouth. If I were in a happy relationship, perhaps I would tell her at some point. If she would be very easy to talk to, I would tell her" (Divorced, male, 42 years).

In contrast, there were people who easily self-disclosed their mental illness. What appeared to be the reason was the realization that others also have struggles in life. "Everyone has something". Self-stigma, or the internalization of prejudice, led to feelings of inferiority. Interviewees expressing self-stigma devalued themselves as a partner. Some interviewees wondered aloud who would like a partner with a mental illness. A "healthy" person might see a partner with a mental illness as "a liability". Reflecting on the first few encounters with her current husband, a female interviewee said:

"I was thinking: you will lose him for sure. Who would want someone with a psychosis?" (Married, female, 57 years).

Category 4: social skills and deficits

After prolonged social isolation, caused by social anxiety or the symptoms of psychosis, people said they felt insecure in the dating world. Eight interviewees (29%) viewed their lack of experience in dating as an obstacle in engaging in intimate relationships. The interviewees described feelings of inadequacy in engaging and managing conversations. There was a fear "of doing something wrong" in a social interaction. This led to heightened self-awareness and a lack of self-esteem in social interactions or an avoidance of social situations.

"I can't pull it off. I'm my worst enemy… (…) When I encounter people, I have no idea what topics are interesting or if he/she will like what I have to tell him/her. Nerves." (Married, male, 42 years).

A third of the interviewees (n = 9, 32%) reported problems with protecting or respecting their own or others' boundaries. Especially female interviewees struggled with protecting their sexual boundaries during and after a psychotic episode.

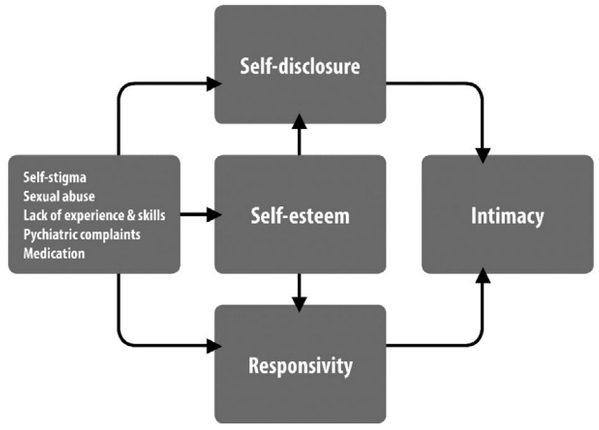
"When I was younger, I let people walk over me. Or I would keep pushing my own boundaries. Especially with boys, I found it hard to say no. I kept wanting to please the other" (Single, female, 34 years).

Category 5: sexual abuse

More than one third of the sample (n = 10, 36%) had experienced sexual abuse, particularly women (n = 6, 67%; men n = 4, 21%). The sexual abuse had a negative effect on (sexual) self-esteem and selfworth. Interviewees said they found it hard to trust others. Lack of trust complicated self-disclosure both emotionally and physically.

Physical contact, especially in the context of a sexual encounter, led to feelings of fear or disgust, reducing the satisfaction of the contact significantly. Interviewees in a relationship often talked about an inability to experience pleasure from physical contact or intercourse with their partner. For some, this even led to the avoidance of any physical contact. The inability to engage in, or to experience pleasure from, physical contact also had a negative effect on self-worth, resulting in a vicious circle. The fact that sexual trauma remains a taboo

Figure 1. *The formation of intimacy and its barriers among people diagnosed with psychosis*



was evidenced by the fact that most interviewees rarely talked about the sexual trauma and the problems arising from it with their spouse or partner. For some, the researchers where the first or one of the few to whom the sexual trauma was ever disclosed.

"I have been divorced for 28 years from my first husband but I have lain in bed with fear for 23 years" (Married, female, 57 years).

Discussion

This study aimed to investigate problems and underlying factors that people with psychotic disorder report in engaging in intimate relationships, by using the interpersonal process model in a qualitative research design (Reis & Shaver, 1988). It was found that symptoms and psychotropic side effects directly affected the ability to self-disclose. Inability to self-disclose in turn often caused feelings of incompetence, decreasing the person's self-esteem. Self-esteem, as defined by Rosenberg, "is the positive or negative attitude people have toward themselves" (1965, p.30). A loss of self-esteem and lack of trust after sexual abuse complicated verbal and nonverbal self-disclosure. In some instances, the willingness to self-disclose was also affected by problems such as suspiciousness and ideas of reference. In other instances, the ability to be responsive towards a partner was reduced due to symptoms or psychotropic side effects such as flattened affect and fatigue. This in turn affected the self-image as a partner, further reducing self-esteem. The fear of involuntary self-disclosure resulted in a decline in social interaction, out of fear of being judged. Almost all participants had experiences of being approached judgementally on account of their mental disorder. Experiencing negative responses to disclosing mental vulnerabilities led to fear of self-disclosure in subsequent encounters. Self-stigma, the internalization of judgments, led people to devaluate themselves as (potential) partners, negatively impacting self-esteem and discouraging them to engage in further intimate contact.

Apart from symptoms and side effects, we found three additional categories of factors that mediated the impact of mental illness on self-disclosure and responsiveness: (self) stigma, social skills, and sexual abuse. The observed impact of these was more pronounced when the attitude interviewees had towards themselves was also negatively affected. In some instances, self-esteem was so seriously affected, that people failed to self-disclose at all, by, for example, isolating themselves from others or giving up on the idea of intimacy altogether. These results suggest that self-esteem plays a central role in the boundaries towards engagement in intimacy and related processes. Although the interpersonal process model of intimacy was useful in categorizing our data, the problems people with a psychotic disorder experience often originate before engagement in intimacy. Therefore, we propose an elaboration, presented in Figure 1, for exploring intimacy and its boundaries among people diagnosed with psychosis in further research.

Because of the explorative design of the study, the implied effect of the five factors on intimacy and the central role of self-esteem cannot be confirmed without further research. A model that includes the construct of self-esteem could conceivably guide future research efforts and, perhaps, aid in tailoring interventions.

The results also showed that it is important to assess the effects of having a psychotic episode on both partners in an intimate relationship. It is not self-evident that partners overcome this by themselves. Involving a partner in treatment, as well as paying attention to the relationship between a patient and his partner is essential in order to promote both intimacy and recovery.

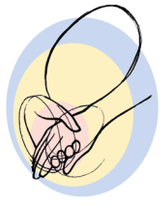
Another topic that appeared to be a taboo among people with psychosis is sexual abuse. This taboo was evidenced by the fact that most interviewees rarely talked about, or were asked about, sexual abuse and the problems arising from it, within and outside mental health services. For some, the researchers where the first to whom the sexual abuse was ever disclosed to. To ask about these topics sensitively and proactively within health care settings appears essential.

In the areas of research and clinical practice, there may be a misconception that people diagnosed with a mental disorder are unwilling or incapable to talk about intimate topics face to face. Noteworthy is the fact that there was no problem recruiting participants for the study. Several participants requested follow-up because the topic of intimacy was perceived as useful, comforting and missing in ongoing treatment. Tennille and Wright (2013) suggest how these topics can be addressed within mental health services in a recovery-oriented fashion.

The study has a number of limitations. First, a convenience sample was used, which may affect generalizability. In order to enhance representativeness of the sample, clinicians were asked to approach each person that met the inclusion criteria for participation. This resulted in the participation of people with and without sexual or intimacy problems. However, the possibility of selection and limited generalizability cannot be excluded. People who were uncomfortable with the research topic or who were content with their relationships and sexuality may have refrained from participation. Another issue relating to the representativeness of the sample is the overrepresentation of men. Although this is in agreement with the observed overrepresentation of males in populations of people with severe mental illness within mental health care settings, several studies suggest gender-specific needs and problems in regard to physical and emotional intimacy (Cardoso et al., 2005; Salokangas, Honkonen, Stengård, & Koivisto, 2001). In further research, it would be useful to explore gender differences in intimacy in this population and include (romantic) partners. Additionally, we recommend examining differences based on sexual orientation and gender identity.

Disclosure statement

No potential conflict of interest was reported by the authors.



References

Agerbo, E., Byrne, M., Eaton, W. W., & Mortensen, P. B. (2004). Marital and labor market status in the long run in schizophrenia. *Archives of General Psychiatry, 61*, 28–33.

Baumeister, R. F., & Leary, M. R. (1995). The need to belong: Desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin, 117*, 497–529.

Campbell, J. L., Quincy, C., Osserman, J., & Pedersen, O. K. (2013). Coding in-depth semistructured interviews: Problems of unitization and intercoder reliability and agreement. *Sociological Methods & Research, 42*, 294–320.

Cardoso, C. S., Caiaffa, W. T., Bandeira, M., Siqueira, A. L., Abreu, M. N. S., & Fonseca, J. O. P. (2005). Factors associated with low quality of life in schizophrenia. *Cadernos de Saúde Pública, 21*, 1338–1340.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative research*. London: Sage Publications.

Corbin, J. M., & Strauss, A. (1990). Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative Sociology, 13*, 3–21. PSYCHOSIS 9

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of ground theory: Strategies for qualitative research*. New York, NY: Aldine Publishing.

de Jager, J., & McCann, E. (2017). Psychosis as a barrier to the expression of sexuality and intimacy: An environmental risk? *Schizophrenia Bulletin*, sbw172.

de Jager, J., Wolters, H. A., & Pijnenborg, G. H. M. (2016). Young adult with psychotic disorders have problems relating to sexuality, intimacy and relationships. An explanatory study based on focus group. *Tijdschrift voor Psychiatrie, 58*, 223–227.

Kelly, D. L., & Conley, R. R. (2004). Sexuality and schizophrenia: A review. *Schizophrenia Bulletin, 30*, 767–779.

Laurenceau, J. P., Barrett, L. F., & Pietromonaco, P. R. (1998). Intimacy as an interpersonal process: The importance of selfdisclosure, partner disclosure, and perceived partner responsiveness in interpersonal exchanges. *Journal of Personality and Social Psychology, 74*, 1238–1251.

Mellor, D., Stokes, M., Firth, L., Hayashi, Y., & Cummins, R. (2008). Need for belonging, relationship satisfaction, loneliness, and life satisfaction. *Personality and Individual Differences, 45*, 213–218.

Nyer, M., Kasckow, J., Fellows, I., Lawrence, C. E., Golshan, S., Solorzano, E., & Zisook, S. (2010). The relationship of marital status and clinical characteristics in middle-aged and older patients with schizophrenia and depressive symptoms. *Annals of Clinical Psychiatry, 22*, 172–179.

Östman, M., & Björkman, A. C. (2013). Schizophrenia and relationships: The effect of mental illness on sexuality. *Clinical Schizophrenia & Related Psychoses, 7*, 20–24

Prager, K. J., & Roberts, L. J. (2004). Deep intimate connection: Self and intimacy in couple relationships. In D. J. Mashek & A. Aron (Eds.), *Handbook of closeness and intimacy* (pp. 43–60). Mahway, NJ: Lawrence Erlbaum Associates.

Reis, H. T., & Shaver, P. (1988). Intimacy as an interpersonal process. In S. Duck (Ed.), *Handbook of personal relationships* (pp. 367–389). Chichester, UK: Wiley.

Rosenberg, M. (1965). *Society and the adolescent self-image*. Princeton, NJ: Princeton University Press.

Salokangas, R. K. R., Honkonen, T., Stengård, E., & Koivisto, A. M. (2001). To be or not to be married–that is the question of quality of life in men with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology, 36*, 381–390.

Tennille, J., & Wright, E. (2013). Addressing the intimacy interests of people with mental health conditions: Acknowledging consumer desires, provider discomforts, and system denial. *Temple University collaborative on community inclusion of individuals with psychiatric disability*.

Werner, S. (2012). Needs assessment of individuals with serious mental illness: Can it help in promoting recovery? *Community Mental Health Journal, 48*, 568–573.

Wright, E. R., Wright, D. E., Perry, B. L., & Foote-Ardah, C. E. (2007). Stigma and the sexual isolation of people with serious mental illness. *Social Problems, 54*, 78–98.

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Title: The impact of childhood sexual trauma on intimacy and sexuality needs among people with non-affective psychosis

de Jager, J., Topper, M., Nugter, A., Os, J., GROUP-investigators (2021)
Under review

THE IMPACT OF CHILDHOOD SEXUAL TRAUMA ON INTIMACY AND SEXUALITY NEEDS AMONG PEOPLE WITH NON-AFFECTIVE PSYCHOSIS

ABSTRACT

Background: *Childhood trauma, in particular childhood sexual abuse (CSA), and unmet sexuality and intimacy needs are prevalent among people with psychosis spectrum disorders. The association between CSA and sexuality and intimacy needs over time in adults with psychosis spectrum disorders were examined.*

Method: *Patients (n = 1119) were recruited as part of the Genetic Risk and OUtcome of Psychosis (GROUP) study, a representative cohort of patients with non-affective psychotic disorder. At baseline, three-year and six-year follow-up, sexuality and intimacy needs were assessed with the Camberwell Assessment of Needs. CSA was assessed with the Childhood Trauma Questionnaire.*

Results: *At baseline, sexuality (26%) and intimacy (40%) needs were prevalent; 90% of these needs remained unmet. Crosssectionally, CSA was associated with sexuality needs (OR=1.68, 95% CI: 1.13-2.04) and intimacy needs (OR=1.75, 95% CI: 1.04- 1.77). Childhood emotional abuse (CEA) was also cross-sectionally associated with sexuality and intimacy needs. Others forms of trauma were not. Prospectively, CSA predicted incidence of a sexuality need (HR=2.1, 95% CI: 1.23-3.74) as well as an intimacy need (HR=1.7, 95% CI: 1.11-2.66), as did CEA (sexuality: HR=1.8, 95% CI: 1.11-2.89; intimacy: HR=1.4, 95% CI: 1.03-1.96). CSA and CEA were not associated with persistence of sexuality or intimacy.*

Conclusion: *CSA and CEA are associated with a higher prevalence and incidence of sexuality and intimacy needs in patients with psychotic disorders. High rates of unmet sexuality and intimacy needs may indicate an underlying need for traumarelated treatment as well as a need for novel interventions targeting these needs.*

INTRODUCTION

The assessment of needs for care is a key component in mental health care (M. Slade et al., 2004). For mental health professionals, need assessment is helpful in clinical decision making and developing adequate treatment plans. For patients, an accurate need

assessment can facilitate recovery, provide a sense of direction, support social rehabilitation and improve quality of life Fleury, Grenier, Bamvita, and Tremblay (2013). For the dyadic relationship between client and caregiver, need assessment may be helpful to provide common ground for communication, collaboration, as well as other non-specific treatment factors such as warmth, respect and understanding (Lambert & Cattani, 2012).

In patients diagnosed with psychosis spectrum disorder, a need for care frequently occurs in the domains of intimate relationships and sexual expression (Drukker et al., 2008; Fleury et al., 2013). In a Swedish sample of 120 people with schizophrenia, 40% had an intimacy need and 33% a sexuality need Bengtsson-Tops and Hansson (1999). The highest prevalence of unmet needs in a study by Wiersma et al. (2009) was also found in the domain of intimate relationships along with company, psychological distress, daytime activities, and physical health (15–28%). Given these findings, it has been argued that mental health care is insufficiently focused on the expression of sexuality and intimacy and related needs (McCann et al., 2019).

Understanding sexuality and intimacy needs, and the factors that impact these needs among people with psychosis spectrum disorder may stimulate the development of interventions that help fulfill these needs. Qualitative studies have highlighted and explored the often unmet needs in intimate and sexual relationships among people diagnosed with psychosis spectrum disorder (de Jager, Cirakoglu, Nugter, & van Os, 2017; de Jager, van Greevenbroek, Nugter, & van Os, 2018). A qualitative systematic review including 21 studies addressing the views and experiences of people with severe mental illness (Ehrhardt et al., 2002) regarding intimacy and sexual expression identified several factors that contribute to these unmet needs (McCann et al., 2019). These include use of antipsychotics (de Boer, Castelein, Wiersma, Schoevers, & Knegtering, 2015 Schoevers, & Knegtering, 2015), self-stigma, difficulties in social cognition, social isolation and loneliness and sexual trauma (McCann et al., 2019). Findings of a recent systematic review of 43 quantitative studies are largely in line with those reported by McCann and colleagues (Cloutier, Francoeur, Samson, Ghostine, & Lecomte, 2020.).

In the general population, experiencing sexual abuse in childhood is one of the most important risk factors for the development of sexual dysfunction in adulthood (Pulverman, Kilimnik, & Meston, 2018), and also linked to intimacy problems in adulthood (Roberts, O'Connor, Dunn, & Golding, 2004). Models that attempt to explain these links have focused on underlying mechanisms such as traumatic sexualization, self-destructive or avoiding coping strategies and physical, affective and cognitive difficulties (Zwickl & Merriman, 2011). There is no reason to assume that these mechanisms would be different in people with SMI.

As systematic reviews indicate high rates of trauma in patients with SMI, including sexual trauma, this is likely even more pertinent to patients with psychosis (Varese et al., 2012). Thus, several studies have suggested that impaired sexual functioning in people with psychosis may be associated with exposure to sexual abuse.

In sum, research indicates that the rates of both sexual trauma and sexuality and intimacy needs are high in patients with psychosis spectrum disorder. It remains largely unclear, however, if and how childhood sexual trauma impacts the sexuality and intimacy needs of adults living with psychosis.

To the best of our knowledge, only one quantitative, cross-sectional study examined the impact of sexual trauma at the level of needs in people with psychosis (Comacchio et al., 2019). The authors found that a history of sexual trauma in both men and women was associated with higher levels of need for care. However, they combined different types of trauma and different types of needs into larger categories, so that specific associations between sexual trauma and sexuality and intimacy needs could not be examined. The current study focusses on the question if and how childhood sexual trauma is associated with sexuality and intimacy needs in adulthood, in both a cross-sectional as well as a prospective framework.

To this end, we examined the cross-sectional and longitudinal association between childhood sexual abuse (CSA) and sexuality and intimacy needs in a large representative sample of patients with non-affective psychotic disorders. More specifically, we assessed the extent to which sexual abuse and sexuality and intimacy needs occur, as well as the percentage of these needs that remained unmet, both absolute and relative to other needs, in order to obtain a reference. To validate the focus on the specific impact of CSA, we hypothesized that CSA would be more strongly associated with sexuality and intimacy needs in comparison with other kinds of childhood adversity, as reported earlier by others (Ağaçhanlı, Alnıak, & Evren, 2018). Finally, we assessed the extent to which CSA predicted the incidence and persistence of sexuality and intimacy needs.

Methods

Design

The patients in this study were recruited as part of the Genetic Risk and OUtcome in Psychosis (GROUP) study, a multi-site longitudinal cohort study focused on gene–environment interactions. In this naturalistic follow-up study, 1119 patients with a psychotic disorder, 1057 siblings, 919 parents, and 590 unrelated control subjects were included and examined. In- and exclusion criteria, details on the procedure of recruitment and population characteristics of the GROUP study have been described elsewhere (Korver et al., 2012). Baseline assessment (T0) was followed by a 3-year first follow-up (T1) and again 3 years later by a second follow-up (T2).

Participants

In this analysis, only the patient sample was included. At T1, 811 patients participated, and 662 at T2. Patients who participated had a diagnosis of non-affective psychotic disorder according to the DSM-IV (Alameda et al.), and their age ranged from 16 to 50 years at baseline. They were selected from representative geographical areas in The Netherlands

and Belgium, and identified by representative clinicians whose caseloads were screened for inclusion criteria. Subsequently, a group of patients presenting consecutively at these services either as outpatients or inpatients were recruited for the study.

Measures

Needs

The Camberwell Assessment scale of Need Short Appraisal Schedule (M. Slade, Leese, Cahill, Thornicroft, & Kuipers, 2005) was used to assess need for care. The CANSAS assesses health and social needs across the following domains: accommodation, food, looking after the home, self-care, daytime activities, physical health, psychotic symptoms, information, psychological distress, safety to self, safety to others, alcohol, drugs, company, intimate relationships, sexual expression, child-care, basic education, telephone, transport, money, and benefits. Each item was clinician-rated and scored 0 (no problem), 1 (there is a problem/need, that is met given an ongoing intervention) or 2 (unmet need). Questions used to asses intimacy needs were; “Do you have a romantic partner?” “Are there problems within this relationship?”). Questions used to asses sexuality needs were; “How is your sexuality?” “Are there any problems concerning your sexuality?”. If needed, follow-up questions were formulated by the interviewer to clarify. An important principle using the CANSAS is client perspective. If not having a partner is not perceived as a problem or unmet need, it is not scored as such. The CANSAS was administered at T0, T1 and T2. Interrater reliability was examined by Andresen and colleagues under routine conditions; overall agreement on areas of need was moderate to very high (Andresen, 2000).

Childhood (sexual) trauma

Childhood trauma was assessed with the Dutch version of the Childhood Trauma Questionnaire Short Form (CTQ) (Thombs, Bernstein, Lobbestael, & Arntz, 2009), a 25-item self-report questionnaire rated on a five-point Likert scale with good internal consistency, reliability and validity (Thombs et al., 2009). The CTQ assesses: physical abuse (bodily assaults on a child by an adult or older person that posed a risk of or resulted in injury); physical neglect (the failure of caretakers to provide for a child’s basic physical needs, including food, shelter, clothing, safety and health care); sexual abuse (unwanted sexual contact or conduct between a child younger than 16 years of age and an adult or older person); emotional abuse (verbal assaults on a child’s sense of worth or well-being or any humiliating or demeaning behavior directed toward a child by an adult or older person); and emotional neglect (the failure of caretakers to meet children’s basic emotional and psychological needs, including love, belonging, nurturance and support), all occurring before the age of 17. The CTQ was administered once, either at T0 or T1, depending on the research site.

Procedure

The ethical review board of the Utrecht University Medical Center provided approval of the study protocol, as did a local review board of all participating institutes. Written informed consent was given by all participants in accordance with the committee’s guidelines. Participants were seen for assessments at their own participating regional psychosis department, at a participant’s home or at the academic centers. Interviewers were research assistants, psychologists, psychiatrists, nurses and PhD students with a background in psychology or medicine. Before the start of the study, all interviewers met for three days of training workshops at one site (Utrecht), to practice the assessments of all measures used in the GROUP project. Over the course of the project, researchers reconvened at 2-month intervals for further training and recalibration to prevent interviewer ‘drift’.

Statistical analysis

We used descriptive statistics to calculate the prevalence of childhood sexual abuse and sexuality and intimacy needs. To obtain a reference, the number of met and unmet needs in other domains were also reported.

For all other analyses, ‘needs’ were expressed as a dichotomized measure of ‘no needs’ versus a joint category of ‘met needs’ and ‘unmet needs’. In the CANSAS, a met need stands for no/moderate problem because of continuing intervention, thus indicating that a need for care is present although its impact is mitigated.

Multi cross-sectional analysis in which associations between childhood trauma and data on sexuality and intimacy pertaining to all 3 timepoints were included and tested in a single analysis, accounting for intracluster correlations, with the data in the ‘long format’, i.e. with each person contributing three observations (T0, T1 and T2).

In the analyses, responses to the CTQ were dichotomized: items with a score of 0 were scored as absent and items with a score of 1, 2, 3 and 4 were scored as present. Associations were expressed as relative risk ratios with corresponding 95% confidence intervals. A priori confounders added to all analyses were gender, age and whether or not the person was using antipsychotics (de boer, 2018; Pulvermann, 2018; Delamater, 2009; (DeLamater & Karraker, 2009).

Cox proportional hazard models, including hazard ratios (HR) and associated confidence intervals (CI), were performed to investigate the risk of developing a sexuality or intimacy need in people with and without a history of childhood trauma. Cox proportional hazard models were calculated for all types of childhood trauma that appeared related to sexuality and intimacy needs in the previous cross-sectional analyses. In these analyses, only participants with no sexuality or intimacy need at T0 were included in order to calculate the incidence of new needs.

Needs persistence was defined as a continuation of the rating of the need at the next assessment (i.e. from T0 to T1 or T1 to T2). In order to investigate whether a sexuality

or intimacy need was more persistent in people with or without a history of childhood trauma, poisson regression analyses yielding relative risks (RR) and 95% confidence intervals were run. In this regression model, the number of changes (from a need to no need in sexuality and intimacy) was calculated to test if sexuality and intimacy needs differ in their persistence over time in people with and without a history of childhood trauma.

Table 1a. *Socio-demographic characteristics of the participants at baseline, t1 and t2*

		T0		T1		T2	
N		1119		811		662	
Demographics		count	%	count	%	count	%
Gender	Male	852	76.1	623	76.8	504	76.1
	Female	267	23.9	188	23.2	158	23.9
Age	Highest	50		1948		1948	
	Lowest	16		1991		1991	
	Mean	27.6		30.6		33.6	
Ethnic minority status	Minority	215	19.2	130	16	99	15
	White	830	74.3	649	80	540	81.6
	Missing	74	6.4	32	3.9	23	3.5
Marital status							
	Not married	950	85	681	84	516	77.9
	Married/living together	98	8.8	109	13.4	125	18.9
	Divorced	30	2.7	20	2.5	21	3.2
	Missing	39	3.5	1	0.1	.	.
Education	No education	7	.6	1	.1	1	.2
	Primary school	144	12.9	58	7.2	31	4.7
	Secondary school	341	30.6	225	27.7	150	22.7
	Highschool	270	24.2	196	24.2	148	22.4
	Vocational education	281	25.2	276	34.1	273	41.2
	University	43	3.8	54	6.7	58	8.8
	Missing	31	2.8	1	.1	1	.2
Other relevant variables							
IQ		96.1		99.2		101.7	
Duration of illness (years)		5		8.1		11.6	
Medication	Currently using	1	.1	571	70.4	466	70.4
	Not using	.	.	37	4.6	11	1.7
	Unknown/missing	1116	99.9	203	25	185	28
Childhood sexual abuse	Yes	185	16.6	176	20.6	125	18.9
	No	565	50.5	509	62.8	419	63.3
	Missing	367	32.9	135	16.6	118	17.8

Results

Participants

Table 1a and b show the socio-demographic characteristics of the sample. At T2, 811 patients participated, at T3 follow-up 662 patients. Given missing data, a Little MCAR test was performed (Little, 1988) which indicated that data were missing completely at random (χ^2 = .11, p = .74).

Prevalence of childhood sexual abuse

Sexual abuse was reported by 25% of the sample. Women were more likely to report sexual abuse (35%) compared to men (21%).

Table 1b. *Socio-demographic characteristics at T0 of the participants with and without childhood sexual abuse*

		Sexual abuse		No sexual abuse	
Demographics		count	%	count	%
Gender	Female	66	35	122	65
	Male	119	21	443	79
Year of birth	mean	1978		1978	
Ethnic minority status	Minority	41	23	73	13
	White	136	77	477	87
Current marital status	Married/living together	1	1	0	0
	Not married	121	99	404	100
Education	No education	2	1	4	1
	Primary school	21	11	59	11
	Secondary school	56	30	173	31
	Highschool	54	29	137	25
	Vocational education	42	23	162	29
	University	9	5	25	5
Other relevant variables					
Cannabis use	No	92	50	345	62
	Yes	93	50	216	38
Mean IQ		96		98	
Mean duration of illness (years)		6.3		5.2	
Medication*	Currently using	122	95	361	95
	Not using	7	5	19	5

*based on T2

Prevalence of needs

At T0, 26% of the participants reported a sexual need. Intimacy needs were present in 40% of the participants. At T1, the prevalence of sexuality needs was 16% and 35% for intimacy needs. At T2, 15% reported a sexuality need and 33% an intimacy need. Table 2 shows the numbers and percentages of all needs, met and unmet, at baseline. The most noteworthy is the ratio between the met and unmet needs in the field of sexuality and intimacy. Compared to the other categories, these needs had the highest proportion of unmet needs. The percentage of needs that was unmet was 90% for sexuality needs and 90% for intimacy needs. The percentage of needs that was unmet for the other categories ranged between 2% (food) and 63% (company) with an average of 43%.

Cross-sectional relationships

A logistic regression showed that CSA was associated with sexuality needs (OR=1.68, 95% CI: 1.13-2.04). and intimacy needs (OR=1.75, 95% CI: 1.04-1.77). Childhood emotional abuse (CEA) was also associated with sexuality (OR=1.68, 95% CI: 1.16-1.98) and intimacy needs (OR=1.75, 95% CI: 1.08-1.72). Physical abuse, physical neglect and emotional neglect were not associated with either sexuality or intimacy needs.

Table 2. Percentages of no needs, met needs and unmet needs at T1, per need category.

Category of needs	No need (%)	Met need (%)	Unmet need (%)	Missing	% of needs that was unmet
Food	706 (72.6)	211 (21.7)	55 (5.7)	147	2.3
Housing	697 (70.8)	209 (21.2)	78 (7.9)	135	3.2
Household	589 (64.4)	263 (28.8)	62 (6.8)	205	18.5
Safety to others	862 (87.2)	98 (9.9)	29 (2.9)	130	22.8
Safety to self	844 (84.9)	115 (11.6)	35 (3.5)	125	23.3
Information on condition and treatment	561 (57.4)	310 (31.7)	107 (10.9)	141	25.7
Child care	814 (96.9)	19 (2.3)	7 (0.8)	279	26.9
Social life	691 (72.5)	180 (18.9)	82 (8.6)	166	31.2
Money	638 (66.1)	224 (23.2)	103 (10.7)	154	31.5
Transport	914 (92.9)	44 (4.5)	26 (2.6)	135	37.1
Psychological distress	343 (34.9)	385 (39.2)	254 (25.9)	137	39.7
Psychotic symptoms	125 (12.7)	504 (51.2)	355 (36.1)	135	41.3
Alcohol	838 (85.3)	84 (8.6)	60 (6.1)	137	41.7
Physical health	787 (70.3)	107 (10.9)	86 (8.8)	139	44.6
Hygiene	856 (86.5)	91 (9.2)	43 (4.3)	129	47
Education	890 (91.1)	42 (4.3)	45 (4.6)	142	51.7
Payed work	434 (45.8)	243 (25.6)	271 (28.6)	171	52.7
Telephone	971 (98.7)	6 (0.6)	7 (0.7)	135	53.8
Activities	418 (42.5)	261 (26.6)	304 (30.9)	136	53.8
Drugs	715 (72.6)	122 (12.4)	148 (15)	134	54.8
Side effects of medication	519 (53.7)	199 (20.6)	248 (25.7)	153	55.5
Company	514 (53)	169 (17.4)	287 (29.6)	149	62.9
Sexual expression	642 (74.3)	23 (2.7)	199 (23)	255	**89.6**
Intimate relationships	561 (60.1)	37 (4)	335 (35.9)	186	**90.1**

Incidence

Cox regression showed that exposure to childhood sexual abuse increased the risk of sexuality needs (HR=2.1, 95% CI: 1.23-3.74) and intimacy needs (HR=1.7, 95% CI: 1.11-2.66). This means that participants with childhood sexual abuse were 2 times more likely to develop a sexuality need compared to participants who did not experience childhood sexual abuse. Those with childhood sexual abuse were 1.7 times more likely to develop an intimacy need. Childhood emotional abuse also increased the risk of developing sexuality needs (HR=1.8, 95% CI: 1.11-2.89) and intimacy needs (HR=1.4, 95% CI: 1.03-1.96).

Persistence

Results from the poisson regression indicated no associations between childhood sexual abuse and the persistence of either sexuality needs (IRR=0.91, 95% CI, 0.50-1.69), or intimacy needs (IRR=1.05, 95% CI, 0.74-1.48). Similarly, there was no association between childhood emotional abuse and the persistence of either sexuality (IRR=1.12, 95% CI, 0.64-1.93) or intimacy needs (IRR=0.88, 95% CI, 0.65-1.19).

Discussion

The current study is one of the first exploring the impact of childhood trauma, and more specifically childhood sexual abuse, on sexuality and intimacy needs in adulthood among people with psychotic disorder over time. Childhood sexual abuse was experienced by 25% of the participants. This number is largely in line with earlier findings (Turner et al. (2019). The prevalence of sexuality and intimacy needs at baseline was 26%, and 40%, respectively. In line with current findings, Bengtsson-Topps and Hansson (1999) found among 120 people with a diagnosis of schizophrenia in Sweden that, using the CAN, 33% had a sexuality need and 40% an intimacy need.

Emotional and sexual abuse were cross-sectionally associated with sexuality and intimacy needs during the 6-year time frame of this study whereas physical abuse and forms of neglect did not appear to be associated with sexuality and intimacy needs. Further analysis showed that the risk of developing a sexuality or intimacy need was higher when patients had been exposed to childhood sexual abuse. Emotional abuse also increased this risk.

Of all the sexuality and intimacy needs that were present, only 10% were met. None of the other needs remained unmet to this degree. The numbers were even higher than those reported by Wiersma & van Busschbach (2001). Among their sample of people with severe mental illness, 73% of the sexuality needs and 50% of the intimacy needs were unmet.

The results suggest that a large proportion of people with psychosis have unmet needs in the areas of sexuality and intimacy. Clinicians may be insufficiently aware and responsive to these needs. This might be the result of the taboo still surrounding sexuality and intimacy in most societies. (Voermans, Van, Peen, & Hengeveld, 2012) handed out 176 questionnaires among mental health professionals about talking to patients about sexuality. It appeared that mental health professionals felt shame when initiating a conversation on sexuality and felt incompetent to do so. These findings are in line with the results of a similar study of similar size conducted in the USA (Magnan, Reynolds & Galvin, 2005). Research also shows that mental health professionals often assume that a discussion about sex is irrelevant because they think that people with a severe mental illness are unlikely to form a relationship (Ford Elizabeth, 2003). As a consequence, mental health professionals are likely to wait for the patient to initiate the topic, while patients often report being too shy to bring up the topic themselves (Katz, 2009). Another issue that might play a role in the large number of unmet needs, is the fact that there is a scarcity of specific interventions available.

The experience of childhood sexual abuse increases the risk of developing sexuality and intimacy needs. Even though there are no conclusive studies yet, researchers have proposed potential pathways that may account for the difference between those with and without childhood sexual abuse. Some of these suggested pathways are sympathetic nervous system (SNS) activation, negative cognitive associations with sexuality, negative sexual self-schema's and emotions of shame and guilt (Meston & Lorenz, 2013; Pulverman, 2017). The relationship between childhood emotional abuse and sexuality and intimacy needs has, until so far, not received much attention. It is likely that both sexuality and intimacy require a degree of emotional closeness, which may be more difficult to either create and/or endure when having the experience of emotional abuse at a sensitive developmental stage. This relationship deserves more attention and may be a topic of future research. Qualitative

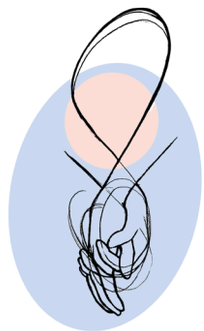
research can help develop a more substantiated insight into this relationship.

Inquiring about and being alert on adverse childhood experiences should be part of routine mental health care. Even though the incidence of sexuality and intimacy needs is higher among people who suffered from childhood sexual abuse, the persistence of needs did not differ between people with and without these adverse experiences. This may be due to the fact that sexuality and intimacy do not receive sufficient attention in ongoing treatment, regardless of a history of childhood trauma. Future research may examine this issue further.

There are several limitations of the current study that require consideration. First, this study consisted of three assessment points over a period of six years. This makes it impossible to draw conclusions on the relationship between sexual needs and variables that are time-variant such as antipsychotic medication. More frequent measurement moments would have allowed to more effectively isolate variable associations. Secondly, to asses incidence, only those without a sexuality or intimacy need at T0 were included. Those who already developed a sexuality or intimacy need at T0 were excluded from this particular analysis. It could be argued that this selection would have resulted in a 'healthier' subsample for incidence analysis, which may have led to an underestimation of the impact of childhood sexual trauma of sexuality and intimacy needs. Future studies should use a longitudinal design starting from the incidence of childhood trauma to avoid this issue. Third, it is important to note that the data used for this study was gathered between 2005 and 2013. The last decade however, the recovery framework, which put a strong emphasis on the client as a whole, has received more attention. With the advent of this framework, more attention towards quality of life in all aspects may have ensued, including sexuality and intimacy. In other words, replication in the current era of psychiatry is required. Nevertheless, other studies using more recent data have reached similar conclusions regarding the position of sexuality and intimacy in mental health care (Cloutier, Francoeur, Samson, Ghostine, & Lecomte, 2020; McCann et al., 2019). Lastly, sexuality and intimacy needs were analyzed quantitatively, but not explored qualitatively. It therefore remains unclear what these needs really represent in the lives of patients. Other studies have explored the content of sexuality and intimacy needs of people with psychosis more extensively. Some examples of these needs are: the desire to find a partner and develop the skills required to do so, and to be sexually active and overcome the consequences of self-stigma and traumatic sexual events (de Jager et al., 2017; de Jager et al., 2018).

This study showed an association between childhood sexual abuse and emotional abuse on one hand and sexuality and intimacy needs on the other. How sexual and emotional abuse may lead to these needs remains unclear. It is known that sexual problems often occur after sexual trauma (Bicanic, Engelhard, & Sijbrandij, 2014). These problems may be induced by the abuse itself but could also be caused or worsened by the onset of post-traumatic stress disorder (PTSD). It would be useful, in future research, to find out how the relationship between (sexual) trauma and sexuality and intimacy needs arises and what the role of PTSD may be. A more concrete suggestion would be to incorporate sexual needs or functioning as an outcome measure in studies focusing on the treatment of PTSD in people with severe mental illness. Since PTSD may play a role in the onset of sexual problems (and needs), it may be hypothesized that sexual functioning will concurrently improve as an outcome of successful PTSD treatment (Schnurr et al., 2009).

Future research should also focus on other factors that might affect sexuality and intimacy needs in people with severe mental illness so that the research community may gain more knowledge on which underlying concepts play a part. With this, the development and testing of interventions that address sexuality and intimacy issues in clinical practice may come closer. A recent development in this field is a CBT-based module focusing on socio-romantic skills for men with psychosis (Hache-Labelle et al., 2020). Including the concept of needs in intervention studies may represent a valuable avenue. Peer support groups as well as skills training trauma focused treatment or stigma interventions may prove effective in reducing the high rate of unmet needs.



References

Ağaçhanlı, R., Alnıak, İ., & Evren, C. (2018). Sexual Dysfunctions are Predicted by Childhood Sexual Abuse in Women with Opioid Use Disorder. *Subst Use Misuse, 53*(13), 2184-2189. doi:10.1080/10826084.2018.1461228

Alameda, L., Ferrari, C., Baumann, P. S., Gholam-Rezaee, M., Do, K. Q., & Conus, P. (2015). Childhood sexual and physical abuse: Age at exposure modulates impact on functional outcome in early psychosis patients. *Psychological Medicine, 45*(13), 2727-2736. doi:10.1017/S0033291715000690

Andresen, R. R. (2000). Interrater reliability of the Camberwell Assessment of Need Short Appraisal Schedule. *Australian and New Zealand Journal of Psychiatry, 34*(5), 856-861.

Bengtsson-Tops, A., & Hansson, L. (1999). Clinical and social needs of schizophrenic outpatients living in the community: The relationship between needs and subjective quality of life. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services, 34*(10), 513-518. doi:10.1007/s001270050169

Bicanic, I., Engelhard, I., & Sijbrandij, M. (2014). Posttraumatische stressstoornis en seksuele problemen na seksueel geweld; prevalentie en behandeling. *Gedragstherapie, 47,* 256-274.

Cloutier, B., Francoeur, A., Samson, C., Ghostine, A., & Lecomte, T. (2020). Romantic relationships, sexuality, and psychotic disorders: A systematic review of recent findings. *Psychiatric Rehabilitation Journal.* doi:10.1037/prj0000409

Comacchio, C., Howard, L. M., Bonetto, C., Lo Parrino, R., Furlato, K., Semrov, E., . . . Ruggeri, M. (2019). The impact of gender and childhood abuse on age of psychosis onset, psychopathology and needs for care in psychosis patients. *Schizophrenia Research, 210*, 164-171. doi:https://doi.org/10.1016/j.schres.2018.12.046

de Boer, M. K., Castelein, S., Wiersma, D., Schoevers, R. A., & Knegtering, H. (2015). The facts about sexual (Dys)function in schizophrenia: an overview of clinically relevant findings. *Schizophr Bull, 41*(3), 674-686. doi:10.1093/schbul/sbv001

de Jager, J., Cirakoglu, B., Nugter, A., & van Os, J. (2017). Intimacy and its barriers: A qualitative exploration of intimacy and related struggles among people diagnosed with psychosis. *Psychosis: Psychological, Social and Integrative Approaches, 9*(4), 301-309. doi:10.1080/17522439.2017.1330895

de Jager, J., van Greevenbroek, R., Nugter, A., & van Os, J. (2018). Sexual Expression and It's Determinants, in People Diagnosed with Psychotic Disorders. *Community Mental Health Journal, 54*(7), 1082-1088. doi:10.1007/s10597-018-0285-1

DeLamater, J., & Karraker, A. (2009). Sexual functioning in older adults. *Curr Psychiatry Rep, 11*(1), 6-11. doi:10.1007/s11920-009-0002-4

Drukker, M., van Dillen, K., Bak, M., Mengelers, R., van Os, J., & Delespaul, P. (2008). The use of the Camberwell Assessment of Need in treatment: what unmet needs can be met? *Social Psychiatry and Psychiatric Epidemiology, 43*(5), 410-417. doi:10.1007/s00127-007-0301-1

Ehrhardt, A., Exner, T., Hoffman, S., Silberman, I., Yingling, S., Adams-Skinner, J., & Smart-Smith, L. (2002). HIV/STD risk and sexual strategies among women family planning clients in New York: Project FIO. *AIDS and Behavior, 6*, 1-13. doi:10.1023/A:1014534110868

Fleury, M.-J., Grenier, G., Bamvita, J.-M., & Tremblay, J. (2013). Factors associated with needs of users with severe mental disorders. *Psychiatric Quarterly, 84*(3), 363-379. doi:10.1007/s11126-012-9252-0

Ford Elizabeth, E. Managing sexual behavior on adult acute care inpatient psychiatric units. *Psychiatric Services, 54*(3), 346-350.

Hache-Labelle, C., Abdel-Baki, A., Lepage, M., Laurin, A. S., Guillou, A., Francoeur, A., . . . Lecomte, T. (2020). Romantic relationship group intervention for men with early psychosis: A feasibility, acceptability and potential impact pilot study. *Early Interv Psychiatry*. doi:10.1111/eip.13012

Katz, A. (2009). *Sex when you're sick: Reclaiming sexual health after illness or injury.* Westport, CT: Praeger Publishers/Greenwood Publishing Group.

Korver, N., Quee, P., Boos, H., Simons, C., de Haan, L., & Beveren, N. (2012). Genetic Risk and Outcome of Psychosis (GROUP), A multi site longitudinal cohort study focused on gene-environment interaction: Objectives, sample characteristics, recruitment and assessment methods. *International journal of methods in psychiatric research, 21*, 205-221. doi:10.1002/mpr.1352

Lambert, M. J., & Cattani, K. (2012). Practice-friendly research review: Collaboration in routine care. *Journal of Clinical Psychology, 68*(2), 209-220. doi:10.1002/jclp.21835

Little, R. J. A. (1988). A Test of Missing Completely at Random for Multivariate Data with Missing Values. *Journal of the American Statistical Association, 83*(404), 1198-1202. doi:10.1080/01621459.1988.10478722

Magnan Morris, A. M. Barriers to addressing patient sexuality in nursing practice. *Medsurg nursing : official journal of the Academy of Medical-Surgical Nurses, 14*(5), 282-289.

McCann, E., Donohue, G., de Jager, J., Nugter, A., Stewart, J., & Eustace-Cook, J. (2019). Sexuality and intimacy among people with serious mental illness: a qualitative systematic review. *JBI Database System Rev Implement Rep, 17*(1), 74-125. doi:10.11124/jbisrir-2017-003824

Pulverman, C. S., Kilimnik, C. D., & Meston, C. M. (2018). The Impact of Childhood Sexual Abuse on Women's Sexual Health: A Comprehensive Review. *Sexual Medicine Reviews, 6*(2), 188-200. doi:https://doi.org/10.1016/j.sxmr.2017.12.002

Roberts, R., O'Connor, T., Dunn, J., & Golding, J. (2004). The effects of child sexual abuse in later family life; mental health, parenting and adjustment of offspring. *Child Abuse*

Negl, 28(5), 525-545. doi:10.1016/j.chiabu.2003.07.006

Schnurr, P., Lunney, C., Forshay, E., Thurston, V., Chow, B., Resick, P., & Foa, E. (2009). Sexual Function Outcomes in Women Treated for Posttraumatic Stress Disorder. *Journal of women's health* (2002), 18, 1549-1557. doi:10.1089/jwh.2008.1165

Slade, M., Leese, M., Cahill, S., Thornicroft, G., & Kuipers, E. (2005). Patient-rated mental health needs and quality of life improvement. *The British Journal of Psychiatry, 187*(3), 256-261. doi:10.1192/bjp.187.3.256

Slade, M. M. (1999). Routine clinical outcome measures for patients with severe mental illness: CANSAS and HoNOS. *The British Journal of Psychiatry, 174*, 404-408.

Thombs, B. D., Bernstein, D. P., Lobbestael, J., & Arntz, A. (2009). A validation study of the Dutch Childhood Trauma Questionnaire-Short Form: Factor structure, reliability, and known-groups validity. *Child Abuse & Neglect, 33*(8), 518-523. doi:https://doi.org/10.1016/j.chiabu.2009.03.001

Turner, S., Harvey, C., Hayes, L., Castle, D., Galletly, C., Sweeney, S., . . . Spittal, M. J. (2019). Childhood adversity and clinical and psychosocial outcomes in psychosis. *Epidemiology and Psychiatric Sciences*. doi:10.1017/S2045796019000684

Varese, F., Smeets, F., Drukker, M., Lieverse, R., Lataster, T., Viechtbauer, W., . . . Bentall, R. P. (2012). Childhood adversities increase the risk of psychosis: a meta-analysis of patient-control, prospective- and cross-sectional cohort studies. *Schizophrenia Bulletin, 38*(4), 661-671. doi:10.1093/schbul/sbs050

Voermans, J. M., Van, H. L., Peen, J., & Hengeveld, M. W. (2012). Het bespreken van seksuele problemen door psychiaters en aiossen = Is there adequate discussion between psychiatrists and their patients regarding patients' sexual problems? *Tijdschrift voor Psychiatrie, 54*(1), 9-16. Retrieved from http://login.ezproxy.ub.unimaas.nl/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2012-01866-001&site=ehost-live&scope=site

Wiersma, D., & van Busschbach, J. (2001). Are needs and satisfaction of care associated with quality of life? *European Archives of Psychiatry and Clinical Neuroscience, 251*(5), 239-246. doi:10.1007/s004060170033

Wiersma, D., van den Brink, R., Wolters, K., McCabe, R., Bullenkamp, J., Hansson, L., . . . Priebe, S. (2009). Individual unmet needs for care: Are they sensitive as outcome criterion for the effectiveness of mental health services interventions? *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services, 44*(4), 317-324. doi:10.1007/s00127-008-0432-z

Zwickl, S., & Merriman, G. (2011). The association between childhood sexual abuse and adult female sexual difficulties. *Sexual and Relationship Therapy, 26*(1), 16-32. doi:10.1080/14681994.2010.530251

Factors associated with sexual expression and intimacy in people diagnosed with severe mental illness (SMI)

de Jager, J., Ensing, A., Topper, M., Nugter, A., Os, J. (2021)

Under review

FACTORS ASSOCIATED WITH SEXUAL EXPRESSION AND INTIMACY IN PEOPLE DIAGNOSED WITH SEVERE MENTAL ILLNESS (SMI)

ABSTRACT

Engaging in sexuality and intimacy appears harder for people suffering from SMI. Previous research has identified several possible barriers in the expression of sexuality and intimacy among people with mental illness and particularly SMI. These factors have mostly been studies separately or in qualitative research design.

Here, using a quantitative research design, the associations between often researched factors, namely medication and symptoms, social skills, self-stigma, (sexual) self-esteem and sexual trauma on the one hand, and sexuality and intimacy on the other were studied. Based on previous research, a mediation effect of (sexual) self-esteem was expected.

We performed a cross-sectional study in 114 participants with SMI. Analyses showed that intimacy was only associated with self-stigma. Sexual functioning appeared to be related to psychotropic side effects and sexual self-esteem. Sexual autonomy was associated with sexual trauma and sexual self-esteem. Even though sexual self-esteem did impact sexual functioning and sexual autonomy, the hypothesized mediation was not found.

The current results may guide caregivers and patients when evaluating sexuality and intimacy problems and the possible factors that could play a role. They indicate that targeting these factors with existing interventions such as PTSD treatment or self-stigma modules may be helpful. Future research should focus on the development of new and highly needed interventions that can help people with SMI meet their sexuality and intimacy needs. Current results may help guide this development.

INTRODUCTION

In people diagnosed with severe mental illness (SMI), being in an intimate relationship is associated with higher well-being, higher quality of life and even with a more favourable course of the mental disorder (Agerbo, Byrne, Eaton, & Mortensen, 2004; Hansson, 2006; Nyer et al., 2010). However, engaging in sexual and intimate relationships appears harder for people suffering from SMI. To date, research has identified at least six possible obstacles

that might interfere with sexual and intimate relationships in persons with SMI.

First, the most researched topic when explaining problems regarding sexuality and intimacy in SMI is the effect of psychotropics such as antidepressants and antipsychotics on sexual functioning (de Jager & McCann, 2017; Van Sant, Ahmed, & Buckley, 2012). Sexual dysfunctions due to side effects of medication play an important role in observed levels of non-compliance to medication (Montejo et al., 2008). Furthermore, psychotropics can result in weight gain and may thereby lead to a negative self-evaluation of the body image. People using psychotropics feel less attractive, which may hamper the expression of sexuality (Östman, 2014; Volman & Landeen, 2007).

Second, SMI often manifests in adolescence or early adulthood, which may impact psychosocial and sexual development in an adverse fashion (Harrop & Trower, 2001; Whisman, Johnson, Li, & Robustelli, 2014 2014). A later onset or absence of sexual experience, less knowledge and fewer skills to develop sexual roles and connect to others in a sexual manner, all may play a part (Volman & Landeen, 2007). In turn, this could lead to low sexual confidence and feelings of sexual incompetence (Kelly & Conley, 2004; Peitl, Rubeša, Peitl, Ljubicic, & Pavlovic, 2009).

Third, after illness onset, symptoms can pose a challenge to maintaining in contact with others (Burns & Patrick, 2007; Lenior, Dingemans, Linszen, de Haan, & Schene, 2001 de Haan & Schene, 2001). A large number of clinical diagnoses such as depression, anxiety disorders or psychotic symptoms are characterized by a tendency to withdraw from companionship and relationships. People diagnosed with SMI may experience limitations in their social skills and social insight (Peitl et al., 2009; Savla, Vella, Armstrong, Penn, & Twamley, 2013 Pennsylvania, and Twamley, 2013). As a result, their social network can be limited to family members and mental health professionals. Several studies show that these restrictions may impede the ability to enter into or maintain sexual relationships (Lysaker, Davis, Warman, Strasburger, & Beattie, 2007 Strasburger, & Beattie, 2007; Van Sant et al., 2012). These difficulties reduce the probability of finding a partner, even more so outside the mental health care system (Perry & Wright, 2006; Redmond, Larkin, & Harrop, 2010).

Fourth, traumatic sexual experiences may strongly affect sexual functioning and intimacy in a negative way (Bebbington, 2009 Morrisson & Ross, 2005). Previous work in the area of victimization and SMI showed high prevalence rates of trauma, including sexual trauma, in this group (Varese et al., 2012). After the onset of, for example, psychosis, the risk of being (sexually) victimized increases.

A fifth barrier is stigelf-stigma, the internalization of prejudice, can lead to social withdrawal and feelings of worthlessness in relation to sexuality and intimacy. The increase in social isolation and feelings of sexual worthlessness may reduce social functioning and opportunities for sexual and intimate engagement. For some, the fear of rejection is a reason to avoid intimate relationships (de Jager, van Greevenbroek, Nugter, & van Os, 2018).

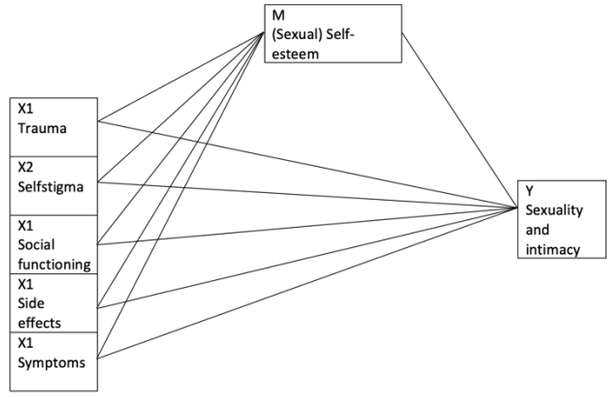
In summary, previous research has identified several possible barriers in the expression

of sexuality and intimacy among people with mental illness and particularly SMI. Previous qualitative research has suggested that potential barriers exert their effects on the expression of sexuality and intimacy both directly and indirectly (de Jager, Cirakoglu, Nugter & van Os. 2017; de Jager, van Greevenbroek, Nugter, & van Os, 2018). These indirect effects may operate through general and sexual self-esteem (de Jager, Cirakoglu, Nugter, & van Os, 2017). For example, psychotropic side effects may hamper sexual functioning directly, but also affect (sexual) self-esteem. Reduced (sexual) self-esteem may, in turn, affect intimate and sexual expression. These findings are in line with studies in the general population that have shown that sexual dysfunction reduces (sexual) self-confidence, while low (sexual) self-confidence in turn can worsen sexual dysfunction (Raja and Azzoni 2003; Baggaley 2008; McCabe et al. 2010).

The impact of (sexual) self-esteem on sexual functioning in people diagnosed with SMI has not received much attention. Peitl and colleagues (2009) and Van Sant and coworkers (2012) found that people diagnosed with SMI experience significantly lower (sexual) self-esteem than the general population, which impacts the ability to build intimacy with others, reducing the probability of a sexual relationship. These findings support our hypothesis that unmet needs for sexual expression and intimacy are explained by a combination of the factors listed above, in which low (sexual) self-esteem plays a central, possibly mediating, role.

Since previous studies in this field were either qualitative or focussed on a single factor, it remains unknown how all factors combined interact and to what extent they affect the expression of sexuality and intimacy among people diagnosed with SMI. In the current study, we aimed to test a hypothetical model including possible determinants of sexuality and intimacy, as identified in previous studies, see Figure 1 (de Jager, Cirakoglu, Nugter & van Os, 2017). Such an analysis may be a starting point towards more specific knowledge on the factors that are related to intimacy and sexual expression in people diagnosed with

Figure 1. Hypothesized model of intimacy and sexuality



SMI and point us in the direction of interventions that may be required to address the unmet needs in this group.

To this end, we explored associations between self-stigma, sexual trauma, symptomatic distress and psychotropic side effects, interpersonal functioning on one hand, and sexuality and intimacy on the other. In addition, associations with, and the (possible mediating) role of, general and sexual self-esteem is explored as suggested by de Jager et al (2017). To the best of our knowledge, this is the first quantitative study that includes multiple possible determinants in an analysis to identify the factors that most strongly affect sexuality and intimacy in people diagnosed with SMI.

Method

Design

Because of the exploratory nature of the study, and the relative novelty of the topic, a cross-sectional research design using self-report questionnaires was chosen.

Sample characteristics

Based on an a priori power sample size analysis (Soper, 2016), 103 participants were required for an analysis using 7 predictor variables with an expected effect size (f)2 of .15, a power of .8, and a significance level set at .05. Participants were people diagnosed with SMI, clinically defined as having a complex set of mental health and social needs.

In and exclusion criteria

Participants were diagnosed with severe mental illnesses and referred for treatment to community mental health care teams catering to the needs of individuals aged 18-65 years. Individuals with personality disorder, addiction or developmental disorder as a single diagnosis were excluded, as were individuals in a florid psychotic state or an estimated IQ of less than 70. Diagnoses and estimated IQ were provided by the participants' clinician. Participants had to be able to understand the study information and procedures and give informed consent.

Procedure

The study was conducted with the approval of the medical ethical committee of the VU Medical Centre in Amsterdam, The Netherlands. Participation was voluntary and no compensation for participation was offered. Possible participants were approached in three ways. First, clinicians were queried to ask each person in their caseload that met the inclusion criteria for participation. Second, all clients who had previously given consent to be asked about participation in research were informed about the study and offered the opportunity to participate. Potential participants were then contacted by the researcher and checked for inclusion criteria. The vast majority of participants were recruited through this

procedure. The third procedure involved an online announcement in the Dutch eCommunity focussing on psychosis (www.psychosenet.nl). After applying, potential participants were also contacted by the researcher and checked for inclusion criteria.

All participants signed an informed consent form. Participants were asked to fill in the questionnaires at the community mental health centre. A quiet room was provided. If this was inconvenient, the possibility to take the questionnaires back home was offered.

Materials

Independent variables:

* Self-esteem

The Rosenberg Self-Esteem Scale (RSES) (Rosenberg, 1965) is a self-report measure of global self-esteem that was previously used to measure self-esteem among people diagnosed with SMI (Lecomte, Corbière, & Laisné, 2006). The 10-items version that consists of 10 statements related to overall feelings of self-worth or self-acceptance was used. The items are rated on a four-point scale ranging from strongly agree to strongly disagree. Some are reverse-keyed items. Scores range from 10 to 40, with higher scores indicating higher self-esteem.

* Sexual self-esteem

The Sexual Esteem Scale (SES) (Snell & Papini, 1989), a subtest of the Sexuality Scale, was used to assess sexual self-esteem. The SES consists of ten items including five reverse-keyed items. Higher scores indicate higher sexual self-esteem. Responses are scored on a five-point scale ranging from 1 (not agreed) to 5 (agreed). Higher scores indicate higher levels of sexual self-esteem.

* Psychotropic side effects

The Liverpool University Neuroleptic Side-Effect Rating Scale (LUNSERS) (Day et al., 1995) was used to asses a broad variety of negative side-effects of psychotropics. The LUNSERS is a 41-item self-rating scale which requires respondents to indicate how much they experienced a range of the side-effects listed in the last month. Responses are scored on a five point scale from 0 (not at all) to 4 (very much). Higher scores indicate higher levels of side effects.

* Self-stigma

The Internalized Stigma of Mental Illness (ISMI) scale is a self-report questionnaire developed with consumer input that includes the following subscales: Alienation, Discrimination Experience, Social Withdrawal, Stereotype Endorsement, and Stigma Resistance. The ISMI-10, which retained the essential properties of the ISMI-29 and has been found to have similar descriptive statistics as the ISMI-29 was used (Boyd, Otilingam, & Deforge, 2014). Responses are scored on a five-point scale from 0 (totally not agree) to 4 (totally agree). Higher scores indicate higher levels of internalized stigma.

* Sexual trauma

The Trauma Screening Questionnaire (TSQ) is developed to screen for lifetime trauma history (Brewin et al., 2002). For each event on the scale, the individual indicates whether he or she had ever experienced it over their lifetime in a binary (yes/no) format (e.g., “Has anyone threatened to kill you or seriously hurt you?”). The TSQ asks about the experience of traumatic events using wording that corresponds with the DSM-IV Criterion A for PTSD. This version of the TSQ was used to screen for trauma exposure in previous studies with persons with SMI (de Bont et al., 2015). For the purpose of the current study, only the question focusing on sexual trauma was used. Since the TSQ does not rate how often a particular trauma has occurred, scores cannot be added. Of all the participants that had experienced trauma, only five experienced a single traumatic event.

* Symptoms

The Outcome Questionnaire- 45 (OQ-45) rates general dysfunction on the basis of different dimensions, based on Lambert’s conceptualization (1983): 1. subjective discomfort (intrapsychic functioning), 2. the (dis)functioning in interpersonal relationships, 3. the (dis) functioning in the social role. These domains indicate how persons feel, how they interact with people who are important to them and how important tasks in life, such as work and school, are performed. For the purpose of measuring symptomatic distress the subscale Symptomatic Distress (SD) of the Dutch version of de OQ-45 was used (de Jong et al., 2007). This subscale consists of 25 items indexing the most common mental disorders, The items are scored on a five-point rating scale, ranging from never (0) to almost always (4). Higher scores indicate more distress.

* Social functioning

For social functioning, the subscale Interpersonal Relationships (IR) of the Dutch OQ-45 was used as an index of social (dis)functioning. The IR scale consists of 11 items, and indexes satisfaction and problems in interpersonal relationships. Higher scores reflect more problems.

Dependent variables:

Sexual expression was operationalized as sexual (dys)functioning and sexual autonomy:

* Sexual functioning

The five-item Arizona Sexual Experience (ASEX) Scale assesses sexual dysfunction and has been used in SMI research (Byerly, Nakonezny, Fisher, Magouirk, & Rush). It assesses the strength of sex drive, ease of sexual arousal, penile erection/vaginal lubrication, ability to reach orgasm and satisfaction with orgasm on a six-point Likert scale, ranging from 1 (no impairment) to 6 (complete impairment). The ASEX scale is applicable to patients regardless of availability of a sexual partner and their sexual orientation. Scores range from 5–30, with higher scores representing greater sexual dysfunction. A total score > 18, or a score > 5 (very difficult) on any single item or any three items with individual scores > 4 is indicative of clinically significant sexual dysfunction (Nunes et al., 2008)

* Sexual Autonomy

Within a sexual context, autonomy refers to the individual’s ability to express sexual desires and exercise choice during sexual activities, and is believed to foster sexually pleasurable experiences (Sanchez, Crocker, & Boike, 2005 2005). The sexual autonomy scale (SAS) (Sanchez, Crocker & Boike, 2005) consists of three items measuring the extent to which participants feel their sexual behaviours are self-determined. Participants are asked to indicate the extent of (dis)agreement-disagreement on a seven-point Likert scale. The range for the total score is 3–21. Higher scores represent higher levels of sexual autonomy.

Intimacy

* Miller Social Intimacy Scale

The Miller Social Intimacy scale (MSIS) (Miller & Lefcourt) is a 17-item self-report measure designed to assess intimacy in interpersonal relationships. The participants choses the person he or she is closest to and answers the questions about this specific person. This could be a romantic partner but also, for example, a neighbour. Each item is scored on a 1- to 10-point scale with possible scores ranging from 17 to 170; higher scores indicate greater levels of intimacy.

The MSIS is the only measurement that was not available in Dutch. Given high face validity of the instrument, and it being one of the few intimacy scales that do not require a partner, and the fact that it has been used in countries which are culturally similar to the Netherlands, the MSIS was chosen. For the purpose of this study, the instrument was translated from English to Dutch with the translate-retranslate method (i.e., retranslation by native speaker).

Data analysis

Hypotheses were tested in Mplus 6.12 (Muthen & Muthen, 2021). Associations were analysed in three steps. First, as a prerequisite to evaluate the hypothesized associations, Pearson correlation coefficients were computed for the continuous independent variables self-stigma, symptomatic distress, social functioning, self-esteem, sexual self-esteem and the dependent variables intimacy, sexual functioning, sexual autonomy. In the next step, variables showing a significant relation ($p < .05$)to a dependent variable were included as predictors for that particular dependent variable in a multivariate multiple regression analysis. Due to skewness, the variable psychotropic side effects was dichotomized as yes

(1) or no (0). The dichotomous variables sexual trauma and psychotropic side effects were also included as independent variables at this stage.

In step 3, a path analysis was performed in which the expected indirect effects via the mediators sexual self-esteem and self-esteem were tested. Only independent variables that significantly predicted the dependent variables in step 2 were included in this final step. Bias-corrected bootstrap confidence intervals (Wiersma et al.) of the indirect effects were calculated using 5,000 bootstrap samples (MacKinnon, Lockwood, & Williams, 2004). According to this method, an indirect effect is significant at the two-tailed .05 level if the value of 0 is not part of the 95% bootstrap confidence interval around the indirect effect. The hypothesized models tested in step 2 and 3 were evaluated by recommended fit indices (χ^2, RMSEA, CFI, and SRMR; Hu and Bentler, 1999), inspection of the significance of included pathways, and the amount of variance explained within each of the dependent

Table 1. Socio-demographic characteristics of the participants

N			
Demographics		Number	%
Gender	Male	52	45.6
	Female	62	54.4
Age (range)	Mean	40 (18-65)	
Ethnic minority status	Minority	7	6.2
	White	107	83.8
Marital status			
	Not married/single	56	49.1
	Married	24	21
	Cohabiting	21	18.4
	Divorced	12	10.5
	Widow(er)	1	0.9
Education	No education	0	0
	Primary school	4	3.5
	Highschool	27	23.7
	Vocational education	55	48.2
	Academic	24	21.1
	Missing	4	3.5
Primary diagnosis	Recurring depression	35	30.7
	Bipolar disorder	15	13.2
	Psychotic disorder	28	24.6
	PTSD	12	10.5
	Anxiety disorder	11	9.6
	Schizoaffective disorder	4	3.5
	Other disorders	9	7.9
Medication use	Yes	89	78.1
	No	25	21.9
Psychotropic side effects	Yes	80	70.2
	No	34	29.8

variables. For the interpretation of the model fit indices, the recommendations made by Hu and Bentler (1999) were followed, such that good model fit was indexed by: a non-significant χ^2 test, RMSEA < .06, CFI > .90, SRMR < .10.

Results

A total of 114 persons participated in the study (Table 1). Given missing data, a Little MCAR test was performed (Little, 1988) which indicated that data were missing completely at random (χ^2 = 10.74, df = 6, p = .09). To deal with missing data, maximum likelihood estimation were performed in step 2 and 3.

Sexual and romantic relationship experience

Overall, most participants had had some romantic relationship experience (Table 2). At the moment of participation, 61% of the sample was single, most of them male. Seven percent had never been in a romantic relationship and 94% of the participants had had sexual intercourse at least once.

Table 2. Sexual and romantic relationship descriptives

	Yes	No	Missing
Currently single	69 (60.5%)	45 (39.5%)	0
Ever been in a relationship	106 (93%)	8 (7%)	0
Ever had sexual intercourse	107 (94%)	7 (6%)	0
Sexual trauma	50 (43.9%)	63 (55.3%)	1 (0.9%)
Current clinically significant sexual dysfunction	59 (51.8%)	46 (40.4%)	9 (7.9%)
	M	SD	
Months since last relationship	47.53	39	
Duration of longest relationship (months)	97.7	120.6	
Months since last sexual intercourse	29.15	76.42	

Table 3 shows the correlations between the independent variables and the continuous independent variables.

Table 3. Descriptive statistics and correlation matrix of all continuous variables based on Spearman's rho

Variables	M	SD	1	2	3	4	5	6	7	8	9	10
1 self-stigma	20.28	4.61	1	-	-	55**	.07	-.53**	-.34**	-.40**	.35**	-.41**
2 sexual trauma	-	-		1	-	-	-	-	-	-	-	-
3 side effects	-	-		-	1	-	-	-	-	-	-	-
4 symptoms	49.22	12.82				1	.22*	-.60**	-.42**	-.18	.24**	-.47**
5 social dysfunctioning	22.10	3.78					1	-.16	-.25**	-.05	-.05	-.30**
6 self esteem	25.18	6.52						1	.43**	.29**	-.17	.42**
7 sexual self esteem	29.94	11.34							1	.21*	-.32**	.66**
8 intimacy	127.02	25.13								1	-.18	.36**
9 sexual dysfunctioning	17.25	5.65									1	-.30**
10 sexual autonomy	14.67	4.51										1

N=114
*p-value<0.05, **p-value<0.01

Intimacy had the weakest association with the independent variables. The only variable that was significantly associated with intimacy was self-stigma. Sexual dysfunctioning was associated with self-stigma, symptomatic distress, and sexual self-esteem. Sexual autonomy was associated with all the continuous independent variables.

General and sexual self-esteem were correlated but not so strongly that it could be assumed that they reflect the same concept (R^2 = .43, p < .01). Therefore, both were included in the next analysis. A multivariate multiple regression was then performed to evaluate the direct effects of the independent variables on the dependent variables. Unstandardized coefficients resulting from the multivariate multiple regression analysis are reported, and standardized coefficients are displayed in Figure 2. The fit indices indicated a good model to data fit ($\chi^2(24)$ = 140.91, p < .001, RMSEA = 0.000 (90 % C.I. 0.00 - 0.14), CFI = 1.000, TLI = 1.008 and SRMR = 0.020). Sexual dysfunction was predicted by side effects of medication (β = 3.29, p < .001) and sexual self-esteem (β = -0.11, p = .02), accounting for 23% of the variance (R^2 = 0.23, p < .001). Intimacy was predicted by self-stigma (β = -1.74, p = .01), accounting for 19% of the variance (R^2 = 0.19, p = .01). Sexual autonomy was predicted by sexual trauma (β = -1.64, p = .01) and sexual self-esteem (β = .22, p < .00), accounting for 55% of the variance (R^2 = 0.55, p < .001).

Finally, a path analysis was performed in which the expected indirect effects via the mediators sexual self-esteem and self-esteem were tested. Independent variables that significantly predicted dependent variables in step 2 were included in this final step. Unstandardized coefficients are reported, and standardized coefficients are displayed in Figure 3. The fit indices indicated a good model to data fit ($\chi^2(35)$= 246.76, p < .001, RMSEA = 0.074 (90 % C.I. 0.000 - 0.157), CFI = .98, TLI = .89 and SRMR = 0.03).

There was no significant indirect effect of side effects on sexual dysfunction (β = .03, p = .93). The indirect effect of stigma on intimacy, was also nonsignificant (β = -.24, p = .30) as was the effect of sexual abuse on sexual autonomy (β = 1.10, p = .39). Results did not indicate a mediation effect of sexual self-esteem.

Figure 2. Standardized coefficients of the associations between the dependent and independent variables

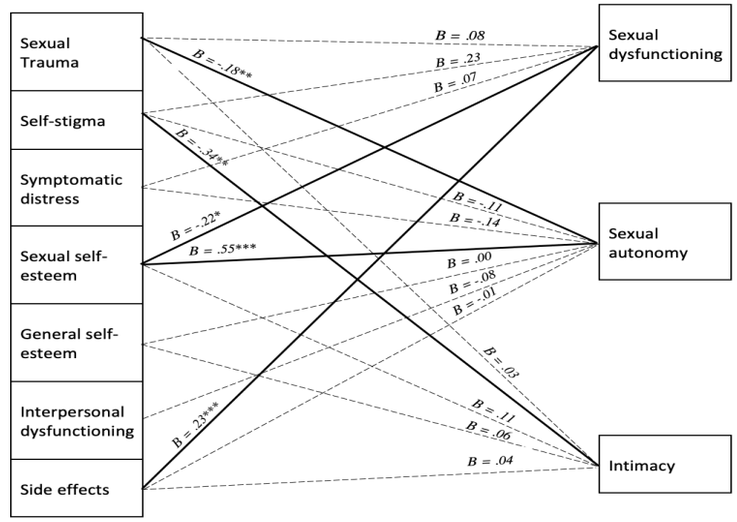
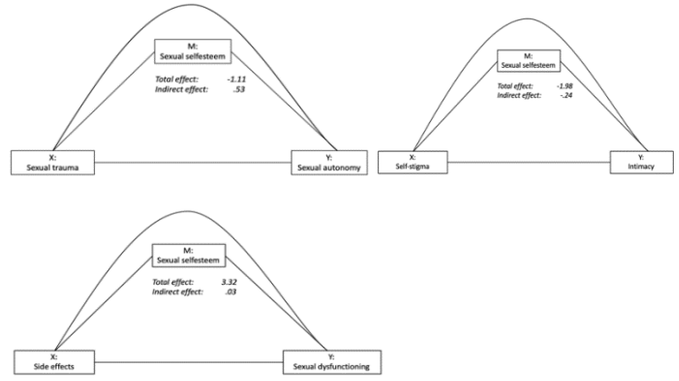


Figure 3. Total and indirect effects of the hypothesized mediation models, displayed here separately



* p <.05; ** p <.01; ***p<.000.

DISCUSSION

To the best of our knowledge, the current study is the first quantitative study that incorporates multiple variables in order to specify the associations between different variables and sexual expression and intimacy in people diagnosed with SMI. Over half of the 114 participants experienced a clinically significant sexual dysfunction. Other studies have

reported higher rates among, for example, people diagnosed with schizophrenia (Harley, Boardman, & Craig, 2010). However, the rates in this study are higher than the general population, in which sexual dysfunction has been estimated to affect 20– 30% of men and 40– 45% of women (Lewis et al., 2010). The lower rates in the current sample, compared to other SMI samples, might be due to our relatively broad definition of SMI.

The level of intimacy reported by participants is in line with the clinical sample, used by Miller and Lefcourt (1982) in their validation study of their intimacy measure; the MSIS. Unfortunately, no data on the SMI population was obtained before. The same goes for sexual autonomy. However, compared to the sample used to represent the general population by Sanchez, Brocker and Boike (Sanchez et al.), participants in the current study had lower sexual autonomy.

To shed light on the main research questions, the association between commonly reported factors and sexuality and intimacy was tested. Analyses showed that, out of the three outcome variables, intimacy was the most difficult to predict. The only variable that was significantly associated with intimacy was self-stigma. This association might be explained through the concept of self-disclosure. Intimacy is conceptualized by Reis and Shaver (Reis & Patrick) as a process in which self-disclosure and responsivity interact over time. Several studies have shown that self-stigma may lead to avoidance, for example avoidance of self-disclosure (Abiri, Oakley, Hitchcock, and Hall (2016); (de Jager et al., 2017). Self-stigma may interfere with intimacy by obstructing its precondition, self-disclosure. Even though no causal inference can be made, it could be hypothesized that addressing self-stigma with sensitivity to the context of romantic and sexual relationships, may help clear the way towards more intimacy. See Yanos, Lucksted, Drapalski, Roe & Lysaker (2015) for a review on interventions targeting mental health self-stigma.

Sexual dysfunctioning appeared to be related to psychotropic side effects and sexual self-esteem. The negative association between psychotropics and sexual dysfunctioning has been researched a number of times (de Jager & McCann, 2017). However, the association between sexual dysfunctioning and sexual self-esteem in people diagnosed with SMI has not, and may require further attention. It is important to note that general self-esteem and sexual self-esteem are not the same concepts. Interventions focusing on general self-esteem improvement might therefore not automatically be successful in improving sexual self-esteem. Sexual autonomy appeared related to sexual trauma and sexual self-esteem. Even though sexual self-esteem did impact two of the three outcome variables, the hypothesized mediation was not found.

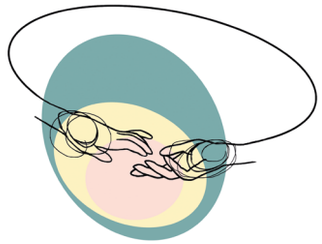
There is a scarcity of interventions available to mental health professionals and patients that focus on sexuality and intimacy needs. Understanding the factors that complicate sexuality and intimacy for people diagnosed with SMI may stimulate the development of interventions that can possibly help meet high rates of unmet sexuality and intimacy needs. The current study can be seen as a starting point in the quest for and development of effective interventions. Its results may guide conversations between caregivers and patients

when analyzing sexuality and intimacy problems and the possible factors that could play a role. Targeting these factors with interventions such as self-stigma modules and (sexual) self-esteem modules might be helpful.

The current study has some limitations that should be taken into account. First, it relies on self-reports. Research has shown that self-reported data on sexual risk behaviour might lack reliability (DiClemente, Swartzendruber, & Brown, 2013; O'Sullivan, 2008). Even though sexual risk behaviour is not the main focus of the study, the sexual demographics might be subject to bias. Since a cross-sectional design was used, the causal direction of the associations between variables remains unknown. We hypothesized, based on previous studies, that self-stigma, sexual trauma side effects, social (dys)functioning, symptomatic distress and self-esteem are determinants of sexuality and intimacy. However, it is equally plausible that, for example, sexuality or intimacy problems cause self-stigma. The same goes for the association between sexual self-esteem and sexual dysfunctioning and the association between sexual trauma and sexual autonomy. Sanchez, Brocker and Boike (2005) have, for example, suggested that people who experienced undermined autonomy may be more sexually compliant and thus be more likely to engage in unwanted sex. Sexual trauma may lower the sexual autonomy, while lowered sexual autonomy might make people more vulnerable toward sexual trauma. It seems likely that there is a reciprocal association between these variables. A longitudinal research design is needed to examine the specific direction of these found associations.

Another limitation that must be considered is the fact that sexual orientation was not included as a variable in the study. Research has shown that individuals diagnosed with a serious mental illness who identify outside of heteronormative relationships, experience what is described as a double stigma, causing difficulties of alienation and identity (McCann et al., 2019). The variables (sexual) self-esteem and stigma could therefore well be have been influenced by sexual orientation. The same goes for gender, which due to the limited sample size, was not included in the analysis. Previous studies did identify gender differences when researching sexuality and intimacy among people diagnosed with SMI (Harley et al., 2010). Future research should incorporate these variables in their analysis.

We hope and believe this study contributes to knowledge on barriers toward sexuality and intimacy among people diagnosed with SMI and can help guide further research in this field. We would also like to point clinicians and researchers in the direction of developing and testing new interventions that target these barriers, so that recovery in these fields can be effectively targeted.



References

Abiri, S., Oakley, L. D., Hitchcock, M. E., & Hall, A. (2016). Stigma Related Avoidance in People Living with Severe Mental Illness (SMI): Findings of an Integrative Review. *Community Ment Health J, 52*(3), 251-261. doi:10.1007/s10597-015-9957-2

Agerbo, E., Byrne, M., Eaton, W. W., & Mortensen, P. B. (2004). Marital and Labor Market Status in the Long Run in Schizophrenia. *Archives of General Psychiatry, 61*(1), 28-33. doi:10.1001/archpsyc.61.1.28

Bebbington, P. (2009). Childhood sexual abuse and psychosis: aetiology and mechanism. *Epidemiol Psichiatr Soc, 18*(4), 284-293.

Boyd, J. E., Otilingam, P. G., & Deforge, B. R. (2014). Brief version of the Internalized Stigma of Mental Illness (ISMI) scale: psychometric properties and relationship to depression, self esteem, recovery orientation, empowerment, and perceived devaluation and discrimination. *Psychiatr Rehabil J, 37*(1), 17-23. doi:10.1037/prj0000035

Brewin, C., Rose, S., Andrews, B., Green, J., Tata, P., McEvedy, C., . . . Foa, E. (2002). Brief Screening Instrument for Post-Traumatic Stress Disorder. *The British journal of psychiatry : the journal of mental science, 181*, 158-162. doi:10.1192/bjp.181.2.158

Burns, T., & Patrick, D. (2007). Social functioning as an outcome measure in schizophrenia studies. *Acta Psychiatr Scand, 116*(6), 403-418. doi:10.1111/j.1600-0447.2007.01108.x

Byerly, M. J., Nakonezny, P. A., Fisher, R., Magouirk, B., & Rush, A. J. (2006). An empirical evaluation of the Arizona sexual experience scale and a simple one-item screening test for assessing antipsychotic-related sexual dysfunction in outpatients with schizophrenia and schizoaffective disorder. *Schizophr Res, 81*(2-3), 311-316. doi:10.1016/j.schres.2005.08.013

de Bont, P., van den Berg, D., van der Vleugel, B., Roos, C., Jongh, A., Gaag, M., & Van minnen, A. (2015). Predictive validity of the Trauma Screening Questionnaire in detecting post-traumatic stress disorder in patients with psychotic disorders. *The British Journal of Psychiatry, 206*. doi:10.1192/bjp.bp.114.148486

de Jager, J., Cirakoglu, B., Nugter, A., & van Os, J. (2017). Intimacy and its barriers: A qualitative exploration of intimacy and related struggles among people diagnosed with psychosis. *Psychosis: Psychological, Social and Integrative Approaches, 9*(4), 301-309. doi:10.1080/17522439.2017.1330895

de Jager, J., & McCann, E. (2017). Psychosis as a barrier to the expression of sexuality and intimacy: An environmental risk? *Schizophrenia bulletin, 43*(2), 236-239.

de Jager, J., van Greevenbroek, R., Nugter, A., & van Os, J. (2018). Sexual Expression and It's Determinants, in People Diagnosed with Psychotic Disorders. *Community Mental Health Journal, 54*(7), 1082-1088. doi:10.1007/s10597-018-0285-1

de Jong, K., Nugter, M., Polak, M., Wagenborg, J. E. A., Spinhoven, P., & Heiser, W. (2007). The Outcome Questionnaire (OQ-45) in a Dutch population: A cross-cultural validation. *Clinical Psychology and Psychotherapy, 14*, 288 - 301 (2007), 14.

DiClemente, R. J., Swartzendruber, A. L., & Brown, J. L. (2013). Improving the validity of self-reported sexual behavior: no easy answers. *Sex Transm Dis, 40*(2), 111-112. doi:10.1097/OLQ.0b013e3182838474

Hansson, L. (2006). Determinants of quality of life in people with severe mental illness. *Acta Psychiatrica Scandinavica, 113*(s429), 46-50. doi:https://doi.org/10.1111/j.1600-0447.2005.00717.x

Harley, E. W., Boardman, J., & Craig, T. (2010). Sexual problems in schizophrenia: prevalence and characteristics. A cross sectional survey. *Soc Psychiatry Psychiatr Epidemiol, 45*(7), 759-766. doi:10.1007/s00127-009-0119-0

Harrop, C., & Trower, P. (2001). Why Does Schizophrenia Develop at Late Adolescence? *Clinical psychology review, 21*, 241-265. doi:10.1016/S0272-7358(99)00047-1

Hu, L.-t., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling, 6*(1), 1-55. doi:10.1080/10705519909540118

Kelly, D., & Conley, R. (2004). Sexuality and Schizophrenia: A Review. *Schizophrenia bulletin, 30*, 767-779. doi:10.1093/oxfordjournals.schbul.a007130

Kim, J., & Hatfield, E. (2004). Love types and subjective well-being: A cross cultural study. *Social Behavior and Personality: An International Journal, 32*(2), 173-182. doi:10.2224/sbp.2004.32.2.173

Lecomte, T., Corbière, M., & Laisné, F. (2006). Investigating self-esteem in individuals with schizophrenia: Relevance of the Self-Esteem Rating Scale-Short Form. *Psychiatry Research, 143*, 99-108. doi:10.1016/j.psychres.2005.08.019

Lenior, M. E., Dingemans, P. M., Linszen, D. H., de Haan, L., & Schene, A. H. (2001). Sociaal functioneren en het beloop van recent ontstane schizofrenie: Een vervolgstudie over de eerste vijf jaar. [Social functioning and the course of recent-onset schizophrenia: A 5-year follow-up study.]. *Tijdschrift voor Psychiatrie, 43*(4), 219-231.

Lewis, R. W., Fugl-Meyer, K. S., Corona, G., Hayes, R. D., Laumann, E. O., Moreira, E. D., Jr., . . . Segraves, T. (2010). Definitions/epidemiology/risk factors for sexual dysfunction. *J Sex Med, 7*(4 Pt 2), 1598-1607. doi:10.1111/j.1743-6109.2010.01778.x

Little, R. J. A. (1988). A Test of Missing Completely at Random for Multivariate Data with Missing Values. *Journal of the American Statistical Association, 83*(404), 1198-1202. doi:10.1080/01621459.1988.10478722

Lysaker, P. H., Davis, L. W., Warman, D. M., Strasburger, A., & Beattie, N. (2007). Stigma, social function and symptoms in schizophrenia and schizoaffective disorder: Associations across 6 months. *Psychiatry Research, 149*(1-3), 89-95. doi:10.1016/j.psychres.2006.03.007

MacKinnon, D., Lockwood, C., & Williams, J. (2004). Confidence Limits for the Indirect Effect: Distribution of the Product and Resampling Methods. *Multivariate Behavioral*

Research, 39, 99-128. doi:10.1207/s15327906mbr3901_4

McCann, E., Donohue, G., de Jager, J., Nugter, A., Stewart, J., & Eustace-Cook, J. (2019). Sexuality and intimacy among people with serious mental illness: a qualitative systematic review. *JBI Database System Rev Implement Rep, 17*(1), 74-125. doi:10.11124/jbisrir-2017-003824

Miller, R. S., & Lefcourt, H. M. (1982). The assessment of social intimacy. *Journal of Personality Assessment, 46*(5), 514-518. doi:10.1207/s15327752jpa4605_12

Montejo, A., Rico-Villademoros, F., Daniel, E., Derecho, J., Franch, J., Franco, M., . . . Sánchez, M. (2008). Montejo AL, Rico-Villademoros F, Spanish Working Group for the Study of Psychotropic-Related Sexual Dysfunction. Changes in sexual function for outpatients with schizophrenia or other psychotic disorders treated with ziprasidone in clinical practice settings: a 3-month prospective, observational study. *Journal of clinical psychopharmacology, 28*, 568-570. doi:10.1097/JCP.0b013e31818501a1

Nunes, L., Dieckmann, L. H., Lacaz, F., Bressan, R., Matsuo, T., & Mari, J. (2008). The accuracy of the Arizona Sexual Experience Scale (ASEX) to identify sexual dysfunction in patients of the schizophrenia spectrum. *Revista de Psiquiatria Clínica, 36*, 182-189. doi:10.1590/S0101-60832009000500002

Nyer, M., Kasckow, J., Fellows, I., Lawrence, E., Golshan, S., Solorzano, E., & Zisook, S. (2010). The relationship of marital status and clinical characteristics in middle-aged and older patients with schizophrenia and depressive symptoms. *Annals of clinical psychiatry : official journal of the American Academy of Clinical Psychiatrists, 22,* 172-179.

O'Sullivan, L. (2008). Challenging Assumptions Regarding the Validity of Self-Report Measures: The Special Case of Sexual Behavior. *The Journal of adolescent health : official publication of the Society for Adolescent Medicine, 42*, 207-208. doi:10.1016/j.jadohealth.2008.01.002

Östman, M. (2014). Low satisfaction with sex life among people with severe mental illness living in a community. *Psychiatry Research, 216*(3), 340-345. doi:10.1016/j.psychres.2014.02.009

Peitl, M., Rubeša, G., Peitl, V., Ljubicic, Đ., & Pavlovic, E. (2009). Aspects of sexual self-perception in schizophrenic patients. E*uropean Journal of Psychiatry - EUR J PSYCHIAT, 23*. doi:10.4321/S0213-61632009000100004

Perry, B. L., & Wright, E. R. (2006). The sexual partnerships of people with serious mental illness. *J Sex Res, 43*(2), 174-181. doi:10.1080/00224490609552312

Redmond, C., Larkin, M., & Harrop, C. (2010). The personal meaning of romantic relationships for young people with psychosis. *Clin Child Psychol Psychiatry, 15*(2), 151-170. doi:10.1177/1359104509341447

Reis, H. T., & Patrick, B. C. (1996). Attachment and intimacy: Component processes. In *Social psychology: Handbook of basic principles*. (pp. 523-563). New York, NY, US: Guilford Press.

Rosenberg, M. (1965). *Society and the Adolescent Self-Image:* Princeton University Press.

Sanchez, D. T., Crocker, J., & Boike, K. R. (2005). Doing gender in the bedroom: investing in gender norms and the sexual experience. *Pers Soc Psychol Bull, 31*(10), 1445-1455. doi:10.1177/0146167205277333

Savla, G. N., Vella, L., Armstrong, C. C., Penn, D. L., & Twamley, E. W. (2013). Deficits in domains of social cognition in schizophrenia: a meta-analysis of the empirical evidence. *Schizophr Bull, 39*(5), 979-992. doi:10.1093/schbul/sbs080

Snell, W. E., & Papini, D. R. (1989). The Sexuality Scale: An instrument to measure sexual-esteem, sexual-depression, and sexual-preoccupation. *Journal of Sex Research, 26*(2), 256-263. doi:10.1080/00224498909551510

Van Sant, S. P., Ahmed, A. O., & Buckley, P. F. (2012). Schizophrenia, sexuality, and recovery. *Journal of Ethics in Mental Health, 7*, 1-5.

Varese, F., Smeets, F., Drukker, M., Lieverse, R., Lataster, T., Viechtbauer, W., . . . Bentall, R. P. (2012). Childhood adversities increase the risk of psychosis: a meta-analysis of patient-control, prospective- and cross-sectional cohort studies. *Schizophrenia Bulletin, 38*(4), 661-671. doi:10.1093/schbul/sbs050

Volman, L., & Landeen, J. (2007). Uncovering the sexual self in people with schizophrenia. *Journal of psychiatric and mental health nursing, 14*, 411-417. doi:10.1111/j.1365-2850.2007.01099.x

Whisman, M. A., Johnson, D. P., Li, A., & Robustelli, B. L. (2014). Intimate relationship involvement, intimate relationship quality, and psychiatric disorders in adolescents. *Journal of Family Psychology, 28*(6), 908-914. doi:10.1037/fam0000026

Wiersma, D., van den Brink, R., Wolters, K., McCabe, R., Bullenkamp, J., Hansson, L., . . . Priebe, S. (2009). Individual unmet needs for care: Are they sensitive as outcome criterion for the effectiveness of mental health services interventions? *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services, 44*(4), 317-324. doi:10.1007/s00127-008-0432-z

Sexual trauma, PTSD and sexual functioning in people with severe mental illness

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Under review

SEXUAL TRAUMA, PTSD AND SEXUAL FUNCTIONING IN PEOPLE WITH SEVERE MENTAL ILLNESS

ABSTRACT

People with severe mental illness (SMI) experience higher levels of sexual dysfunction compared to the general population. Previous research has suggested that sexual dysfunction can be a consequence of exposure to sexual trauma as well as a consequence of PTSD, regardless of the nature of the trauma that caused the PTSD. A cross-sectional study including 118 people with SMI was conducted with the aim to better understand the association between sexual trauma and PTSD on the one hand, and sexual dysfunction on the other. Results show that exposure to sexual abuse was associated with a 3.30-fold increased risk of sexual dysfunction compared to people without such exposure. The risk of sexual dysfunction was 3.57 times higher for those with sexual abuse and PTSD compared to people with neither. These effect sizes were not significantly different form each other. The results suggest that in people diagnosed with SMI, the additional impact of PTSD does not have a significant impact on sexual dysfunction over and above sexual abuse. The presence of SMI in the current study may have rendered the analyses less sensitive to the effects of PTSD on sexual functioning over and above any effect of SMI itself. Future research should assess the impact of PTSD-related interventions on sexual functioning in people diagnosed with SMI.

INTRODUCTION

People with severe mental illness experience higher levels of sexual dysfunction compared to the general population (Ehrhardt et al., 2002). Psychotropics are a known factor, but not the only one. One of the other factors that may contribute to elevated rates of sexual dysfunction is sexual trauma, to which people diagnosed with SMI are more frequently exposed (Varese et al., 2012 ; Khalifeh et al., 2015). In the general population, sexual dysfunction rates are increased in men and women who have experienced sexual abuse or assault (Becker, Skinner, Abel, & Cichon, 1986 & Cichon, 1986; Oberg, Fugl-Meyer, & Fugl-Meyer, 2004). Haase, Boos, Schoefeld & Hoyer (2009) found that people who experienced sexual trauma were four times more likely to report sexual problems compared with non-sexual trauma. There are no specific estimates on risk of sexual dysfunction after sexual trauma in people diagnosed with SMI. However, a recent study by de Jager, Topper,

Nugter & van Os (submitted) showed that a history of childhood sexual abuse increases the risk of care needs in the area of sexuality and intimacy in adult people with psychosis spectrum disorder.

Sexual trauma and dysfunction may also be linked to Post Traumatic Stress Disorder (PTSD). Even though the terms may be considered to overlap to a degree, there is a substantial difference. Sexual trauma refers to the traumatic sexual incident. PTSD refers to specific psychopathology that may arise as a consequence of the traumatic incident. Nearly 45% of rape survivors have been found to experience PTSD 3 months after the trauma (Elklit & Christiansen, 2010).

Sexual dysfunction rates tend to be higher in people suffering from PTSD, compared with similarly exposed victims without PTSD, regardless of the nature of the trauma (Cook, Riggs, Thompson, Coyne, & Sheikh, 2004 Coyne, Sheikh, 2004; Dekel & Solomon, 2006; Letourneau, Resnick, Kilpatrick, Saunders, & Best, 1996 Saunders, Best, 1996). Symptoms of PTSD may interfere with several aspects of sexual functioning, including desire, arousal, activity, consummation, and satisfaction. So, even though sexual dysfunction has often been linked to exposure to sexual trauma rather than to the presence of PTSD, studies on trauma, sexual dysfunction and PTSD suggest that PTSD, rather than trauma exposure per se, might be the more relevant antecedent to sexual problems. Alternatively, trauma and PTSD may have additive effects.

The only study that examined the association between sexual trauma exposure, PTSD and sexual functioning compared female PTSD patients and female patients with trauma exposure but without PTSD in healthy women in the domain of sexual functioning (Bornefeld-Ettmann et al., 2018). The results indicated that the development of PTSD may have a greater impact on sexual functioning than the experience of a traumatic sexual event per se.

In conclusion, there is a lack of knowledge regarding the relationship between sexual abuse and PTSD on the one hand, and sexual functioning on the other. Some preliminary evidence suggests that the occurrence of PTSD symptoms has a greater impact on the development of sexual impairments than the experience of a sexual trauma itself. However, sexual abuse and PTSD may also impact additively or interactively on sexual functioning. Since data on this subject are scarce, the current study was conducted with the aim to better understand the association between sexual trauma and PTSD on the one hand, and sexual dysfunction on the other, in people diagnosed with SMI.

Method

Design

We employed a cross-sectional research design using self-report questionnaires. Cross-sectional associations between sexual trauma and PTSD and sexual functioning were explored, taking the possible effects of psychotropic use and gender in to account.

Sample characteristics

Participants were recruited from community mental health teams specialized in Flexible Assertive Community Treatment for people with severe mental illness (Flexible ACT; van Veldhuizen, 2007). We included participants with severe mental illness (Ehrhardt et al., 2002). We use the term SMI to describe people with 1) a mental illness diagnosed with DSM-5 (American Psychiatric Association, 2013), 2) a duration, or presumed duration of symptoms for more than 6 months that 3) affected daily functioning to the degree that care by a Flexible ACT team was required. Individuals living with 'first episode psychosis' were also considered to meet criteria for SMI (NICE 2014). Clinical diagnoses were used, based on the information provided by the participant's clinician. Participants had to be able to understand the (Dutch) study information and procedures and give informed consent. Additional exclusion criteria were a florid psychotic state affecting capacity to consent and an estimated IQ of less than 70.

Based on an *a priori* power sample size analysis (Soper, 2016), 91 participants were required for an analysis using 5 predictor variables with an expected effect size of .15 and an anticipated power of .8 at alpha of .05.

Procedure

The study was conducted with the approval of the medical ethical committee of the VUmc in Amsterdam. Participation was voluntary and no compensation was offered. We approached possible participants in three ways. First, clinicians were asked to ask each person in their caseload that met the inclusion criteria for participation. Second, all clients who had previously given consent for being asked to participate in research were informed about the study and asked to participate. Potential participants were then contacted by the researcher and checked for inclusion criteria. Almost all participants were recruited using this procedure. The third procedure involved an advertisement on the Dutch eCommunity focusing on psychosis (www.psychosenet.nl), that invited people to contact the researchers if they wanted to participate.

The clinician of each participant, or the researcher, assessed whether the participant met the inclusion criteria and had the capacity to provide informed consent. All participants signed an informed consent form. Participants were asked to fill in the questionnaires at the community mental health centre. A quiet room was provided. If this was inconvenient, the possibility to take the questionnaires back home was offered.

Materials

* Sexual trauma

The Trauma Screening Questionnaire (TSQ) is developed to screen for lifetime trauma history (Brewin et al., 2002). For each event on the scale, the individual indicates whether he or she had ever experienced it over their lifetime in a binary (yes/no) format. The TSQ asks

about the experience of traumatic events using wording that corresponds with the DSM-IV criterion A for PTSD. This version of the TSQ was used to screen for trauma exposure in previous studies with persons with SMI (de Bont et al., 2015). For the purpose of the current study, only the question regarding sexual trauma was used (have you experienced sexual acts against your will?). In addition, frequency of trauma was assessed in the TSQ as well in a binary format with the options; 0= single sexual trauma, 1= multiple sexual trauma.

* PTSD-symptoms

The second part of the TSQ consists of a 10-item symptom screening tool derived from the 17-item PTSD Symptom Scale, Self-Report version (PSS SR). The TSQ items are rated 'yes' (symptom is present two times a week or more) or 'no' (symptom is not present or present less than twice a week). The minimum score is zero and the maximum score is 10. The optimum cut-off when screening for PTSD in a complex and often multi-traumatized group lies at 6 (de Bont et al., 2015), a cutoff score that was used in the current sample as well.

* Sexual functioning (NL) 5 items

The five item Arizona Sexual Experience (ASEX) Scale assesses sexual dysfunction and was used previously in a sample of persons with SMI (Ma, Chao, Hung, Sung, & Chao, 2018; Peitl, Rubeša, Peitl, Ljubicic, & Pavlovic, 2009; Sabry, Taweel, & Zyada, 2017). It assesses the strength of sex drive, ease of sexual arousal, penile erection/vaginal lubrication, ability to reach orgasm and satisfaction with orgasm on a six-point Likert scale, ranging from 1 (no impairment) to 6 (complete impairment). The ASEX scale is applicable to patients regardless of availability of a sexual partner and their sexual orientation. Scores range from 5–30, with higher scores representing greater sexual dysfunction. Clinically significant sexual dysfunction is defined as: a total score > 18, a score > 5 (very difficult) on any single item, or three items with scores > 4 are indicative of (Nunes et al., 2008).

* Use of psychotropics

Use of psychotropics was assessed by a simple multiple choice question format, filled in by the participants.

Data analysis

Statistical analysis was performed using SPSS version 26. To assess the association between sexual trauma, PTSD and different aspects of sexual functioning, participants were first divided into 3 groups. Group 1 were participants with no sexual abuse (N=51). Group 2 were participants who experienced sexual abuse but did not meet criteria for PTSD (N=32), and group 3 were participants with sexual abuse and PTSD (N=30). A multivariate Kruskal-Wallis test was conducted with 1 factor and 3 steps (groups) and 5 dependent variables

(drive, arousal, erection or lubrication, orgasm and satisfaction).

Binary logistic regression was used to test if sexual abuse and PTSD were associated with sexual dysfunction, with group as a dummy variable with three levels (the 'no sexual abuse' category being the reference) and sexual dysfunction as the dichotomized dependent variable. Gender and use of psychotropics were added as covariates. Significance of the covariates was assessed by two-tailed significance criterion (p value < 0.05) and effect sizes were expressed as odds ratios (OR) and 95% confidence intervals (CI) for association between predictor variables and sexual dysfunction. To avoid multicollinearity, trauma severity was not added as a covariate. A Chi-square test was used to assess the association between trauma frequency and sexual functioning.

To asses possible interplay between sexual trauma and PTSD on sexual dysfunction, a logistic regression moderation analysis was performed with gender and psychotropics use as covariates.

Results

A total of 118 participants were recruited (Table 1). Sexual trauma was reported by 46.1% of the participants and was more prevalent among women (67.7%) than men (18%). Of the sample, 57.4% met the criteria for sexual dysfunction, which also appeared more prevalent in women (69.5%), than in men (42.9%). PTSD was reported by 39.1% of the sample, 47.7% in women and 28.0% in men.

Results for 5 domains of continuous sexual functioning variables

Means and SD of the aspects of sexual functioning for the 3 groups are presented in Table 2. Table 2 shows that sexual dysfunction rates were mostly higher in group 2 compared to group 1, and in group 3 compared to group 1. However, these differences only appeared significant for orgasm (H=8.16, p .02), particularly in the comparison between group 1 and group 3, as group 3 had significantly higher scores of orgasm-related problems compared to group 1. However, there was no significant difference between group3 and group 2 on this measure. This suggests that the combination of trauma exposure and PTSD increases the probability of having orgasm-related problems, but not significantly different from any association with sexual trauma alone.

Results for dichotomous summary measure of sexual dysfunction

For further analysis, the dichotomous measure of the ASEX was used to determine if a sexual dysfunction was present following the decision rules suggested by Nunes (2008). In the total sample, 57.8% met the criteria of a sexual dysfunction. A Chi-square test showed that sexual dysfunction was associated with sexual trauma ($\chi^2(1) = 5.98$, $p = .02$). Among the people with a history of sexual abuse, 70.8% met the criteria of a sexual dysfunction, compared to 47.5% in people without a history of sexual abuse. The difference between

Table 1. *Socio-demographic characteristics of the participants (N=118)*

Demographics		count	%
Gender	Male	53	44.9
	Female	65	55.1
Age	Mean (range)	40 (18-65)	
Ethnic minority status	Minority	7	5.9
	White	111	94.1
Marital status	Not married/single	56	49.1
	Married	24	21
	Cohabiting	21	18.4
	Divorced	12	10.5
	Widow(er)	1	0.9
Education	No education	0	0
	Primary school	4	3.3
	Highschool	29	24.6
	Vocational education	57	48.3
	University	24	20.3
	Missing	4	3.5
Primary diagnosis	Recurring depression	35	29.7
	Bipolar disorder	15	12.7
	Psychotic disorder	28	23.7
	PTSD	16	13.6
	Anxiety disorder	11	9.3
	Schizoaffective disorder	4	3.4
	Other disorders	9	7.6

single trauma or multiple sexual traumas was not apparent in the association with sexual dysfunction ($\chi^2(1) = 2.19$, $p = .14$). PTSD was also associated with sexual dysfunction ($\chi^2(1) = 7.18$, $p = .01$). Among the people with PTSD, 73.8% met the criteria of a sexual dysfunction, compared to 47.8% in people without PTSD.

The logistic regression model was statistically significant ($\chi^2(5) = 16.80$, $p = .00$. The model explained 21.5% (Nagerkerke R^2) of the variance in sexual dysfunction and correctly classified 72.9% of the cases. The odds of having a sexual dysfunction was 3.30 times higher with exposure to sexual trauma (OR=3.30 (95% CI: 1.12, 9.70), Table 3).

Table 2. *Means and SD of the items measuring sexual functioning and group differences using Kruskal-Wallis (H) tests and Mann-Whitney (U) test as post-hoc test*

	1 No sexual trauma (SD)	2 Sexual trauma, no PTSD (SD)	3 Sexual trauma and PTSD (SD)	H	1-2 (U)	2-3 (U)	3-1 (U)
Drive	3.91 (1.43)	3.83 (1.37)	4.17(1.39)	1.81			
Arousal	3.42 (1.37)	3.47 (1.32)	3.76 (1.38)	2.76			
Erection/lubrication	3.40 (1.49)	3.70 (1.42)	3.48 (1.49)	3.35			
Orgasm	3.68 (1.41)	3.80 (1.56)	4.10 (1.21)	8.16*	606.50	421.50	504***
Satisfaction	2.84 (1.34)	3.17 (1.60)	2.82 (1.36)	1.87			

* Significant at .05 level

** Significant at .01 level

*** significant at .00 level

The odds of having a sexual dysfunction was 3.57 times higher when being exposed to both sexual trauma and symptomatic PTSD compared to no sexual trauma exposure (OR=3.57 (95% CI: 1.11, 11.47). The effect sizes of sexual trauma alone (OR=3.30) and sexual trauma and PTSD (OR=3.57) had overlapping confidence intervals, indicating that one was not significantly different from the other. This was confirmed by modelling the PTSD x sexual trauma interaction term which was neither large nor significant (B=-2.14, p=.16).

Discussion

The aim of the study was to examine the associations between sexual trauma and PTSD on the one hand and sexual (dys)functioning on the other, in people diagnosed with SMI. To the best of our knowledge, this is the first study that examined the association between sexual abuse and PTSD in relation to sexuality in people diagnosed with SMI.

The analysis of variance showed that trauma exposure with an additional diagnosis of PTSD increases the probability of orgasm-related problems, but not significantly different

Table 3. Results of the logistic regression

	OR	95% CI
Group 2	3.30	1.21-9.70
Group 3	3.57	1.11-11.47
Psychotropic use	.57	.20-1.58
Gender	2.40	.94-6.11

Reference group = group 1

Group 1: No sexual trauma exposure

Group 2: Sexual trauma exposure, no PTSD

Group 3: Sexual trauma exposure and PTSD

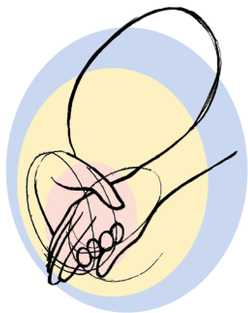
from any association with sexual trauma alone. Being female was associated with a higher risk of being exposed to sexual trauma. The regression findings show that exposure to sexual abuse was associated with a 3.30 higher risk of sexual dysfunction compared to people without such exposure. The risk of sexual dysfunction was 3.57 times higher for those with sexual abuse and PTSD compared to people with neither. The difference between the group with sexual trauma exposure and no PTSD and the group with sexual abuse exposure and additionally PTSD was neither large nor significant. These results suggest that in people diagnosed with SMI, the additional impact of PTSD does not have a significant impact on sexual dysfunction over and above sexual abuse.

These findings are not in line with previous reports. Other studies have suggested that PTSD, rather than trauma exposure *per se* is the more relevant mediator of risk for sexual dysfunction. Sexual difficulties such as pain, sexual aversion, and sexual satisfaction appear closely connected to PTSD symptoms. Fear and heightened arousal may act as inhibitors of sexual pleasure. However, in the current study, people diagnosed with SMI were included. Results from a recent systematic review (Vargas-Cáceres, Cera, Nobre, & Ramos-Quiroga, 2021 202) suggest that sexual dysfunction may be intrinsic to the development of severe mental illness like psychosis. Impaired sexual functioning is, for example, common in the onset of psychosis or during the so-called 'ultra-high risk' state, and before the commencement of treatment (Vargas-Cáceres et al., 2021 202). The link between psychotic symptoms and sexual functioning suggests that they may share some degree of common etiological pathways in the psychosocial as well as neurobiological domain. Thus, the presence of SMI in the current study may have rendered the analyses less sensitive to the effects of PTSD on sexual functioning given high base rates of both exposure and outcome in the context of SMI itself.

There are some limitations that should be taken into account. To asses a clinical sexual dysfunction, a clinical interview covering all DSM-5 or ICD-10 criteria should be carried out. In the current study sexual functioning was examined by self-report measures only and not by clinical interviews. Also, we did not assess distress related to sexual problems. The same goes for our measure of PTSD. We used a self-report measure which has shown to have strong predictive validity but may not be sufficient to establish a diagnosis of PTSD in terms of the DSM-5 or ICD-10. The sample size was relatively small, so that any additive effects of PTSD over sexual trauma alone may have been obscured. Nevertheless, the current analyses suggests that any additive effect of PTSD likely is very small and not clinically relevant.

A conclusive statement on the influence of sexual abuse per se cannot be given because almost all participants experienced other forms of trauma, which is common among people diagnosed with SMI. To examine the unique influence of sexual abuse on sexual dysfunction, groups of people diagnosed with SMI who experienced only sexual abuse would have to be compared to those who did not experience any trauma. However, due to high levels of trauma exposure in this population, this is not feasible.

Studies on PTSD treatment in people diagnosed with SMI have shown that PTSD can be safely and effectively targeted. An RCT on the effectivity of PTSD treatment in people with psychosis has shown a reduction in not only PTSD symptoms, but also on symptoms of psychosis (van den Berg et al., 2015). The same may hold for sexual functioning problems. Future research should asses the impact of PTSD-treatment on sexual functioning in people diagnosed with SMI.



References

Becker, J. V., Skinner, L. J., Abel, G. G., & Cichon, J. (1986). Level of postassault sexual functioning in rape and incest victims. *Archives of Sexual Behavior, 15*(1), 37-49. doi:10.1007/BF01542303

Bornefeld-Ettmann, P., Steil, R., Lieberz, K. A., Bohus, M., Rausch, S., Herzog, J., . . . Müller-Engelmann, M. (2018). Sexual Functioning After Childhood Abuse: The Influence of Post-Traumatic Stress Disorder and Trauma Exposure. *J Sex Med, 15*(4), 529-538. doi:10.1016/j.jsxm.2018.02.016

Brewin, C., Rose, S., Andrews, B., Green, J., Tata, P., McEvedy, C., . . . Foa, E. (2002). Brief Screening Instrument for Post-Traumatic Stress Disorder. *The British journal of psychiatry : the journal of mental science, 181*, 158-162. doi:10.1192/bjp.181.2.158

Cook, J. M., Riggs, D. S., Thompson, R., Coyne, J. C., & Sheikh, J. I. (2004). Posttraumatic stress disorder and current relationship functioning among World War II ex-prisoners of war. *J Fam Psychol, 18*(1), 36-45. doi:10.1037/0893-3200.18.1.36

de Bont, P., van den Berg, D., van der Vleugel, B., Roos, C., Jongh, A., Gaag, M., & Van minnen, A. (2015). Predictive validity of the Trauma Screening Questionnaire in detecting post-traumatic stress disorder in patients with psychotic disorders. *The British Journal of Psychiatry, 206*. doi:10.1192/bjp.bp.114.148486

Dekel, R., & Solomon, Z. (2006). Marital relations among former prisoners of war: Contribution of posttraumatic stress disorder, aggression, and sexual satisfaction. *Journal of Family Psychology, 20*(4), 709-712. doi:10.1037/0893-3200.20.4.709

Ehrhardt, A., Exner, T., Hoffman, S., Silberman, I., Yingling, S., Adams-Skinner, J., & Smart-Smith, L. (2002). HIV/STD risk and sexual strategies among women family planning clients in New York: Project FIO. *AIDS and Behavior, 6*, 1-13. doi:10.1023/A:1014534110868

Elklit, A., & Christiansen, D. M. (2010). ASD and PTSD in Rape Victims. *Journal of Interpersonal Violence, 25*(8), 1470-1488. doi:10.1177/0886260509354587

Haase, A., Boos, A., Schönfeld, S., & Hoyer, J. (2009). Sexuelle Dysfunktionen und sexuelle Zufriedenheit bei Patientinnen mit posttraumatischer Belastungsstörung. *Verhaltenstherapie, 19*(3), 161-167. doi:10.1159/000228725

Khalifeh, H., Moran, P., Borschmann, R., Dean, K., Hart, C., Hogg, J., . . . Howard, L. M. (2015). Domestic and sexual violence against patients with severe mental illness. *Psychol Med, 45*(4), 875-886. doi:10.1017/s0033291714001962

Letourneau, E., Resnick, H., Kilpatrick, D., Saunders, B., & Best, C. (1996). Comorbidity of sexual problems and posttraumatic stress disorder in female crime victims. *Behavior Therapy, 27*, 321-336. doi:10.1016/S0005-7894(96)80020-7

Ma, M.-C., Chao, J.-K., Hung, J.-Y., Sung, S.-C., & Chao, I. H. C. (2018). Sexual activity, sexual dysfunction, and sexual life quality among psychiatric hospital inpatients with schizophrenia. *Journal of Sexual Medicine, 15*(3), 324-333. doi:10.1016/j.jsxm.2018.01.008

Nunes, L., Dieckmann, L. H., Lacaz, F., Bressan, R., Matsuo, T., & Mari, J. (2008). The accuracy of the Arizona Sexual Experience Scale (ASEX) to identify sexual dysfunction in patients of the schizophrenia spectrum. *Revista de Psiquiatria Clínica, 36*, 182-189. doi:10.1590/S0101-60832009000500002

Oberg, K., Fugl-Meyer, A. R., & Fugl-Meyer, K. S. (2004). On categorization and quantification of women's sexual dysfunctions: an epidemiological approach. *Int J Impot Res, 16*(3), 261-269. doi:10.1038/sj.ijir.3901151

Peitl, M., Rubeša, G., Peitl, V., Ljubicic, Đ., & Pavlovic, E. (2009). Aspects of sexual self-perception in schizophrenic patients. *European Journal of Psychiatry - EUR J PSYCHIAT, 23*. doi:10.4321/S0213-61632009000100004

Sabry, W., Taweel, M., & Zyada, F. (2017). Sexual dysfunctions in drug-naive male patients with first-episode schizophrenia: A case-control study. *Middle East Current Psychiatry, 24*, 168-173. doi:10.1097/01.XME.0000520063.00808.3d

van den Berg, D., de Bont, P., van der Vleugel, B., Roos, C., Jongh, A., Van minnen, A., & Gaag, M. (2015). Prolonged Exposure vs Eye Movement Desensitization and Reprocessing vs Waiting List for Posttraumatic Stress Disorder in Patients With a Psychotic Disorder A Randomized Clinical Trial. *JAMA Psychiatry, 72*, 259-267. doi:10.1001/jamapsychiatry.2014.2637

Varese, F., Smeets, F., Drukker, M., Lieverse, R., Lataster, T., Viechtbauer, W., . . . Bentall, R. P. (2012). Childhood adversities increase the risk of psychosis: a meta-analysis of patient-control, prospective- and cross-sectional cohort studies. *Schizophrenia Bulletin, 38*(4), 661-671. doi:10.1093/schbul/sbs050

Vargas-Cáceres, S., Cera, N., Nobre, P., & Ramos-Quiroga, J. A. (2021). The Impact of Psychosis on Sexual Functioning: A Systematic Review. *The Journal of Sexual Medicine*. doi:https://doi.org/10.1016/j.jsxm.2020.12.007

10

General discussion

GENERAL DISCUSSION

Introduction

The research presented in this dissertation focuses on the expression of sexuality and intimacy among people with severe mental illness (SMI). More specifically, the purpose of this dissertation was to generate a deeper knowledge on how sexuality and intimacy are experienced by people with SMI and the factors that may help or hinder their experiences. Qualitative and quantitative research methods were used to address these issues.

As intimate relationships and the experience of sexuality should be appreciated as a fundamental part of a person's identity and environment, it is evident that this area of life should be incorporated when trying to support the recovery and enhancement of lives of people with a mental illness. With this dissertation, we have gathered knowledge that is needed and may help to understand and address the reported needs for care among people with SMI in the fields of sexuality and intimacy within mental health care settings.

This final chapter provides a summary of the main findings of this dissertation as well as a discussion of several cross-cutting issues.

Summary of main findings

The biopsychosocial model of sexuality

It is generally accepted by clinicians that sexuality should be approached from a biopsychosocial framework, in which it is recognized that biological, psychological, interpersonal, and sociocultural factors interact with each other in a dynamic system, over time. In order to understand and address sexuality and related intimacy issues within the context of mental health care, all perspectives need to be taken into consideration. **Chapter 2** provides an overview of literature published in the last decade on sexuality and intimacy among people with psychosis. This overview shows that recent research on these themes is largely of a biomedical focus, such as the study of psychotropic side effects and sexual risks like HIV and STIs. Research focusing on psychosocial aspects of sexuality is highly needed in order to develop strategies to address the often-reported unmet needs in the field of intimacy and sexuality among people with a psychosis.

Sexuality and intimacy in the context of mental health care challenges and facilities

Chapter 3 encompasses a broader systematic literature review with the aim of synthesizing the best available qualitative evidence on the experiences and support needs of people with SMI regarding sexuality and intimacy within hospital and community settings. The review shows that living with a serious mental illness can be a difficult and lifelong

journey. This journey may involve loss, trauma and victimization. In the midst of these multi-faceted challenges, the question of sexuality is one that is often neglected by both mental health clinicians and people with SMI themselves. The challenge is even bigger for persons with a serious mental illness who identify outside of heteronormative relationships. This situation may lead to what is described as a double stigma, causing difficulties such as alienation and issues with identity. The effect of self-stigma is expressed in difficulties in acceptance of self and feelings of inadequacy. The onset or exacerbation of mental health problems also poses a large challenge for individuals and their partners. The psychosocial needs of families are often unrecognized and support for partners and relatives is usually lacking. This is significant as they are an important source of support to the individual with SMI.

The expression and experience of sexuality is also highly influenced by the context. The setting of a mental health institution poses several challenges for caregivers, consumers and their loved ones when it comes to the expression of sexuality, disclosures of (past) sexual experiences and the risks related to these issues. Awareness of the potential challenges of having a SMI for an intimate relationship and involving partners in the treatment, may help to promote intimacy and recovery.

Young adults' perspective on barriers towards sexuality and intimacy

In order to find out if and how attention for sexuality and intimacy should take shape within mental health, a qualitative study was conducted. In **chapter 4**, a focus group-based study describes the needs for care regarding sexuality and intimacy of young adults with a psychotic disorder within the context of their treatment, from the perspective of both the young adults and professionals. The young adults indicated that attention for sexuality and intimacy should play a role in their current recovery-oriented treatment. In clinical practice however, this appeared not to be the case. It is likely that caregivers are too careful: half of the healthcare professionals that participated in the study indicated that talking about sexuality and intimacy within a group setting would be too unsettling, while the young adults indicate that they actually wish to share experiences concerning sexuality and intimacy in a group context.

Some caution is warranted however: topics directly related to one's own sexual functioning, such as a sexual function disorder, should be addressed individually. Clients indicated that it is important that caregivers actively inquire about these topics. Taking the initiative to raise the topic is challenging for most young adults. The fear of having insufficient knowledge about sexuality and intimacy raises a threshold among caregivers to do so. However, the study suggests that substantive knowledge is not required: the largest need among young adults lies in the exchange of experiences with peers in a safe environment. Group dynamic skills of caregivers might be of more importance than substantive knowledge about sexuality, intimacy and relationships. However, as focus groups form a group setting as well, issues of a more personal nature may have become

overshadowed in this study. The following studies, described in **chapter 5 and 6**, used in depth interviews focusing on creating a deeper understanding of personal experiences of people with SMI.

In **chapter 5**, the personal experiences and possible barriers of people with SMI concerning their sexual expression were explored. In-depth interviews were carried out with twenty-eight participants, aged 22 to 62 years. Five factors that have an impact on sexual expression were identified. Firstly, sexual (side) effects of antipsychotics appeared common. Other side effects such as increased salvia, fatigue and weight gain had an indirect effect by lowering the sexual self-esteem.

Secondly, having (had) a psychotic episode appeared to have an effect on the sexual identity. A number of participants explained that they lost contact with reality during a psychotic episode. Some experienced an unstable self-image and doubts about their sexual orientation and gender identity during such an episode. In some, this led to experimenting with sexuality, which afterwards resulted in confusion, as well as lingering doubts about one's sexual orientation. These topics were particularly difficult to talk about with loved ones.

Also, being vulnerable for psychosis made some participants wary in the context of sexuality and intimacy. Falling in love, sexual intercourse, rejection and relationship problems were seen as a possible cause for psychotic decompensation. On the other hand, for others, the experience of a psychosis and overcoming the related struggles meant growing as a person, boosting (sexual) self-confidence.

Thirdly, more than half of the participants had experienced a sexual trauma in the past, varying from sexual assault to multiple rapes. All indicated an effect on their sexuality. At least half of the participants who had been sexually abused, never or hardly ever told others. Particularly guilt and shame about sexual abuse appeared to act as barriers in communicating these experiences.

Difficulties in social skills were the fourth factor of influence and mainly reflected impairments in social cognition. These difficulties can have several consequences such as misunderstandings and decreased (sexual) communication among partners and reduced access to sexual partners among unmarried participants

Lastly, more than two-thirds of the participants experienced public stigma because of their psychotic disorder. Fearing negative responding to the disclosure of having a psychotic disorder, the majority of the participants refrained from disclosing at all. In more than half of the participants, internalization of stigma occurred.

In **chapter 6**, the same sample was used to further explore experiences of, and possible barriers for, intimacy by using the interpersonal process model in a qualitative research design. In this model, two important concepts in the formation of these intimate relationships are self-disclosure and responsiveness. Self-disclosure is the verbal and non-

verbal communication of information about oneself. Responsiveness refers to the reaction of a partner to the disclosed feelings, thoughts and needs. The five factors that were identified in **chapter 5** appeared to impact the preconditions needed for self-disclosure as well as responsiveness in multiple ways, thus hampering the development of intimacy.

Psychotic symptoms and psychotropic side effects were found to directly affect the ability to self-disclose. In some instances, the willingness to self-disclose was also affected by problems such as suspiciousness and ideas of reference. In other instances, the ability to be responsive towards a partner was reduced due to symptoms or psychotropic side effects such as flattened affect and fatigue. For others, the idea of being socially less competent than others led to avoidance of self-disclosure or of responsive behavior all together. This in turn affected the self-image, further reducing self-esteem. The fear of involuntary self-disclosure (for example by visible side effects) resulted in a decline in social interaction, out of fear of being judged. Self-stigma, the internalization of judgments, led people to devaluate themselves as (potential) partners, negatively impacting self-esteem and discouraging them to self-disclose or engage in further intimate contact. Sexual trauma appeared particularly difficult to disclose and hampered intimacy in several ways. Although the interpersonal process model of intimacy was useful in categorizing our data on intimacy, the problems people with a psychotic disorder experience often originate before engagement in intimacy.

The results described in **chapter 5 and 6** suggest that besides and through the five factors, self-esteem plays a central role in the barriers towards sexuality and intimacy and related processes. However, because of the explorative design of the study, the implied effects of the five factors on sexuality and intimacy and the hypothesized central role of self-esteem could not be confirmed. Testing a model that includes the construct of self-esteem, the listed five factors and measures of sexuality and intimacy could conceivably guide future research efforts and, perhaps, aid in tailoring interventions. These insights are translated into the quantitative study that is described in **chapter 8**.

The role of sexual trauma explored

One of the five identified barriers towards sexuality and intimacy, as described in **chapter 5 and 6**, concerns sexual trauma. Our research indicated that the rates of both sexual trauma and sexuality and intimacy needs are high in persons with a psychosis spectrum disorder, which is in line with other research. It remains largely unclear, however, if and how sexual trauma impacts these sexuality and intimacy needs. In **chapter 7**, we report a study using longitudinal data of 1119 persons diagnosed with a psychotic disorder. In this study, the relationship between childhood sexual abuse and sexuality and intimacy needs for care was tested.

The study showed that both sexuality (26%) and intimacy (40%) needs for care were prevalent among persons with a psychosis. Ninety percent of these needs appeared unmet. Childhood sexual abuse appeared to increase the incidence of sexuality and intimacy needs in persons with psychotic disorders, suggesting a need for integrated assessment of these areas. High rates of unmet sexuality and intimacy needs may indicate a lack of trauma-related treatments in mental health care that address these needs.

Testing the model

In **chapter 8**, a cross-sectional data study is described in which we tested the assumptions formulated in **chapter 5 and 6** regarding the five factors that play a role in sexuality and intimacy and the central role of self-esteem. 114 participants diagnosed with SMI were included. Analyses showed that of the three outcome variables, sexual autonomy, sexual functioning and intimacy, intimacy was the most difficult to predict. The only variable that was significantly associated with intimacy was self-stigma. Sexual dysfunctioning appeared to be associated with psychotropic side effects and sexual self-esteem. Sexual autonomy was associated with sexual trauma and sexual self-esteem. Even though sexual self-esteem did impact two of the three outcome variables, the hypothesized mediation was not found. The results may guide conversations between caregivers and patients when analyzing sexuality and intimacy problems and the possible factors that could play a role. They may also be a starting point in the quest for and development of effective interventions. However, since a cross-sectional design was used, the causal direction of the relationships between variables remains unknown. A longitudinal research design is needed to examine the specific direction of these found relationships.

In **chapter 9**, a cross-sectional data study is presented in which we tested the association between sexual abuse, PTSD and sexual functioning in people with SMI. Our analysis of variance showed that trauma exposure and PTSD increase the chance of having orgasm-related problems. Being female is associated with a higher risk of being exposed to sexual trauma but not to the risk of developing a PTSD. Long term sexual abuse is associated with an increased the risk of having an additional PTSD. Regression analysis showed that the odds of having a sexual dysfunction was 4.75 times higher when being exposed to sexual trauma compared to those with no sexual abuse exposure. The odds of having a sexual dysfunction was 5.82 times higher when having been exposed to sexual trauma and suffering from symptoms of PTSD compared to no sexual trauma exposure. However, this effect was only marginally significant. The difference between the group with trauma exposure without PTSD and the group with trauma exposure with PTSD was not significant in terms of sexual dysfunctioning. There was no interaction effect between sexual abuse and PTSD on sexual dysfunctioning. Future research should assess the impact of PTSD-treatment on sexual functioning in people with SMI.

Conclusions

The studies described in this dissertation enhance knowledge on the barriers that people with SMI encounter when navigating their sexual and romantic lives. Several factors were identified as possible barriers for sexuality and intimacy. Personal stories, examples, experiences and views of those encountering these barriers have helped deepen the understanding of these factors. The most important conclusions are:

- People with SMI have sexuality and intimacy needs that are largely similar to those observed in the general population.
- However, people with SMI experience barriers for sexuality and intimacy, some of which were (indirectly) related to having a SMI.
- These barriers are: self-stigma, sexual trauma, diminished social skills, lower (sexual) self-esteem, symptoms and psychotropic side-effects.
- In some, these barriers lead to a need for care. Childhood sexual abuse is associated with higher needs for care concerning sexuality and intimacy in adulthood.
- Needs for care concerning sexuality and intimacy are rarely met.
- Most clients welcome a conversation about sexuality and intimacy.
- Group interventions focused on sharing experiences and learning from each other are valuable, especially in young adults.
- Further quantitative explorations showed that intimacy is mainly associated with self-stigma. Sexual disfunctioning is associated with sexual self-esteem and psychotropic side effects, while sexual autonomy is associated with sexual trauma and sexual self-esteem.
- Sexual trauma increases the risk of having a sexual dysfunction. It is unclear if an additional PTSD further increases this risk.

Discussion of main findings

People with SMI have sexuality and intimacy needs that are similar to those in the general population. Fulfilling those needs however, is more difficult and comes, in some, with a need for care. The fact that these needs remain largely unmet is noteworthy. One of the possible explanations is that sexuality and intimacy are often neglected within mental health care services. This appears to have several causes, one of them being mental health professionals' reluctance to discuss these themes with their clients (Quinn, Happell, & Browne, 2011). Studies have shown that many nurses and psychiatrists are uncomfortable addressing sexuality and intimacy issues in their care for people with SMI (Nnaji & Friedman, 2008; Östman, 2014). Caregivers often assume that a discussion about sex is irrelevant because they think that people with SMI are unlikely to form a relationship (Ford, Rosenberg, Holsten, & Boudreaux, 2003). Also, caregivers are likely to wait for the client to initiate the topic, while clients often report being too shy to bring up the topic themselves (Katz, 2009). Other barriers might be a lack of education (Shell, 2007) or the idea that the conversation might be distressing and embarrassing for clients (Higgins, Barker, & Begley, 2005).

These examples illustrate that, in some cases, mental health facilities and their workers may create extra challenges for their clients in the area of sexuality and intimacy and finding access to possible partners. For example, despite the fact that people with SMI have the legal right to be sexually active while in treatment, many clients appear not to be allowed to date or have sex with other clients while being in treatment programs (Lukoff, Sullivan, and Goisman 1992; Miller and Finnerty 1996; Wright and Gayman 2005). Wright (2001) has argued that there generally is a restrictive sexual culture in mental health treatment settings. This culture may discourage clients from talking about sexuality-related concerns and may even restrict them from being able to meet their sexuality and intimacy needs. In a way, this negative sexual culture of mental health settings can be viewed as a form of structural stigmatization.

Grant (2010) approaches the negotiability of difficult topics such as sexuality from a more psychoanalytic point of view, by arguing that communication is the most ancient taboo. He claims that it is through words and language that people articulate boundaries and violations of boundaries in a clear, explicit, and consensual manner. By keeping quiet, by not addressing difficult or painful topics, uncomfortable intrapersonal and interpersonal feelings are avoided. He states that many of us have explicitly or implicitly learned that 'we do not speak openly about difficult subjects' and that 'is not polite, not tactful', which reinforces the tendency to remain silent. Nevertheless, he states that: *"speaking against the gradient of silence engendered by difficulty addressing pain and shame, while uncomfortable, may be ultimately useful and preferential"*. This suggest that the willingness of caregivers to overcome this taboo, the willingness to be present in the face of discomfort and actively endure these feelings is crucial.

In the context of this possible discomfort however it is interesting to note that we did not encounter problems recruiting participants for the different studies of this dissertation. Also, during our qualitative studies with in-depth interviews, some of the participants requested a follow-up because the topic was perceived as useful, comforting and missing in ongoing treatment. Additionally, about half of the participants of the qualitative studies attended a mini symposium that we organized, in which the results were presented. These notions invalidate the misconception that people diagnosed with a mental disorder are unwilling or incapable to talk about intimate topics. It could be hypothesized that clients are more willing than clinicians to face the (discomfort that may arise in) conversations, as for them there might be something to be gained. Nevertheless, the responsibility to raise the topic should be felt by caregivers.

One of the topics that appeared to be particularly avoided in the context of mental health treatment is sexual abuse. This taboo was evidenced by the fact that most interviewees reported that they rarely talked about, or were asked about, sexual abuse

and the problems arising from it, within and outside mental health services. For some, the researchers where the first to whom the sexual abuse was ever disclosed to. To ask about these topics sensitively and proactively within health care settings appeared essential for them.

Our quantitative studies in the third part of the dissertation explored the factors associated with sexuality and intimacy. Lack of intimacy appeared mainly associated with self-stigma. In the light of forming intimate connections, self-stigma might be more influential than general or institutional stigma, although these forms of stigma often overlap and interact. The studies in this dissertation, as well as other studies, have suggested that self-stigma leads to avoidance. Link and Phelan (2001) suggest that the stigma associated with some psychiatric diagnoses leads to the fear of rejection. As a consequence, people with SMI often let go of goals such as engaging in sexual relationships, marriage, and family (Wahl, 1999). Some qualitative evidence suggests that people with SMI sometimes choose to avoid relationships or withdraw from social interaction altogether to avoid rejection (Davidson & Stayner, 1997; Dickerson et al, 2004; Estroff, 1981; Link, 1987). Self-stigma can thus lead to sexual isolation, which is conceptualized by Link and Phelan (2001) as a process, initiated by psychosocial adaptations within the stigmatized individual and may lead to intentional withdrawal from others in an effort to protect him or herself from identity-threatening situations such as rejection, thereby reducing access to potential romantic or sexual partners.

Other studies have suggested that when people with SMI do engage in intimate relationships, self-stigma can pose challenges that affect the formation of intimacy. Our qualitative studies, together with the reviews, have shown that self-stigma may lead to a lower tendency to self-disclose. This is noteworthy since several studies have reported on the reinforcing relationship between self-disclosure and intimacy (Collins & Miller, 1994; Gibbs, Ellison, & Heino, 2006; Laurenceau, Barrett, & Pietromonaco, 1998; Laurenceau & Kleinman, 2006; Park, Jin, & Jin, 2011). Also, individuals tend to be more attracted to those who disclose to them, but also to those to whom they disclose (Collins & Miller, 1994). Fear of saying or doing the wrong thing may hamper attempts to be responsive. Therefore, self-stigma can impede the development of intimacy by complicating the mechanisms of self-disclosure and responsiveness, that can be seen as a perquisite to the formation of intimacy. The qualitative studies and reviews in this dissertation suggest a causal or, at least, a sequential relationship. However, the quantitative studies in this dissertation used a cross-sectional design and were thus not able to conform this. We will elaborate on this matter when discussing the limitations of this dissertation.

Besides self-stigma, our qualitative studies and reviews identified several other factors that may hamper sexual expression among people with SMI, one of them requiring further elaboration, being sexual trauma. Several studies pointed towards trauma as a significant factor in the barriers toward sexuality and intimacy, see chapter 2,3,4,5,7 and 9. However, when we tested our hypothesized model, sexual trauma appeared to be

solely associated with sexual autonomy, not to intimacy or the amount sexual dysfunction. This was unexpected and might by due to how we used the ASEX scores, as we used a cumulative score in this study. In Chapter 9, sexual dysfunction measured by the ASEX was used as a dichotomized measure (having a sexual dysfunction yes or no) based on Nunes et al (2008). When used in this manner, a relationship between sexual trauma and sexual dysfunctioning did show.

In our quantitative analyses, only sexual self-esteem and side effects of medication were found to be significantly associated with sexual functioning, while sexual self-esteem and sexual trauma appeared associated with sexual autonomy. These quantitative findings do not suggest that the other factors such as general self-esteem, social skills and symptoms, should be discarded as causes. A limited sample and the complicated issue of operationalizing complex constructs such as sexuality and intimacy are likely to play a part. This is discussed more elaborately in the paragraph on strengths and limitations. Future research should replicate and elaborate on our findings to see if the hypothesized relationships hold up in other studies.

Strengths and limitations

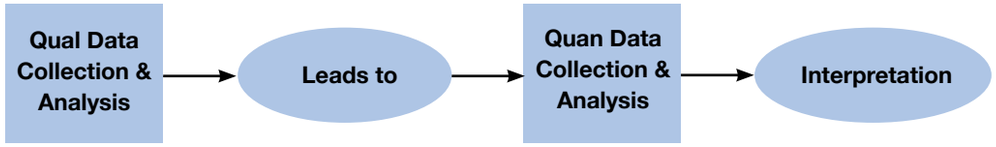
As discussed in the different papers, there are several strengths and limitations associated with the research described in this dissertation. As the specific strengths and limitations of the studies are described in the different chapters, we will here discuss the strengths and limitations of the dissertation as whole.

A strength of this dissertation lies in its structure. The first part focusses on what is already known, and this knowledge is further explored and elaborated by qualitative research. Qualitative research fits the general aims of this dissertation that emphasizes the exploration of meaning of social phenomena as experienced by individuals themselves, in their natural context. Even though sexuality is as old as human kind, it has been often been overlooked and neglected by scientists. Qualitative research therefore also fits with the relative novelty of the position of this topic in research on people with SMI from a recovery perspective. The hypotheses that were developed based on the qualitative studies, were then translated in to quantitative research questions. In the second part of this thesis, these quantitative studies are presented.

The combination of qualitative and quantitative data fits a sequential mixed methods research design. These designs are known for their ability to overcome weaknesses of qualitative and quantitative methods by complementary strengths of each tradition. A sequential mixed methods design consists of qualitative studies to help identify core issues and to develop theoretical concepts and hypotheses. This step is done in chapter 4,5 and 6. In a sequential mixed methods design, these findings should be further examined in a subsequent quantitative study, aiming to test whether concepts are relevant in a comparable small number of cases and whether they describe and explain social phenomena in a

greater domain accordingly. This step is taken in chapter 7,8 and 9.

Figure1. Exploratory sequential mixed methods research design



(Creswell, 2015)

Even though a mixed methods design is helpful in overcoming some weaknesses of both qualitative and quantitative research, there are still some serious limitations that should be taken in to account. A substantial part of this dissertation comprises of qualitative studies. Although qualitative research has the ability to generate important findings, the generated findings are not easily generalized and often don't allow for more sophisticated statistical analyses like meta-analyses (Latour-Desjardins, Lecomte, Abdel-Baki, Auclair, & Collins, 2019; Yilmaz, 2013). Other key aspects that warrant discussion are our sample characteristics, outcome measures and direction of causality.

Sample characteristics

The different studies presented in this dissertation have used different samples with slightly different in- and exclusion criteria. Chapter 2,4,5,6 and 7 focus on people with psychosis. In chapter 3,8 and 9, the participants were selected on having a SMI, which is broader than solely psychosis. Since psychosis is a SMI, it could be argued that all results reflect the SMI population. However, the results from chapter 3,8 and 9 may not be so easily generalized toward the population of people with a psychosis.

Outcome measures

In chapter 8, the hypothesized model is tested. The concepts used in this model however, appeared difficult to operationalize. Even though selected questionnaires were well considered, the optional instruments available to us were very limited and we therefore had to turn to less ideal options, such as a measure for intimacy which was not available in Dutch and not validated for the SMI population. The latter also applies to our measure of sexual self-esteem and sexual autonomy. Another issue was the operationalization of social skills. As we were interested in participants' own perception of their skills, we wanted to use a questionnaire. We made the decision to use the subscale of the OQ-45 'interpersonal functioning', but when looking at the items, one could argue that this scale has substantial overlap with our outcome variable intimacy. Also, the OQ-45 is not specifically developed for the SMI population. Future research should take this in to consideration. The limited availability of instruments in the field of sexuality and intimacy, particularly concerning people with SMI, calls for development of new instruments.

Direction of causality

Two out of the three quantitative studies presented in this dissertation uses a cross-sectional design. Even though these studies shed extra light on the relationships between the barriers towards sexuality and intimacy, and the expression of sexuality and intimacy, it remains unclear how these relationships are established over time. This is noteworthy since the relationship between sexuality and intimacy and possible determinants often appear bidirectional.

The current findings have enhanced our knowledge on the barriers towards sexuality and intimacy in people with SMI. But, even though the current findings provide starting points to do so, this dissertation has not yet led to tools or interventions that can be used in daily clinical practice. The next step is to further quantify these finding to get a better grasp of what should be targeted when addressing needs for care among people with SMI concerning sexuality and intimacy. Then the development and testing of tools or interventions that target recovery of sexuality and intimacy should be addressed. This is further discussed in the paragraph future research.

Implications

The findings presented in this dissertation highlight areas requiring attention in terms of practice, education and future research developments and may help policy makers, clients and their clinicians in their attempts to address sexuality and intimacy in the context of mental health care.

Implications for policy makers:

Policymakers as well as clinicians should feel a responsibility in guarding the universal sexual rights in people with SMI. It could be argued that the current position of sexuality and intimacy within mental health care context does not facilitate the emulation of these universal sexual rights. The world health organization (WHO, 2006a) formulated a working definition of sexual rights, which they note is not fixed but aims to contribute to the continuing dialogue on human rights related to sexual health, as follows: "The fulfilment of sexual health is tied to the extent to which human rights are respected, protected and fulfilled. Sexual rights embrace certain human rights that are already recognized in international and regional human rights documents and other consensus documents and in national laws" (WHO, 2006a). Rights critical to the realization of sexual health can be found in box 1.

It is recommended and encouraged that policy makers in mental health settings make their policies on sexuality issues clear, explicit and known among caregivers in the workplace. These considerations should include issues such as privacy during admission; assessment

of sexual risks, such as STIs or unwanted pregnancies; and the use of contraception. Seeking co-operation with institutes providing sexual health care such as the Gemeentelijke GezondheidsDienst could be an asset.

Box 1. *Rights critical to the realization of sexual health as formulated by the World Health Organization*

- the right to equality and non-discrimination
- the right to be free from torture or to cruel, inhumane or degrading treatment or punishment
- the right to privacy
- the rights to the highest attainable standard of health (including sexual health) and social security
- the right to marry and to found a family and enter into marriage with the free and full consent of the intending spouses, and to equality in and at the dissolution of marriage
- the right to decide the number and spacing of one's children
- the rights to information, as well as education
- the rights to freedom of opinion and expression, and
- the right to an effective remedy for violations of fundamental rights (WHO, 2006a)

Implications for clinicians:

The responsibility to raise the topics of sexuality and intimacy should be by felt by clinicians. Clinicians should therefor routinely enquire about sexuality and intimacy issues. It might help if assessments and care planning include sexuality and intimacy issues. This involves awareness to and responsiveness of practitioners towards sexual trauma.

Onset or exacerbation of symptoms may have a big impact on a (romantic) relationship and it is not evident that a relationship automatically recovers from the role shifts that may occur during, for example, a psychosis. Partner involvement and support can be an essential ingredient towards different aspects of recovery.

When exploring the needs for care concerning sexuality and intimacy of clients, clinicians may use the model presented in chapter 8 as a framework to understand and discus possible barriers.

A period of mental decompensation can influence sexuality and intimacy in many ways. In some, the sexual identity, orientation or sense of self becomes more fluid causing doubts, insecurities and/or sexual behaviors that are outside the scope of someone's usual state. Exploring thoughts, emotions and meaning around sexuality and sexual experiences during a period of dysregulation may increase acceptance, facilitate self-esteem and decrease feelings of shame and guilt. Psychoeducation and normalization is important. Screening for possible risks of unprotected sex such STD or unplanned or unwanted pregnancies should be obvious after or during an episode of, for example, mania.

Implications for clients:

Be aware of the fact that mental health issues can have a strong impact on sexual expression and the experience of intimacy. These experiences can be burdensome but are also common. It does not make you weird or different. It makes you human.

Even though raising the topic of sexuality and intimacy is difficult, it's important to know that is very much acceptable to do so. For some of the sustaining factors of sexuality and intimacy problems, interventions are available. For example, PTSD symptoms as a consequence of sexual trauma can be targeted by cognitive behavioral therapy or EMDR and not all psychotropic medication have the same impact on sexual functioning. Discussing the pros and cons of your medications with your psychiatrist may enable you to choose whether or not the pros outweigh the cons and to explore if alternatives are available.

Peer workers are professionals who have experienced the rocky roads of recovery themselves and have learned to use these experiences to help others in their trajectory. Sticking up for your needs is not easy and requires a certain amount of empowerment. Peer workers may be able to assist in this quest.

Implications for researchers:

There is a need to shift away from solely exploring sexuality and intimacy issues and related barriers among people with SMI. Even though further explorations are valuable, there is a need to move towards developing and evaluating interventions that target the identified barriers and help people with SMI to fulfil their unmet needs.

I believe in trying to practice what you preach. Therefore I tried to translate the gaps in the studies of this dissertation and the related recommendations into further research as described in the next section.

Future research: current follow-up studies

We are working on three follow-up studies that follow from the findings we have gathered so far. These three studies will be briefly discussed here.

Let's talk about sex, a module

To help fulfill the clients' needs to talk about sexuality and intimacy within mental health care settings and create tools for doing so, we developed a game, called "Let's talk about sex". Both form and content of the game are based on findings from previous qualitative studies on sexuality, intimacy and relationships among people diagnosed with SMI

described in chapter 4,5 and 6. This game consists of cards with questions, statements and dilemma's that are common among clients. This game can be played in a group. Four themes are represented:

- Knowledge on sexual health such as: 'Can an STD be transmitted through French kissing?'.
- Boundaries: 'A stranger squeezes your ass in the supermarket, what do you do?'
- Communication skills: 'How can you tell someone is interested in you?'
- Sex and mental health: 'Would you tell your psychiatrist if your medications had sexual side effects and if yes, how?'

All questions end by: 'ask the others what they think' to stimulate discussion. By introducing this game, professional caregivers provide patients both permission and the opportunity to discuss their problems, feelings, insecurities and experiences in a low-threshold environment with peers. Caregivers are provided with a tool for creating the opportunity to discuss these issues with their clients. We will undertake an uncontrolled pragmatic pilot study that includes adults aged 18-65 years who meet the SMI criteria (Delespaul, 2013) and receive treatment in a specialized mental health care organization in the Netherlands. Through the pragmatic pilot study, we aim to answer the following research questions:

1) To what extent is it feasible for clients with SMI and professional caregivers to talk about intimacy and sexuality by the use of the let's talk about sex game?
2) How satisfied are clients and professional caregivers with the let's talk about sex game?
3) Explorative: what is the effect of the intervention in clients with SMI and professional caregivers providing the intervention with regard to their comfort with discussing sexuality?
4) Explorative: to what extent does the intervention stimulate the discussion of sexuality and intimacy outside the intervention-setting in clients and professional caregivers?

Unfortunately, the Corona-crisis has delayed the implementation of the pilot. It is expected that results will be available in the summer of 2022.

Add-on study: The effect of trauma-focused-treatment (TFT) on sexual functioning in people with SMI and PTSD

Sexual dysfunction refers to a wide-ranging set of problems associated with an impaired ability to 'respond sexually or to experience sexual pleasure' (Association, 2013 p. 423) and has often been linked to a history of sexual trauma (Bicanic, Engelhard, & Sijbrandij, 2014). However, sexual dysfunction rates tend to also be higher in people suffering from PTSD, compared with similarly exposed victims without PTSD, regardless of the nature of the trauma (Cook, Riggs, Thompson, Coyne, & Sheikh, 2004; Coyne, Sheikh, 2004; Dekel & Solomon, 2006; Letourneau, Resnick, Kilpatrick, Saunders, & Best, 1996 Saunders, Best, 1996). So even though sexual dysfunction has often been linked with exposure to sexual trauma rather than to the presence of PTSD, some studies suggest that PTSD, rather than trauma exposure per se, might be the more proximal antecedent to sexual problems. Since PTSD may play a role in the onset of sexual dysfunction, there may be an assumption that sexual functioning will concurrently improve as an outcome of successful PTSD treatment (Schnurr et al., 2009).

The rates of sexual dysfunction, sexual victimization, as well as PTSD are largely higher among people with SMI, compared to the general populations (Bebbington, 2009; Morrisson & Ross, 2005; Kelly & Conley, 2004). However, there are no specific numbers on the increased risk of sexual dysfunction after sexual trauma available or onset of PTSD in people with SMI.

It has long been thought that the treatment of PTSD in people with SMI, and people with psychosis specifically, could be a 'dangerous business', and could lead to an exacerbation of symptoms. The same has been thought of talking about sexuality and intimacy with people with psychosis. Therefore, these topics have long been ignored in the field of mental health care. Recent studies have shown, that these prejudices seem to be untrue (de Jager, Cirakoglu, Nugter, & van Os, 2017; de Jager & McCann, 2017; Swan, Keen, Reynolds, & Onwumere, 2017). These recent insights provide the opportunity to seek out more on how to support people with sexual dysfunction, SMI and PTSD due to sexual trauma. This brings us to ask the following research question;

1) What is the degree of sexual dysfunction in the population of people with SMI and PTSD?
2) Is the degree of sexual dysfunction at baseline higher in people that suffer from PTSD after sexual trauma compared to other trauma?
3) What is the effect of TFT for PTSD on sexual dysfunctioning in people with SMI?

This study is an add-on and as such part of the Trauma-focused therapies for Posttraumatic stress In Psychosis (RE.PROCESS). This study involves a single-blind multicentre randomised controlled trial with four arms: guideline informed PTSD treatment consisting of EMDR or Prolonged Exposure, cognitive restructuring and waiting list.

Improving sexual assertiveness in young people with psychosis using virtual reality. Part of: VRT-SOAP - Virtual Reality Treatment for improving SOcial Activities and Participation of young people with psychosis

Young people with psychosis have the same needs, desires and goals in life as their healthy peers. However, their social networks are usually smaller, they participate less often in social leisure activities and are less successful in work and education. It also appears relatively hard for them to find a partner and engage in a pleasurable romantic relationship. To target this issue, a novel Virtual Reality (VR) Treatment for improving social contacts,

(leisure) activities and participation of young people with a psychotic disorder (VR-SOAP) has been developed (Muijsson et al., 2020).

In this study, the primary outcome is the quantity and quality of social contacts, (leisure) activities and participation. The treatment program that will be tested consist of several modules targeting determinants that may hamper social participation such as: negative symptoms, impaired social cognition, paranoid ideations, social anxiety, low self-esteem, self-stigma and poor communication skills. All participating clients will end with a module on communication and interaction skills in which experiences, knowledge and skills from other modules are integrated and applied in role-plays.

For the purpose on this last module, we have been involved to ensure that social skills needed in the field of sexuality, intimacy and relationships are taken in to account. Based on the often-reported difficulties by people with psychosis (de Jager et al., 2017; de Jager, van Greevenbroek, Nugter, & van Os, 2018; de Jager, Wolters, & Pijnenborg, 2016), certain situations and specific interactions were translated in to role-play exercises, see figure one for an example. The overarching goal of these exercises is to improve the romantic and sexual assertiveness of participants. This goal and subsequent research question is one of the sub questions in this trial. During data analysis, we will report how many participants report social goals associated with sexuality, intimacy and relationships and test if the exercises in module 5 lead to improved assertiveness, the research questions being:

1) What percentage of young people with psychosis have social goals in the field of sexuality and intimacy? What are these goals?
2) How is the sexual assertiveness at baseline among young people with psychosis?
3) Does role-play enhance the sexual assertiveness in young people with psychosis?

Figure 2

Future research: suggested follow-up studies

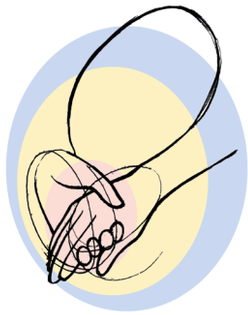
As stated before, there are several lines of research that require continuation. More longitudinal research is needed to further explore the relationship between the possible determinants and the expression of sexuality and intimacy. Longitudinal data can shed light on causality questions that for now remain unanswered.

Another issue is the fact that mental health professionals appear uncomfortable and reluctant to discuss sexuality and intimacy with their clients (Quinn et al., 2011 2011) (Nnaji & Friedman, 2008; Östman, 2014). There is hardly any research on how this discomfort or reluctance can be overcome (Cloutier, Francoeur, Samson, Ghostine, & Lecomte, 2020). Future research should focus on what may help caregivers to pay attention to sexuality and intimacy in the context of mental health.

Lastly, there is a need for interventions that can be used to meet the need for care regarding sexuality and intimacy in people with SMI in mental healthcare. Following this recommendation, we plan to develop and test the feasibility of a CBT-based module focusing on increasing interaction skills and social-sexual assertiveness in people with SMI. The module will focus on the skills that are needed to enter into contact that is wanted, and the skills needed to avoid or break-off contact that is unwanted. For the development of the intervention, we will partially base the content on the 'power of two' intervention. The 'power of two' involves a recently developed CBT-based group intervention for young men with psychosis focusing on romantic relationship skills, which proved feasible and preliminary effective (Hache-Labelle et al., 2020). The aim is to start with a small pilot and then continue towards conducting a pragmatic trail testing both the feasibility and the effectiveness of the intervention.

Final remarks

It has been both an honor and a joy to work on this dissertation. To talk to and learn from people with lived experience about how sexuality and intimacy are perceived has been enriching. This process has provided me with the opportunity to become a scientist, but has also helped me develop as a therapist. To touch upon sensitive topics, to actually break the taboo and offer the opportunity to really discuss topics that usually remain unspoken, is my biggest lesson and probably the most connecting thing we can do.



SAMENVATTING EN ALGEMENE DISCUSSIE

INTRODUCTIE

Intieme relaties en de ervaring van seksualiteit moeten gezien worden als een fundamenteel onderdeel van het mens-zijn, van iemands identiteit en diens omgeving. Het onderzoek in dit proefschrift richt zich op de expressie van seksualiteit en intimiteit bij mensen met een ernstige psychische aandoening (EPA). De perceptie en beleving van seksualiteit, intimiteit en relaties kunnen sterk worden beïnvloed door psychische problemen. Het is voor mensen met EPA dan ook lastiger dan voor mensen zonder EPA, om invulling te geven aan een prettig seksualiteits- en intimiteitsleven. Het doel van dit proefschrift was om kennis te genereren die nodig is om antwoord te kunnen geven op de overkoepelende onderzoeksvraag; hoe worden seksualiteit en intimiteit ervaren door mensen met EPA en welke factoren kunnen deze ervaringen bevorderen of belemmeren? Om de onderzoeksvragen te beantwoorden werden kwalitatieve en kwantitatieve onderzoeksmethoden gebruikt. Met dit proefschrift hebben we kennis verzameld die kan helpen bij het begrijpen en aanpakken van de gerapporteerde zorgbehoeften van mensen met EPA op het gebied van seksualiteit en intimiteit binnen GGZ-instellingen. Dit laatste hoofdstuk biedt een samenvatting van de belangrijkste bevindingen van dit proefschrift en een discussie.

SAMENVATTING VAN BELANGRIJKSTE UITKOMSTEN

Het biopsychosociale model van seksualiteit

Het is algemeen aanvaard door behandelaren dat seksualiteit benaderd moet worden vanuit een biopsychosociaal kader, waarin erkend wordt dat biologische, psychologische, interpersoonlijke en sociaal-culturele factoren in de loop van de tijd met elkaar interacteren in een dynamisch systeem. Om seksualiteit en gerelateerde intimiteitskwesties binnen de context van de geestelijke gezondheidszorg te begrijpen en aan te pakken, dienen alle perspectieven in overweging te worden genomen. Hoofdstuk 2 geeft een overzicht van literatuur die in het afgelopen decennium is gepubliceerd over seksualiteit en intimiteit bij mensen met psychose. Uit dit overzicht blijkt dat recent onderzoek naar deze thema's een grotendeels biomedische focus heeft, bijvoorbeeld onderzoek naar de invloed van (bijwerkingen van) medicatie en seksuele risico's zoals hiv en andere soa's. Onderzoek gericht op psychosociale aspecten van seksualiteit is hard nodig om strategieën te ontwikkelen die kunnen helpen om tegemoet te komen aan de vaak onvervulde behoeften op het gebied van intimiteit en seksualiteit bij mensen met een psychose.

Seksualiteit en intimiteit in de context van de geestelijke gezondheidszorg

Hoofdstuk 3 omvat een bredere systematische literatuurstudie met als doel de synthetisatie van het best beschikbare kwalitatieve bewijs van de ervaringen en zorgbehoeften van mensen met EPA met betrekking tot seksualiteit en intimiteit binnen de zorg en binnen de samenleving. Uit de review blijkt dat leven met een ernstige psychische aandoening een ingewikkelde en levenslange reis kan zijn. Deze reis kan verlies, trauma en slachtofferschap met zich meebrengen. Te midden van deze uitdagingen, is seksualiteit een kwestie die vaak wordt verwaarloosd door zowel hulpverleners in de geestelijke gezondheidszorg als mensen met EPA zelf. De uitdaging is nog groter voor personen met een EPA die zich identificeren buiten hetero-normatieve relaties. Deze situatie kan leiden tot wat wordt beschreven als een dubbel stigma waardoor problemen kunnen ontstaan zoals vervreemding en identiteitsproblemen. Het effect van zelfstigma, het internaliseren van bestaande (voor)oordelen, is zichtbaar in de ervaren moeilijkheden bij zelfacceptatie en gevoelens van ontoereikendheid. Het ontstaan of toenemen van psychische problemen vormt ook een grote uitdaging voor eventuele partners. De psychosociale behoeften van gezinnen worden vaak niet erkend en hulp voor partners en familieleden ontbreekt meestal. Deze hulp is belangrijk omdat naasten een belangrijke bron van steun zijn voor de persoon met EPA.

De expressie en beleving van seksualiteit en intimiteit wordt ook sterk beïnvloed door de context. De setting van een GGZ-instelling stelt zorgverleners, cliënten en diens naasten voor verschillende uitdagingen als het gaat om het uiten van seksualiteit, het bespreekbaar maken van (eerdere) seksuele ervaringen en de risico's die hieraan verbonden zijn. Bewustwording van de mogelijke uitdagingen die het hebben van een EPA met zich mee kan brengen voor een intieme relatie en het betrekken van partners bij de behandeling, kan helpen om intimiteit en herstel te bevorderen.

Het perspectief van jongvolwassenen op barrières voor seksualiteit en intimiteit

Om erachter te komen of en hoe aandacht voor seksualiteit en intimiteit vorm moet krijgen binnen de GGZ is een kwalitatief onderzoek uitgevoerd. Hoofdstuk 4 beschrijft een focusgroepstudie waarin de zorgbehoeften op het gebied van seksualiteit en intimiteit van jongvolwassenen met een psychotische stoornis binnen de context van hun behandeling, vanuit het perspectief van zowel jongvolwassenen als professionals wordt beschreven. De jongvolwassenen gaven aan dat aandacht voor seksualiteit en intimiteit een rol zou moeten spelen in hun huidige herstelgerichte behandeling. In de klinische praktijk bleek dit echter niet het geval te zijn. Het is denkbaar dat behandelaren te voorzichtig zijn: de helft van de deelnemende zorgprofessionals gaf aan dat praten over seksualiteit en intimiteit binnen een groepssetting te stresserend zou zijn, terwijl de jongvolwassenen aangaven dat ze ervaringen met intimiteit en seksualiteit juist met elkaar wilden delen in een groepscontext.

Enige voorzichtigheid is echter geboden: onderwerpen die direct verband houden met het eigen seksueel functioneren, zoals een seksuele functiestoornis, dienen wel binnen een individuele setting aan de orde te komen. Cliënten gaven aan dat het belangrijk is dat behandelaren actief informeren naar seksualiteit, intimiteit en relaties. Zelf het initiatief nemen om het onderwerp aan de orde te stellen, is voor de meeste jongvolwassenen te lastig. De angst voor onvoldoende kennis over seksualiteit en intimiteit verhoogt de drempel bij behandelaren om deze onderwerpen aan te kaarten. Het onderzoek suggereert echter dat inhoudelijke kennis niet noodzakelijk is: de grootste behoefte bij cliënten ligt in het uitwisselen van ervaringen met leeftijdsgenoten in een veilige omgeving. Groepsdynamische vaardigheden van behandelaren zijn wellicht belangrijker dan inhoudelijke kennis over seksualiteit, intimiteit en relaties. Omdat focusgroepen ook een groepsomgeving vormen, kunnen kwesties van meer persoonlijke aard in deze studie onderbelicht zijn gebleven. In de hierop volgende studies, beschreven in hoofdstuk 5 en 6, zijn diepte-interviews gebruikt, gericht op het creëren van een dieper begrip van persoonlijke ervaringen met seksualiteit en intimiteit van mensen met EPA.

In hoofdstuk 5 zijn de persoonlijke ervaringen en mogelijke barrières van mensen met EPA met betrekking tot hun seksuele expressie onderzocht. Er zijn diepte-interviews afgenomen met achtentwintig deelnemers in de leeftijd van 22 tot 62 jaar. Er werden vijf factoren geïdentificeerd die van invloed zijn op seksuele expressie. Ten eerste kwamen seksuele bijwerkingen effecten van medicatie vaak voor. Andere bijwerkingen zoals verhoogde speekselvloed, vermoeidheid en gewichtstoename hadden een indirect effect doordat deze het seksuele zelfvertrouwen leken te verminderen.

Ten tweede bleek het (gehad) hebben van een psychotische episode, effect te hebben op de seksuele identiteit. Een aantal deelnemers legde uit dat ze het contact met de werkelijkheid verloren tijdens een psychotische episode. Sommigen ervoeren tijdens zo'n episode een onstabiel zelfbeeld en twijfels over hun seksuele geaardheid en genderidentiteit. Bij sommigen leidde dit tot het experimenteren met seksualiteit, wat bij een aantal achteraf verwarring en aanhoudende twijfels over de seksuele geaardheid veroorzaakte. Deze onderwerpen waren bijzonder moeilijk om met dierbaren te bespreken.

Ook maakte de kwetsbaarheid voor psychose sommige deelnemers meer terughoudend in de context van seksualiteit en intimiteit. Verliefdheid, geslachtsgemeenschap, afwijzing en relatieproblemen werden gezien als mogelijke oorzaken van psychotische decompensatie. Aan de andere kant betekende het ervaren van een psychose en het overwinnen van de daarmee samenhangende worstelingen voor sommige anderen juist groei als persoon en groei van (seksueel) zelfvertrouwen.

Ten derde heeft meer dan de helft van de deelnemers in het verleden een seksueel trauma meegemaakt, variërend van aanranding tot meervoudige verkrachtingen. Alle slachtoffers benoemden een effect van deze ervaringen te bemerken op hun seksualiteit. Minstens de helft van de deelnemers die seksueel trauma meemaakte, heeft dit nooit of nauwelijks aan anderen verteld. Vooral schuldgevoelens en schaamte over seksueel

misbruik bleken een belemmering te zijn voor het onthullen van deze ervaringen.

Moeilijkheden in sociale vaardigheden waren de vierde factor van invloed. Deze waren voornamelijk het gevolg van stoornissen in sociale cognitie. Deze moeilijkheden kunnen verschillende gevolgen hebben, zoals misverstanden en verminderde (seksuele) communicatie tussen partners en verminderde toegang tot seksuele partners onder vrijgezelle deelnemers. Tot slot ervoer meer dan tweederde van de deelnemers publiekelijk stigma vanwege hun psychotische stoornis. Omdat de meerderheid van de deelnemers bang was negatieve reacties te ontvangen op de onthulling van een psychotische stoornis, onthielden zij zich volledig van deze onthulling. Bij meer dan de helft van de deelnemers trad internalisatie van stigma op.

In hoofdstuk 6 werd dezelfde steekproef gebruikt om ervaringen van, en mogelijke barrières voor intimiteit te onderzoeken, waarbij het interpersoonlijke procesmodel gebruikt is in een kwalitatief onderzoeksdesign. In dit model zijn twee concepten belangrijk bij het vormen van intieme relaties; zelfonthulling en responsiviteit. Zelfonthulling is de verbale en non-verbale communicatie van informatie over zichzelf. Responsiviteit verwijst naar de reactie van een ander op de onthulde gevoelens, gedachten en behoeften. De vijf factoren die in hoofdstuk 5 werden geïdentificeerd, leken op meerdere manieren van invloed te zijn op de voorwaarden die nodig zijn voor zelfonthulling en responsiviteit, waardoor de ontwikkeling van intimiteit werd belemmerd.

Psychotische symptomen en psychotrope bijwerkingen bleken rechtstreeks van invloed te zijn op het vermogen om zichzelf te onthullen. In sommige gevallen werd de bereidheid tot zelfonthulling ook beïnvloed door problemen zoals achterdocht en betrekkingsideeën. In andere gevallen was het vermogen om op een partner te reageren lager als gevolg van symptomen of psychotrope bijwerkingen zoals afgevlakt affect en vermoeidheid. Voor anderen leidde het idee sociaal minder competent te zijn dan anderen, tot het vermijden van zelfonthulling of van responsief gedrag. Dit had op zijn beurt weer een negatieve invloed op het zelfbeeld en de eigenwaarde. De angst voor onvrijwillige onthulling (bijvoorbeeld door zichtbare bijwerkingen) leidde tot een afname van de sociale interactie. Zelfstigma, de internalisering van oordelen, leidde ertoe dat mensen zichzelf gingen devalueren als (potentiële) partners, waardoor het zelfvertrouwen negatief werd beïnvloed. De neiging tot zelfonthulling of aangaan van verder intiem contact nam hierdoor af. Seksueel trauma bleek bijzonder moeilijk te onthullen en belemmerde de ervaring van intimiteit op verschillende manieren.

Hoewel het interpersoonlijke procesmodel van intimiteit nuttig was bij het categoriseren van onze gegevens over intimiteit, ontstaan de problemen die mensen met een psychotische stoornis ervaren vaak al voordat intimiteit tot stand komt.

De resultaten beschreven in hoofdstuk 5 en 6 suggereren dat naast de vijf geïdentificeerde factoren, (seksueel) zelfvertrouwen een centrale rol speelt in de ervaren barrières voor seksualiteit en intimiteit. Vanwege de exploratieve opzet van de studies konden de effecten van de vijf factoren op seksualiteit en intimiteit en de hypothetische centrale rol van zelfrespect echter niet worden bevestigd. Het testen van een model met seksualiteit en intimiteit, de genoemde vijf barrières en het concept (seksueel) zelfvertrouwen zou mogelijk inzichten kunnen bieden voor toekomstig onderzoek en het ontwikkelen van interventies. Deze suggestie is uitgewerkt en vertaald naar de kwantitatieve studie die wordt beschreven in hoofdstuk 8.

De rol van seksueel trauma

Een van de vijf geïdentificeerde barrières in de beleving van seksualiteit en intimiteit, zoals beschreven in hoofdstuk 5 en 6, betreft seksueel trauma. Deze barrière kan leiden tot zorgbehoeftes. Het is echter grotendeels onduidelijk of en hoe seksueel trauma zorgbehoeftes op het gebied van seksualiteit en intimiteit beïnvloedt. In hoofdstuk 7 wordt een studie met longitudinale gegevens van 1119 personen bij wie een psychotische stoornis is vastgesteld beschreven. In dit onderzoek is de relatie tussen seksueel trauma in de kindertijd aan de ene kant en de behoefte aan zorg voor seksualiteit en intimiteit aan de andere kant getoetst.

Uit het onderzoek bleek dat een behoefte aan zorg op het gebied van zowel seksualiteit (26%) als intimiteit (40%) veel voorkwam bij personen met een psychose. In negentig procent van deze behoeften werd niet voorzien. Seksueel trauma in de kindertijd leek de incidentie van zorgbehoeften op het gebied van seksualiteit en intimiteit bij personen met psychotische stoornissen te vergroten, wat suggereert dat er behoefte is aan een geïntegreerd assessment van deze gebieden. Hoge percentages onvervulde zorgbehoeften op het gebied van seksualiteit en intimiteit kunnen wijzen op een gebrek aan (trauma gerelateerde) behandelingen in de geestelijke gezondheidszorg die in deze behoeften voorzien.

Het model testen

In Hoofdstuk 8 wordt een cross-sectionele datastudie beschreven waarin de hypotheses zijn getest die in hoofdstuk 5 en 6 zijn geformuleerd aangaande de vijf factoren die een mogelijke rol spelen bij seksualiteit en intimiteit en de centrale rol van (seksueel) zelfvertrouwen. 114 deelnemers met EPA werden geïncludeerd. Analyses lieten zien dat van de drie uitkomstvariabelen, namelijk seksuele autonomie, seksueel functioneren en intimiteit, intimiteit het moeilijkst te voorspellen was. De enige factor die significant werd geassocieerd met intimiteit was zelfstigma. Seksueel disfunctioneren leek verband te houden met bijwerkingen van medicatie en seksueel zelfvertrouwen. Seksuele autonomie was geassocieerd met seksueel trauma en seksueel zelfvertrouwen. Hoewel seksueel zelfvertrouwen invloed had op twee van de drie uitkomstvariabelen, werd de gehypothetiseerde mediatie niet gevonden. De resultaten kunnen handvatten bieden voor gesprekken tussen zorgverleners en patiënten bij het analyseren van seksualiteits- en intimiteitsproblemen en de mogelijke factoren die een rol kunnen spelen. Ze kunnen ook een startpunt zijn voor het zoeken naar en ontwikkelen van effectieve interventies.

Omdat er een cross-sectioneel design is gebruikt, blijft de causale richting van de relaties tussen variabelen onbekend. Een longitudinaal onderzoeksdesign is nodig om de specifieke richting van deze gevonden relaties te onderzoeken.

In hoofdstuk 9 wordt een cross-sectionele datastudie gepresenteerd waarin de associatie tussen seksueel misbruik, PTSS en seksueel functioneren bij mensen met EPA is getest. Onze variantieanalyse toonde aan dat blootstelling aan trauma en PTSS de kans op orgasme gerelateerde problemen vergroten. Vrouw-zijn gaat gepaard met een hoger risico om te worden blootgesteld aan seksueel trauma. Daarnaast wordt langdurig seksueel misbruik in verband gebracht met een verhoogd risico op een bijkomende PTSS. Regressieanalyse toonde aan dat de kans op een seksuele disfunctie 3 keer hoger was bij blootstelling aan seksueel trauma in vergelijking met de mensen zonder blootstelling aan seksueel misbruik. De kans op een seksuele disfunctie was 3 keer hoger wanneer men was blootgesteld aan seksueel trauma en leed aan symptomen van PTSS in vergelijking met geen blootstelling aan seksueel trauma. Het verschil tussen de groep met blootstelling aan trauma zonder PTSS en de groep met blootstelling aan trauma met PTSS was niet significant in termen van seksueel disfunctioneren. Er was geen interactie-effect tussen seksueel misbruik en PTSS op seksueel disfunctioneren. Toekomstig onderzoek moet de impact van PTSS-behandeling op seksueel functioneren bij mensen met EPA in kaart brengen.

Conclusies

De onderzoeken die in dit proefschrift worden beschreven, vergroten de kennis over de ervaringen van mensen met EPA in hun seksuele en romantische leven. Verschillende factoren werden geïdentificeerd als mogelijke barrières voor seksualiteit en intimiteit. Persoonlijke verhalen, voorbeelden, ervaringen en opvattingen van degenen die met deze barrières te maken hebben, hebben bijgedragen aan een beter begrip van deze factoren. De belangrijkste conclusies zijn:

- Mensen met EPA hebben behoeften op het gebied van seksualiteit en intimiteit die grotendeels gelijk zijn aan die van de algemene bevolking.
- Mensen met EPA ervaren echter barrières voor seksualiteit en intimiteit, waarvan sommige (indirect) verband houden met het hebben van een EPA.
- Deze barrières zijn: zelfstigma, seksueel trauma, verminderde sociale vaardigheden, lager (seksueel) zelfvertrouwen, symptomen en bijwerkingen van medicatie.
- In sommige gevallen leiden deze barrières tot zorgbehoefte. Seksueel trauma in de kindertijd is geassocieerd met een grotere behoefte aan zorg op het gebied van seksualiteit en intimiteit op volwassen leeftijd.
- In zorgbehoeften op het gebied van seksualiteit en intimiteit wordt zelden voorzien.
- De meeste cliënten verwelkomen een gesprek over seksualiteit en intimiteit.
- Groepsinterventies gericht op het delen van ervaringen en het leren van elkaar zijn waardevol, vooral voor jongvolwassenen.
- Verdere kwantitatieve exploraties toonden aan dat intimiteit voornamelijk wordt geassocieerd met zelfstigma. Seksueel disfunctioneren wordt geassocieerd met seksueel zelfvertrouwen en bijwerkingen van medicatie. Seksuele autonomie wordt geassocieerd met seksueel trauma en seksueel zelfvertrouwen.
- Seksueel trauma is geassocieerd met een hoger risico op een seksuele disfunctie. Het is niet duidelijk of een additionele PTSS dit risico verder doet toenemen.

Bespreking van de belangrijkste bevindingen

Mensen met EPA hebben behoeften op het gebied van seksualiteit en intimiteit die vergelijkbaar zijn met die in de algemene bevolking. Het vervullen van deze behoeften is echter moeilijker en gaat bij sommigen gepaard met een behoefte aan zorg. Het is opmerkelijk dat grotendeels niet wordt voorzien in deze behoefte aan zorg. Eén van de mogelijke verklaringen is dat seksualiteit en intimiteit vaak worden verwaarloosd binnen de geestelijke gezondheidszorg. Dit lijkt verschillende oorzaken te hebben, waaronder de onwil van professionals in de geestelijke gezondheidszorg om deze thema's met hun cliënten te bespreken (Quinn, Happell & Browne, 2011). Verschillende onderzoeken hebben aangetoond dat veel verpleegkundigen en psychiaters zich ongemakkelijk voelen bij het bespreken van problemen met seksualiteit en intimiteit met EPA (Nnaji & Friedman, 2008; Östman, 2014). Behandelaren gaan er vaak van uit dat een gesprek over seks niet relevant is, omdat ze denken dat het onwaarschijnlijk is dat mensen met EPA een relatie aangaan of seksueel actief zijn (Ford, Rosenberg, Holsten & Boudreaux, 2003). Ook zijn zorgverleners geneigd om te wachten tot de cliënt het onderwerp aankaart, terwijl cliënten vaak aangeven te verlegen te zijn om het onderwerp zelf ter sprake te brengen (Katz, 2009). Andere belemmeringen kunnen een gebrek aan opleiding zijn (Shell, 2007) of het idee dat het gesprek stresserend en gênant kan zijn voor cliënten (Higgins, Barker, & Begley, 2005).

Deze voorbeelden illustreren dat instellingen voor geestelijke gezondheidszorg en hun werknemers in sommige gevallen voor extra uitdagingen kunnen zorgen voor hun cliënten op het gebied van seksualiteit en intimiteit en het vinden van toegang tot mogelijke partners. Ondanks het feit dat mensen met EPA het wettelijke recht hebben om seksueel actief te zijn tijdens de behandeling, lijken sommige cliënten geen toestemming te hebben om bijvoorbeeld te daten of seks te hebben met andere cliënten tijdens het volgen van behandelingsprogramma's (Wright en Gayman, 2005). Wright (2001) heeft betoogd dat er over het algemeen een restrictieve seksuele cultuur bestaat binnen de geestelijke gezondheidszorg. Deze cultuur kan cliënten ontmoedigen om over seksualiteit en gerelateerde problemen te praten en kan hen zelfs belemmeren om in hun behoeften op het gebied van seksualiteit en intimiteit te voorzien. In zekere zin kan deze negatieve seksuele cultuur van instellingen voor geestelijke gezondheid worden gezien als een vorm van structurele stigmatisering.

Grant (2010) benadert de bespreekbaarheid van moeilijke onderwerpen zoals

seksualiteit vanuit een meer psychoanalytisch standpunt, door te stellen dat communicatie het oudste taboe is. Hij stelt dat dat mensen grenzen en schendingen van grenzen op een duidelijke, expliciete en consensuele manier communiceren door middel van woorden en taal. Door te zwijgen en moeilijke of pijnlijke onderwerpen niet aan te pakken, worden ongemakkelijke intrapersoonlijke en interpersoonlijke gevoelens vermeden. Hij stelt dat velen van ons expliciet of impliciet hebben geleerd dat 'je niet hoort te praten over moeilijke onderwerpen' en dat 'niet beleefd en tactvol is', wat de neiging tot zwijgen versterkt. Desalniettemin stelt hij dat: "je uitspreken tegen de neiging tot stilte in, een neiging die wordt veroorzaakt door vermijding van pijn en schaamte, hoewel ongemakkelijk, uiteindelijk nuttig is en de voorkeur verdient". Dit suggereert dat de bereidheid van zorgverleners om dit taboe te doorbreken, de bereidheid vraagt om gevoelens van schaamte of ongemak actief te verdragen.

In de context van dit mogelijke ongemak is het echter interessant om te noemen dat het geen probleem is geweest om deelnemers te vinden voor de verschillende studies binnen dit proefschrift. Ook vroegen sommige deelnemers tijdens onze kwalitatieve onderzoeken met diepte-interviews om een follow-up omdat het gesprek als nuttig en prettig ervaren werd en dit gesprek ontbrak binnen de lopende behandeling. Daarnaast woonde ongeveer de helft van de deelnemers aan de kwalitatieve onderzoeken een door ons georganiseerd minisymposium bij, waarin de resultaten werden gepresenteerd. Deze bevindingen ontkrachten de soms nog bestaande misvatting dat mensen bij wie een psychische stoornis is vastgesteld, niet bereid of in staat zijn om over intieme onderwerpen te praten. Een hypothese zou kunnen zijn dat cliënten, meer dan behandelaren bereid zijn om het (ongemak dat kan ontstaan in) gesprekken onder ogen te zien, omdat er voor hen misschien iets te winnen valt. Desalniettemin moet de verantwoordelijkheid om het onderwerp aan de orde te stellen door zorgverleners worden gevoeld.

Een van de onderwerpen die binnen de context van psychiatrische behandelingen leek te worden vermeden, is seksueel misbruik. Dit taboe bleek onder andere uit het feit dat de meeste geïnterviewden aangaven dat ze binnen en buiten de GGZ zelden over seksueel misbruik en de daaruit voortvloeiende problemen spraken. Daarnaast werd er binnen de GGZ zelden tot niet naar gevraagd. Voor sommige deelnemers waren de onderzoekers de eersten aan wie het seksueel misbruik werd onthuld. Zodoende lijkt op gepaste wijze en proactief vragen stellen over deze onderwerpen binnen de gezondheidszorg essentieel.

Onze kwantitatieve studies in het derde deel van het proefschrift hebben de factoren onderzocht die verband houden met seksualiteit en intimiteit. Gebrek aan intimiteit bleek vooral verband te houden met zelfstigma. De studies in dit proefschrift, evenals andere studies, suggereren dat zelfstigma tot vermijding kan leiden. Link en Phelan (2001) stellen dat het stigma dat bij sommige psychiatrische diagnoses voortkomt, gepaard kan gaan met de angst voor afwijzing. Als gevolg hiervan laten mensen met EPA vaak doelen los, zoals het aangaan van seksuele relaties, een huwelijk en/of een gezin (Wahl, 1999). Kwalitatief bewijs suggereert dat mensen met EPA er soms voor kiezen om relaties geheel te vermijden en

zich terug te trekken uit sociale interactie om afwijzing te voorkomen (Davidson & Stayner, 1997; Dickerson et al, 2004; Estroff, 1981; Link, 1987). Zelfstigma kan dus leiden tot seksuele isolatie, wat door Link en Phelan (2001) wordt geconceptualiseerd als een proces, geïnitieerd door psychosociale aanpassingen binnen het gestigmatiseerde individu, wat kan leiden tot terugtrekken in een poging zichzelf te beschermen tegen voor de identiteit bedreigende situaties zoals afwijzing, waardoor de toegang tot potentiële romantische of seksuele partners wordt beperkt.

Onze kwalitatieve onderzoeken, hebben aangetoond dat zelfstigma kan leiden tot een lagere neiging tot zelfonthulling. Dit is van belang aangezien verschillende onderzoeken hebben gerapporteerd over de onderling versterkende relatie tussen zelfonthulling en intimiteit (Collins & Miller, 1994; Gibbs, Ellison, & Heino, 2006; Laurenceau, Barrett, & Pietromonaco, 1998; Laurenceau & Kleinman, 2006; Park , Jin en Jin, 2011). Ook hebben mensen de neiging zich meer aangetrokken te voelen tot degenen aan wie ze zichzelf onthullen (Collins & Miller, 1994). Angst om iets verkeerds te zeggen of te doen, kan pogingen tot responsiviteit belemmeren. Zelfstigma kan zodoende de ontwikkeling van intimiteit belemmeren door de mechanismen van zelfonthulling en responsiviteit te compliceren, mechanismen die kunnen worden gezien als voorwaarde voor de vorming van intimiteit. De kwalitatieve studies en reviews in dit proefschrift suggereren een causaal of in ieder geval een sequentieel verband. De kwantitatieve studies in dit proefschrift gebruikten echter een cross-sectioneel onderzoeksdesign en konden deze hypothese zodoende niet bevestigen. We zullen deze kwestie uitdiepen wanneer we de beperkingen van dit proefschrift bespreken.

Naast zelfstigma, identificeerden onze kwalitatieve onderzoeken en reviews een aantal andere factoren die seksuele expressie bij mensen met EPA kunnen belemmeren. Een van deze factoren die verdere toelichting behoeft, is seksueel trauma. Verschillende onderzoeken wezen op trauma als een significante factor in de barrières voor seksualiteit en intimiteit, zie hoofdstuk 2,3,4,5,7 en 9. Toen we ons hypothetische model testten, bleek seksueel trauma echter uitsluitend verband te houden met seksuele autonomie en niet met intimiteit of het seksuele functioneren. Dit was onverwacht en kan te wijten zijn aan de manier waarop we de ASEX-scores hebben gebruikt, aangezien we in deze studie een cumulatieve score hebben gebruikt. In Hoofdstuk 9 werd de ASEX gebruikt als een gedichotomiseerde maat (met een seksuele disfunctie ja of nee) gebaseerd op Nunes et al (2008). Bij gebruik op deze manier was er wel een verband tussen seksueel trauma en seksueel disfunctioneren. Het lijkt zinvol om in vervolgstudies de ASEX op deze wijze in te zetten.

In onze kwantitatieve analyses bleken alleen seksueel zelfvertrouwen en bijwerkingen van medicatie significant geassocieerd te zijn met seksueel functioneren, terwijl seksueel vertrouwen en seksueel trauma geassocieerd bleken te zijn met seksuele autonomie. Deze kwantitatieve bevindingen suggereren niet dat de andere factoren, zoals algemeen zelfvertrouwen, sociale vaardigheden en symptomen van psychiatrische aandoeningen,

als mogelijke oorzaak losgelaten moeten worden. Een beperkte steekproef en de ingewikkeldheid van het operationaliseren van complexe constructies zoals seksualiteit en intimiteit spelen waarschijnlijk een rol. Deze kwestie wordt uitgebreider besproken in de paragraaf over de beperkingen van het proefschrift. Toekomstig onderzoek zou onze bevindingen moeten proberen te herhalen om te zien of de veronderstelde relaties standhouden in andere onderzoeken.

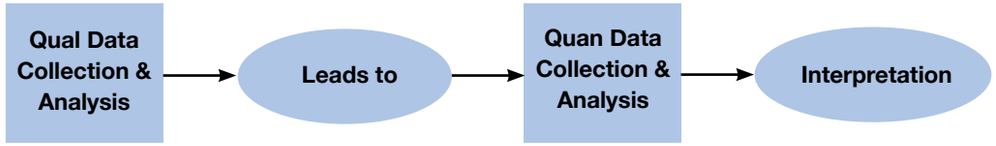
Sterke punten en beperkingen

Zoals besproken in de verschillende artikelen, zijn er verschillende sterke punten en beperkingen verbonden aan het onderzoek dat in dit proefschrift wordt beschreven. Aangezien de specifieke sterke punten en beperkingen van de studies in de verschillende hoofdstukken worden beschreven, zullen we hier de sterke punten en beperkingen van het proefschrift als geheel bespreken.

Een sterk punt van dit proefschrift ligt in de structuur. Het eerste deel focust op wat al bekend is, en deze kennis wordt verder verkend en uitgewerkt door kwalitatief onderzoek. Kwalitatief onderzoek past bij de algemene doelstellingen van dit proefschrift waarbij de nadruk ligt op de verkenning van de betekenis van sociale verschijnselen zoals ervaren door individuen zelf, in hun natuurlijke context. Hoewel seksualiteit zo oud is als de mensheid, is het door wetenschappers vaak over het hoofd gezien en verwaarloosd. Kwalitatief onderzoek past dus ook bij de relatieve nieuwheid van de positie van dit onderwerp in onderzoek naar mensen met EPA vanuit herstelperspectief. De hypothesen die op basis van de kwalitatieve onderzoeken zijn ontwikkeld, zijn vervolgens vertaald naar kwantitatieve onderzoeksvragen. In het derde deel van dit proefschrift worden deze kwantitatieve studies beschreven. De combinatie van kwalitatieve en kwantitatieve gegevens past in een sequentieel onderzoeksdesign met zogenaamde mixed-methods. Kwalitatieve en kwantitatieve methoden zijn complementair aan elkaar en zodoende heeft dit design het vermogen om zwakke punten van elke methode te overwinnen met de inzet van de andere methode. Een sequentieel mixed-methods design bestaat uit kwalitatieve studies die gericht zijn op het identificeren van het kernprobleem om hierbij theoretische concepten en hypothesen te ontwikkelen. Deze stap wordt gezet in hoofdstuk 4,5 en 6. Bij een sequentieel mixedmethod design moeten deze bevindingen vervolgens verder worden onderzocht in kwantitatieve studies, met als doel te testen of concepten relevant zijn en zodoende sociale verschijnselen in een groter domein kunnen verklaren. Deze stap wordt gezet in hoofdstuk 7,8 en 9.

Hoewel een mixed-methods design nuttig is om bepaalde zwakke punten van zowel kwalitatief als kwantitatief onderzoek te verhelpen, zijn er nog steeds enkele beperkingen waarmee rekening moet worden gehouden. Een substantieel deel van dit proefschrift bestaat uit kwalitatieve studies. Hoewel kwalitatief onderzoek belangrijke bevindingen kan

Figuur 1. exploratief onderzoeksdesign met sequentiële mixed-methods



(Creswell, 2015)

genereren, zijn de gegenereerde bevindingen niet gemakkelijk generaliseerbaar en laten ze vaak geen geavanceerde statistische analyses toe, zoals metaanalyses (Latour-Desjardins, Lecomte, Abdel-Baki, Auclair, & Collins, 2019; Yilmaz , 2013). Andere belangrijke aspecten die een kritische beschouwing vereisen zijn onze steekproefkenmerken, de gekozen uitkomstmaten en de richting van causaliteit.

Steeproefkenmerken

In de verschillende studies die in dit proefschrift worden gepresenteerd, zijn verschillende steekproeven gebruikt met enigszins verschillende in- en exclusiescriteria. De hoofdstukken 2,4,5,6 en 7 gaan over mensen met een psychose gevoeligheid. De hoofdstukken 3,8 en 9 betreffen deelnemers die voldoen aan de EPA-criteria, een definitie die breder is dan alleen psychose. Aangezien psychose een EPA is, zou kunnen worden gesteld dat alle resultaten de EPA-populatie weerspiegelen. De resultaten van hoofdstuk 3, 8 en 9 kunnen echter niet zo gemakkelijk worden gegeneraliseerd naar de populatie van mensen met een psychose.

Uitkomstmaten

In hoofdstuk 8 wordt het hypothetische model getest. De concepten die in dit model werden gebruikt, bleken echter moeilijk te operationaliseren. Hoewel de geselecteerde vragenlijsten zorgvuldig zijn gekozen, waren de optionele instrumenten waarover we beschikten zeer beperkt en moesten we ons daarom richten op minder ideale opties, zoals een maat voor intimiteit die niet in het Nederlands beschikbaar was en niet gevalideerd was voor de EPA-populatie. Dit laatste geldt ook voor onze maten voor seksueel zelfvertrouwen en seksuele autonomie. Een ander probleem was de operationalisering van sociale vaardigheden. Omdat we geïnteresseerd waren in de perceptie van de deelnemers van hun vaardigheden, wilden we een vragenlijst gebruiken. We hebben besloten om de subschaal van de OQ-45 ‘interpersoonlijk functioneren’ te gebruiken. Echter als we naar de items kijken, zou je kunnen stellen dat deze schaal aanzienlijke overlap heeft met de vragenlijst voor het meten van onze uitkomstvariabele intimiteit. Ook is de OQ-45 niet specifiek ontwikkeld voor de EPA-populatie. Toekomstig onderzoek zou hiermee rekening moeten houden. De beperkte beschikbaarheid van instrumenten op het gebied van seksualiteit

en intimiteit, met name bij mensen met EPA, vraagt ook om de ontwikkeling van nieuwe instrumenten.

Richting van causaliteit

Twee van de drie kwantitatieve studies die in dit proefschrift worden gepresenteerd, maken gebruik van een cross-sectioneel design. Hoewel deze onderzoeken extra licht werpen op de relaties tussen de barrières voor seksualiteit en intimiteit, en de uiting van seksualiteit en intimiteit, blijft het onduidelijk hoe deze relaties in de loop van de tijd tot stand komen. Dit is van belang omdat de relaties tussen seksualiteit en intimiteit aan de ene kant en mogelijke determinanten aan de andere kant vaak bidirectioneel zijn.

De huidige bevindingen hebben onze kennis over de barrières voor seksualiteit en intimiteit bij mensen met EPA vergroot. Hoewel de huidige bevindingen aanknopingspunten bieden voor de klinische praktijk, heeft dit proefschrift nog niet geleid tot tools of interventies die in de dagelijkse klinische praktijk kunnen worden gebruikt. De volgende stap is om de huidige bevindingen verder te kwantificeren om een beter begrip te krijgen van de factoren waarop moet worden gericht bij het aanpakken van de zorgbehoeften van mensen met EPA met betrekking tot seksualiteit en intimiteit. Vervolgens moet aandacht worden besteed aan het ontwikkelen en testen van tools of interventies die gericht zijn op herstel van seksualiteit en intimiteit. Dit wordt verder besproken in de paragraaf toekomstig onderzoek.

Implicaties

De bevindingen die in dit proefschrift worden gepresenteerd, benadrukken gebieden die aandacht vereisen in termen van praktijk, onderwijs en toekomstige onderzoeksontwikkelingen en kunnen beleidsmakers, cliënten en hun behandelaren helpen bij hun pogingen om seksualiteit en intimiteit aan te pakken in de context van de geestelijke gezondheidszorg.

Implicaties voor beleidsmakers

Zowel beleidsmakers als behandelaren moeten zich verantwoordelijk voelen voor het bewaken van de universele seksuele rechten bij mensen met EPA. Men zou kunnen stellen dat de huidige positie van seksualiteit en intimiteit binnen de context van de geestelijke gezondheidszorg de navolging van deze universele seksuele rechten niet bevordert. De Wereldgezondheidsorganisatie (WHO, 2006) heeft een werkdefinitie van seksuele rechten geformuleerd, waarvan zij opmerken dat deze niet vaststaat, maar beoogt bij te dragen aan de voortdurende dialoog over mensenrechten met betrekking tot seksuele gezondheid. Deze definitie luidt als volgt: “De vervulling van seksuele gezondheid is verweven met de mate waarin mensenrechten worden gerespecteerd, beschermd en nageleefd. Seksuele rechten omvatten bepaalde mensenrechten die al erkend zijn in internationale en regionale mensenrechtendocumenten en andere consensusdocumenten en in nationale wetten ”

(WHO, 2006). Rechten die cruciaal zijn voor het realiseren van seksuele gezondheid zijn te vinden in kader 1.

Het is aanbevolen dat beleidsmakers in instellingen voor geestelijke gezondheidszorg hun beleid inzake seksualiteitskwesties duidelijk, expliciet en openbaar maken bij zorgverleners op de werkplek. Tot deze overwegingen behoren zaken als privacy tijdens opname; beoordeling van seksuele risico’s, zoals soa’s of ongewenste zwangerschappen en het gebruik van anticonceptie. Samenwerking zoeken met instellingen voor seksuele gezondheidszorg, zoals de Gemeentelijke Gezondheids Dienst, kan een aanwinst zijn.

Kader 1. *Rechten die cruciaal zijn voor de realisatie van seksuele gezondheid, zoals geformuleerd door de Wereldgezondheidsorganisatie*

- de hoogst haalbare standaard van seksuele gezondheid, inclusief toegang tot voorzieningen (anticonceptie, veilige abortus, seksuologische hulp, et cetera)
- toegang tot en het verkrijgen van betrouwbare informatie over seksualiteit
- seksuele en relationele vorming
- respect voor lichamelijke integriteit
- vrije partnerkeuze
- keuzevrijheid om wel of niet seksueel actief te zijn
- seksuele relaties met wederzijdse instemming
- huwelijk of partnerschap met wederzijdse instemming
- keuzevrijheid om wel of niet kinderen te krijgen en wanneer
- het nastreven van een bevredigend, veilig en plezierig seksleven (WHO, 2006)

Implicaties voor behandelaren

De verantwoordelijkheid om de onderwerpen seksualiteit en intimiteit ter sprake te brengen, moet door behandelaren worden gevoeld. Behandelaren moeten daarom routinematig informeren naar kwesties op het gebied van seksualiteit en intimiteit.

Het ontstaan of verergeren van symptomen kan een grote impact hebben op een (romantische) relatie en het is niet evident dat een relatie automatisch herstelt van de rolverschuivingen die kunnen optreden tijdens bijvoorbeeld een psychose. Betrokkenheid bij en ondersteuning van partners kan een essentieel ingrediënt zijn voor verschillende aspecten van herstel.

Bij het in kaart brengen van de zorgbehoeften met betrekking tot seksualiteit en intimiteit van cliënten, kunnen behandelaren het model uit hoofdstuk 8 gebruiken als raamwerk om mogelijke barrières te begrijpen en bespreken.

Een periode van mentale decompensatie kan seksualiteit en intimiteit op veel manieren

beïnvloeden. Bij sommigen wordt de seksuele identiteit, geaardheid of het zelfgevoel meer fluïde, wat twijfels en onzekerheden met zich mee kan brengen. Ook kan dit leiden tot seksueel gedrag wat buiten iemands normale seksuele repertoire valt. Voor sommigen is dit achteraf ingewikkeld. Het onderzoeken van gedachten, emoties en zingeving rond seksualiteit en seksuele ervaringen tijdens een periode van ontregeling kan de acceptatie vergroten, het zelfrespect bevorderen en gevoelens van schaamte en schuld verminderen. Psycho-educatie en normalisatie is belangrijk. Screening op mogelijke risico's van onbeschermde seks, zoals SOA of ongeplande zwangerschappen dient plaats te vinden na of tijdens een episode van bijvoorbeeld manie.

Implicaties voor mensen met EPA

Houd er rekening mee dat psychische problemen een sterke invloed kunnen hebben op seksuele expressie en de ervaring van intimiteit. Deze ervaringen kunnen lastig zijn, maar komen ook vaak voor. Het maakt iemand niet raar of anders. Het maakt iemand een mens.

Hoewel het moeilijk is om het onderwerp seksualiteit en intimiteit ter sprake te brengen, is het belangrijk om te weten dat dit zeer acceptabel is. Voor enkele van de mogelijk instandhoudende factoren van seksualiteits- en intimiteitsproblemen zijn interventies beschikbaar. PTSS-symptomen als gevolg van seksueel trauma kunnen bijvoorbeeld goed behandeld worden met cognitieve gedragstherapie of EMDR en niet alle medicatie heeft dezelfde impact op seksueel functioneren. Door de voor- en nadelen van de medicijnen met een psychiater te bespreken, kan iemand de geïnformeerde keuze maken of de voordelen al dan niet opwegen tegen de nadelen, en kan eventueel onderzocht worden of er alternatieven beschikbaar zijn. Ervaringsdeskundigen zijn professionals die de rotsachtige wegen van herstel zelf hebben ervaren. Zij hebben geleerd deze ervaringen te gebruiken om anderen te helpen in hun traject. Opkomen voor behoeften is niet eenvoudig en vereist een zekere mate van empowerment. Ervaringsdeskundigen kunnen iemand mogelijk helpen bij deze zoektocht.

Implicaties voor onderzoekers

Er is inmiddels enigszins zicht op de factoren die van invloed zijn op seksualiteits- en intimiteitskwesties en gerelateerde barrières bij mensen met EPA. Het is nu tevens van belang om binnen het onderzoeksveld verder te kijken. Hoewel verdere verkenningen van beïnvloedende factoren waardevol zijn, is er vooral behoefte aan het ontwikkelen en evalueren van interventies die de geïdentificeerde barrières aanpakken en mensen met EPA kunnen helpen om deze barrières te overwinnen.

'Practise what you preach', is belangrijk. Daarom is geprobeerd de hiaten in de studies van dit proefschrift en de bijbehorende aanbevelingen te vertalen naar verder onderzoek zoals beschreven in de volgende paragraaf.

Toekomstig onderzoek: huidige vervolgstudies

We werken aan drie vervolgonderzoeken die voortvloeien uit de bevindingen die we tot nu toe hebben verzameld. Deze drie onderzoeken worden hier kort besproken.

Let's talk about sex, een module

Om te voldoen aan de behoefte van cliënten om te praten over seksualiteit en intimiteit binnen de GGZ en om hulpmiddelen te creëren voor professionals om dit te faciliteren, hebben we een spel ontwikkeld met de naam 'Let's talk about seks'. Zowel de vorm als de inhoud van het spel zijn gebaseerd op bevindingen uit de kwalitatieve onderzoeken naar seksualiteit, intimiteit en relaties bij mensen met EPA, beschreven in hoofdstuk 4,5 en 6. Dit spel bestaat uit kaarten met vragen, stellingen en dilemma's die veel voorkomen bij cliënten. Het spel kan in een groep worden ingezet. Vier thema's komen aan bod:

- Kennis over seksuele gezondheid zoals: 'Kan een SOA worden overgedragen via tongzoenen?'.
- Grenzen: 'Een onbekende knijpt in je billen in de supermarkt, wat doe je?'
- Communicatieve vaardigheden: 'Hoe weet je of iemand in je geïnteresseerd is?'
- Seks en geestelijke gezondheid: 'Zou je het je psychiater vertellen als je medicijnen seksuele bijwerkingen hadden en zo ja, hoe?'

Alle vragen eindigen met: 'vraag de anderen wat ze denken' om de discussie te stimuleren. Met de introductie van dit spel geven zorgverleners patiënten zowel toestemming als de mogelijkheid om hun problemen, gevoelens, onzekerheden en ervaringen in een laagdrempelige omgeving met leeftijdsgenoten te bespreken.

We zullen een ongecontroleerde pragmatische pilotstudie uitvoeren met volwassenen van 18-65 jaar die voldoen aan de EPA-criteria en die worden behandeld in een gespecialiseerde GGZ-instelling in Nederland. Via de pragmatische pilotstudie willen we de volgende onderzoeksvragen beantwoorden:

1) In hoeverre is het haalbaar voor cliënten met EPA en zorgverleners om te praten over intimiteit en seksualiteit met behulp van de 'let's talk over sex' module?
2) Hoe tevreden zijn cliënten en zorgverleners over de module?
3) Exploratief: wat is het effect van de module bij cliënten met EPA en zorgverleners die de interventie aanbieden op het ervaren comfort bij het bespreken van seksualiteit?
4) Exploratief: in hoeverre stimuleert de interventie het bespreken van seksualiteit en intimiteit buiten de interventie-setting bij cliënten en zorgverleners?

Helaas heeft de Covid 19 pandemie de uitvoering van de pilot vertraagd. Het is op dit moment niet duidelijk op welk termijn de groepen weer kunnen gaan draaien.

Add-on studie: Het effect van traumagerichte behandeling (TFT) op seksueel functioneren bij mensen met EPA en PTSS

Deze studie is onderdeel van de trauma-gerichte therapieën voor posttraumatische stress in psychose (RE.PROCESS). Deze studie omvat een enkelblinde multicenter gerandomiseerde gecontroleerde studie met vier condities: richtlijn geïnformeerde PTSS-behandeling bestaande uit EMDR of Prolonged Exposure, cognitieve herstructurering en wachtlijst.

Een seksuele disfunctie verwijst naar een brede reeks problemen die verband houden met een verminderd vermogen om 'seksueel te reageren of seksueel genot te ervaren' (Association, 2013 p. 423) en is vaak in verband gebracht met een geschiedenis van seksueel trauma (Bicanic, Engelhard, & Sijbrandij, 2014). De percentages seksuele disfunctie zijn ook hoger bij mensen die lijden aan PTSS, vergeleken met vergelijkbare blootgestelde slachtoffers zonder PTSS, ongeacht de aard van het trauma (Cook, Riggs, Thompson, Coyne & Sheikh, 2004; Dekel & Solomon, 2006; Letourneau, Resnick, Kilpatrick, Saunders, & Best, 1996). Dus hoewel seksuele disfunctie vaak in verband wordt gebracht met blootstelling aan seksueel trauma in plaats van met de aanwezigheid van PTSS, suggereren sommige onderzoeken dat PTSS, in plaats van blootstelling aan trauma op zich, het meest proximale antecedent zou kunnen zijn van seksuele problemen. Aangezien PTSS een rol kan spelen bij het ontstaan van seksuele disfunctie, is het denkbaar dat het seksuele functioneren gelijktijdig zal verbeteren als gevolg van een succesvolle PTSS-behandeling (Schnurr et al., 2009).

De percentages seksuele disfunctie, seksueel slachtofferschap en PTSS zijn grotendeels hoger bij mensen met EPA, vergeleken met de algemene populatie (Bebbington, 2009; Read, van Os, Morrisson & Ross, 2005; Kelly & Conley, 2004). Er zijn echter geen specifieke cijfers over het verhoogde risico op seksuele disfunctie na seksueel trauma of het ontstaan van PTSS bij mensen met EPA.

Men heeft lang gedacht dat de behandeling van PTSS bij mensen met EPA, en in het bijzonder bij mensen met psychose, een 'gevaarlijke zaak' zou kunnen zijn en zou kunnen leiden tot een verergering van de symptomen. Hetzelfde is gedacht over praten over seksualiteit en intimiteit met mensen met psychose. Deze onderwerpen zijn zodoende lange tijd genegeerd in de geestelijke gezondheidszorg. Recente onderzoeken hebben aangetoond dat deze vooroordelen niet waar lijken. De meeste mensen verwelkomen een gesprek over seksualiteit en intimiteit en PTSS is goed en veilig behandelbaar bij mensen met EPA (de Jager, Cirakoglu, Nugter, & van Os, 2017; de Jager & McCann, 2017; Swan, Keen, Reynolds, & Onwumere, 2017). Deze recente inzichten bieden de mogelijkheid om meer te weten te komen over het ondersteunen van mensen met seksuele disfunctie, EPA en PTSS als gevolg van seksueel trauma. Dit brengt ons bij de volgende onderzoeksvragen:

1) Wat is de mate van seksueel disfunctioneren in de populatie van mensen met EPA en PTSS?
2) Is de mate van seksueel disfunctioneren bij aanvang hoger bij mensen die lijden aan PTSS na een seksueel trauma in vergelijking met ander trauma?
3) Wat is het effect van TFT voor PTSS op seksueel disfunctioneren bij mensen met EPA?

Add-on studie: Verbetering van seksuele assertiviteit bij jongeren met psychose met behulp van virtual reality. Onderdeel van: VRT-SOAP - Virtual Reality-behandeling ter verbetering van sociale activiteiten en participatie van jongeren met psychose

Jongeren met psychose hebben dezelfde behoeften, verlangens en doelen in het leven als hun gezonde leeftijdsgenoten. Hun sociale netwerken zijn echter meestal kleiner, ze nemen minder vaak deel aan sociale vrijetijdsbesteding en zijn minder succesvol op het gebied van werk en onderwijs. Het lijkt ook relatief moeilijker voor hen om een partner te vinden en een plezierige romantische relatie aan te gaan. Om dit probleem aan te pakken, is een nieuwe Virtual Reality (VR) behandeling ontwikkeld gericht op het verbeteren van sociale contacten, (vrijetijds) activiteiten en participatie van jongeren met een psychotische stoornis (VR-SOAP) ((Muijsson et al., 2020).

In dit onderzoek is de primaire uitkomst de kwantiteit en kwaliteit van sociale contacten, (vrijetijds) activiteiten en participatie. Het behandelprogramma dat zal worden getest, bestaat uit verschillende modules die gericht zijn op determinanten van sociale participatie, zoals: negatieve symptomen, verminderde sociale cognitie, paranoïde ideaties, sociale angst, een laag zelfbeeld, zelfstigma en slechte communicatieve vaardigheden. Alle deelnemers zullen eindigen met een module over communicatie- en interactievaardigheden waarin ervaringen, kennis en vaardigheden uit andere modules worden geïntegreerd en toegepast in rollenspellen.

Bij deze laatste module ben ik betrokken geweest met als doel het waarborgen van aandacht voor de sociale vaardigheden die nodig zijn op het gebied van seksualiteit, intimiteit en relaties. Vaak gerapporteerde problemen door mensen met psychose (de Jager et al., 2017; de Jager, van Greevenbroek, Nugter, & van Os, 2018; de Jager, Wolters, & Pijnenborg, 2016), zijn vertaald in rollenspeloefeningen, zie figuur 1 voor een voorbeeld. Het overkoepelende doel van deze oefeningen is om de romantische en seksuele assertiviteit van deelnemers te verbeteren. Dit doel en de daaropvolgende onderzoeksvraag is een van de deelvragen in deze studie. Tijdens data-analyse zullen we rapporteren hoeveel deelnemers sociale doelen rapporteren die verband houden met seksualiteit, intimiteit en relaties en testen of de oefeningen in module 5 leiden tot verbeterde assertiviteit, met als onderzoeksvragen:

1) Welk percentage jongeren met psychose heeft sociale doelen op het gebied van seksualiteit en intimiteit? Wat zijn deze doelen?
2) Hoe is de seksuele assertiviteit bij aanvang onder jongeren met psychose?
3) Verbetert rollenspelen de seksuele assertiviteit bij jongeren met psychose?

Figuur 2

Toekomstig onderzoek: voorgestelde vervolgstudies

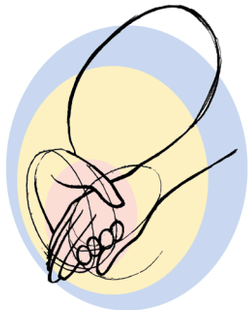
Zoals eerder vermeld, zijn er meerdere onderzoekslijnen die vervolg behoeven. Meer longitudinaal onderzoek is nodig om de relatie tussen de mogelijke determinanten en de uiting van seksualiteit en intimiteit verder te onderzoeken. Longitudinale gegevens kunnen licht werpen op causaliteitsvragen die voorlopig onbeantwoord blijven.

Een ander probleem is het feit dat professionals in de geestelijke gezondheidszorg ongemakkelijk en terughoudend lijken om seksualiteit en intimiteit met hun cliënten te bespreken (Quinn et al., 2011; Nnaji & Friedman, 2008; Östman, 2014). Er is nauwelijks onderzoek naar hoe dit ongemak of deze onwil kan worden overwonnen (Cloutier, Francoeur, Samson, Ghostine, & Lecomte, 2020). Toekomstig onderzoek zou zich moeten richten op wat zorgverleners kan helpen om aandacht te besteden aan seksualiteit en intimiteit in de context van de geestelijke gezondheidzorg.

Ten slotte is er behoefte aan interventies die kunnen worden ingezet om te voorzien in de zorgbehoeftes rond seksualiteit en intimiteit bij mensen met EPA. Op basis van deze aanbeveling zijn we van plan om een op CGT-gebaseerde module te ontwikkelen en te testen die gericht is op het vergroten van de sociaal-seksuele assertiviteit van mensen met EPA. De module zal zich gaan richten zich op de vaardigheden die nodig zijn om gewenst contact aan te gaan en ongewenst contact af te houden. Voor de ontwikkeling van de interventie zullen we de inhoud gedeeltelijk baseren op de ‘power of two’-interventie. Dit betreft een recent ontwikkelde op CGT-gebaseerde groepsinterventie voor jonge mannen met psychose, gericht op romantische relatievaardigheden. Deze interventie bleek zowel haalbaar als voorlopig effectief (Hache-Labelle et al., 2020). Het doel is om te beginnen met een kleine pilot en vervolgens door te gaan met het uitvoeren van een pragmatisch haalbaarheidsstudie waarbij zowel de haalbaarheid als de voorlopige effectiviteit van de interventie worden getoetst.

Laatste opmerkingen

Het was zowel een eer als een plezier om aan dit proefschrift te werken. Praten met en leren van mensen met ervaring over hoe seksualiteit en intimiteit worden ervaren, is verrijkend. Dit proces heeft mij de kans gegeven om mij te ontwikkelen als wetenschapper, en heeft mij ook geholpen om mij als therapeut verder te ontwikkelen. Gevoelige onderwerpen aanraken, daadwerkelijk het taboe doorbreken en de mogelijkheid bieden om echt in gesprek te gaan over onderwerpen die meestal onuitgesproken blijven, is mijn grootste les en waarschijnlijk het meest verbindende wat we kunnen doen.



References

American Psychiatric Association, A. P. (2013). Diagnostic and Statistical Manual of Mental Disorders, fifth edition. *Arlington, VA: American Psychiatric Association*.

Bebbington, P. (2009). Childhood sexual abuse and psychosis: aetiology and mechanism. *Epidemiol Psichiatr Soc, 18*(4), 284-293.

Bicanic, I., Engelhard, I., & Sijbrandij, M. (2014). Posttraumatische stressstoornis en seksuele problemen na seksueel geweld; prevalentie en behandeling. *Gedragstherapie, 47,* 256-274.

Cloutier, B., Francoeur, A., Samson, C., Ghostine, A., & Lecomte, T. (2020). Romantic relationships, sexuality, and psychotic disorders: A systematic review of recent findings. *Psychiatric Rehabilitation Journa*l. doi:10.1037/prj0000409

Collins, N. L., & Miller, L. C. (1994). Self-disclosure and liking: a meta-analytic review. *Psychol Bull, 116*(3), 457-475. doi:10.1037/0033-2909.116.3.457

Cook, J. M., Riggs, D. S., Thompson, R., Coyne, J. C., & Sheikh, J. I. (2004). Posttraumatic stress disorder and current relationship functioning among World War II ex-prisoners of war. *Journal of Family Psychology, 18*(1), 36-45. doi:10.1037/0893-3200.18.1.36

Creswell, J. W. (2015). A concise introduction to mixed methods research. *SAGE publications.*

Davidson, L., & Stayner, D. (1997). Loss, loneliness, and the desire for love: Perspectives on the social lives of people with schizophrenia. *Psychiatric Rehabilitation Journal, 20*(3), 3-12. doi:10.1037/h0095369

de Jager, J., Cirakoglu, B., Nugter, A., & van Os, J. (2017). Intimacy and its barriers: A qualitative exploration of intimacy and related struggles among people diagnosed with psychosis. *Psychosis: Psychological, Social and Integrative Approaches, 9*(4), 301-309. doi:10.1080/17522439.2017.1330895

de Jager, J., & McCann, E. (2017). Psychosis as a barrier to the expression of sexuality and intimacy: An environmental risk? *Schizophrenia Bulletin, 43*(2), 236-239.

de Jager, J., van Greevenbroek, R., Nugter, A., & van Os, J. (2018). Sexual Expression and It's Determinants, in People Diagnosed with Psychotic Disorders. *Community Mental Health Journal, 54*(7), 1082-1088. doi:10.1007/s10597-018-0285-1

de Jager, J., Wolters, H. A., & Pijnenborg, G. H. M. (2016). Jongeren met een psychotische kwetsbaarheid over seksualiteit, intimiteit en relaties: Een exploratief onderzoek middels focusgroepen = Young adult with psychotic disorders have problems relating to sexuality, intimacy and relationships An explanatory study based on focus group. *Tijdschrift voor Psychiatrie, 58*(3), 223-227.

Dekel, R., & Solomon, Z. (2006). Marital relations among former prisoners of war: Contribution of posttraumatic stress disorder, aggression, and sexual satisfaction. *Journal of Family Psychology, 20*(4), 709-712. doi:10.1037/0893-3200.20.4.709

Delespaul, P. H. (2013). [Consensus regarding the definition of persons with severe mental illness and the number of such persons in the Netherlands]. *Tijdschr Psychiatr, 55*(6), 427-438.

Dickerson, F., Brown, C., Kreyenbuhl, J., Goldberg, R., Fang, L., & Dixon, L. (2004). Sexual and Reproductive Behaviors Among Persons With Mental Illness. *Psychiatric services (Washington, D.C.)*, 55, 1299-1301. doi:10.1176/appi.ps.55.11.1299

Estroff, S. E. (1981). Psychiatric deinstitutionalization: A sociocultural analysis. *Journal of Social Issues, 37*(3), 116-132. doi:10.1111/j.1540-4560.1981.tb00832.x

Ford, E., Rosenberg, M., Holsten, M., & Boudreaux, T. (2003). Managing sexual behavior on adult acute care inpatient psychiatric units. *Psychiatr Serv, 54*(3), 346-350. doi:10.1176/appi.ps.54.3.346

Gibbs, J. L., Ellison, N. B., & Heino, R. D. (2006). Self-Presentation in Online Personals:The Role of Anticipated Future Interaction, Self-Disclosure, and Perceived Success in Internet Dating. *Communication Research, 33*(2), 152-177. doi:10.1177/0093650205285368

Grant. (2010). To Speak or Not to Speak—The Taboo of Communication. *Journal of Gay & Lesbian Mental Health, 14*, 230-239. doi:10.1080/19359705.2010.485535

Hache-Labelle, C., Abdel-Baki, A., Lepage, M., Laurin, A. S., Guillou, A., Francoeur, A., ... Lecomte, T. (2020). Romantic relationship group intervention for men with early psychosis: A feasibility, acceptability and potential impact pilot study. *Early Interv Psychiatry.* doi:10.1111/eip.13012

Higgins, A., Barker, P., & Begley, C. M. (2005). Neuroleptic medication and sexuality: the forgotten aspect of education and care. *J Psychiatr Ment Health Nurs, 12*(4), 439-446. doi:10.1111/j.1365-2850.2005.00862.x

Katz, A. (2009). *Sex when you're sick: Reclaiming sexual health after illness or injury.* Westport, CT: Praeger Publishers/Greenwood Publishing Group.

Kelly, D., & Conley, R. (2004). Sexuality and Schizophrenia: A Review. *Schizophrenia Bulletin, 30*, 767-779. doi:10.1093/oxfordjournals.schbul.a007130

Latour-Desjardins, A., Lecomte, T., Abdel-Baki, A., Auclair, V., & Collins, C.-A. (2019). Étude sur l'expérience des relations amoureuses des jeunes hommes ayant vécu un premier épisode psychotique. *Canadian Journal of Community Mental Health, 38,* 1-17. doi:10.7870/cjcmh-2019-001

Laurenceau, J.-P., Barrett, L. F., & Pietromonaco, P. R. (1998). Intimacy as an interpersonal process: The importance of self-disclosure, partner disclosure, and perceived partner responsiveness in interpersonal exchanges. *Journal of Personality and Social Psychology, 74*(5), 1238-1251. doi:10.1037/0022-3514.74.5.1238

Laurenceau, J.-P., & Kleinman, B. M. (2006). Intimacy in Personal Relationships. In *The Cambridge handbook of personal relationships.* (pp. 637-653). New York, NY, US: Cambridge University Press.

Letourneau, E., Resnick, H., Kilpatrick, D., Saunders, B., & Best, C. (1996). Comorbidity of

sexual problems and posttraumatic stress disorder in female crime victims. *Behavior Therapy, 27*, 321-336. doi:10.1016/S0005-7894(96)80020-7

Link, B. G. (1987). Understanding labeling effects in the area of mental disorders: An assessment of the effects of expectations of rejection. *American Sociological Review, 52*(1), 96-112. doi:10.2307/2095395

Link, B. G., & Phelan, J. C. (2001). Conceptualizing Stigma. *Annual Review of Sociology, 27*(1), 363-385. doi:10.1146/annurev.soc.27.1.363

Muijsson, D., Stouwe, E., Greaves-Lord, K., Nijman, S., Pijnenborg, M., & Veling, W. (2020). M230. VIRTUAL REALITY FOR IMPROVING SOCIAL ACTIVITIES AND PARTICIPATION (VR-SOAP): DEVELOPMENT OF A NEW TREATMENT FOR YOUNG PEOPLE WITH PSYCHOSIS. *Schizophrenia Bulletin, 46*, S224-S224. doi:10.1093/schbul/sbaa030.542

Nnaji, R., & Friedman, T. (2008). Sexual dysfunction and schizophrenia: Psychiatrists' attitudes and training needs. *Psychiatric Bulletin, 32*, 208-210. doi:10.1192/pb.bp.107.016162

Nunes, L., Dieckmann, L. H., Lacaz, F., Bressan, R., Matsuo, T., & Mari, J. (2008). The accuracy of the Arizona Sexual Experience Scale (ASEX) to identify sexual dysfunction in patients of the schizophrenia spectrum. *Revista de Psiquiatria Clínica, 36*, 182-189. doi:10.1590/S0101-60832009000500002

Östman, M. (2014). Low satisfaction with sex life among people with severe mental illness living in a community. *Psychiatry Research, 216*(3), 340-345. doi:10.1016/j.psychres.2014.02.009

Park, N., Jin, B., & Annie Jin, S.-A. (2011). Effects of self-disclosure on relational intimacy in Facebook. *Computers in Human Behavior, 27*(5), 1974-1983. doi:https://doi.org/10.1016/j.chb.2011.05.004

Quinn, C., Happell, B., & Browne, G. (2011). Talking or avoiding? Mental Health nurses' views about discussing sexual health with consumers. *International journal of mental health nursing, 20*, 21-28. doi:10.1111/j.1447-0349.2010.00705.x

Schnurr, P., Lunney, C., Forshay, E., Thurston, V., Chow, B., Resick, P., & Foa, E. (2009). Sexual Function Outcomes in Women Treated for Posttraumatic Stress Disorder. *Journal of women's health (2002)*, 18, 1549-1557. doi:10.1089/jwh.2008.1165

Shell, J. A. (2007). Including sexuality in your nursing practice. *Nurs Clin North Am, 42*(4), 685-696; ix. doi:10.1016/j.cnur.2007.08.007

Swan, S., Keen, N., Reynolds, N., & Onwumere, J. (2017). Psychological Interventions for Post-traumatic Stress Symptoms in Psychosis: A Systematic Review of Outcomes. *Front Psychol, 8*, 341. doi:10.3389/fpsyg.2017.00341

Wahl, O. F. (1999). Mental Health Consumers' Experience of Stigma. *Schizophrenia Bulletin, 25*(3), 467-478. doi:10.1093/oxfordjournals.schbul.a033394

WHO. (2006a). Defining sexual health: Report of a technical consultation on sexual health, 28-31 January 2002. *Geneva, World Health Organization.*

Wright, E. (2001). The sexual culture of psychiatric treatment facilities and mental illness clients' HIV risk: A theoretical framework and pilot study. *Research in Social Problems and Public Policy, 8*, 275-309. doi:10.1016/S0196-1152(01)80014-4

Yilmaz, K. (2013). Comparison of Quantitative and Qualitative Research Traditions: epistemological, theoretical, and methodological differences. *European Journal of Education, 48*, 311-325. doi:10.1111/ejed.12014

CURRICULUM VITAE AND PUBLICATIONS

Work

2020- current	Clinical psychologist/psychotherapist at GGZ Noord-Holland Noord
2016- 2021	PhD student at the University of Utrecht and GGZ Noord Holland Noord
2017- 2020	Healthcare psychologist in training to specialist at GGZ Noord-Holland Noord
2016- current	Teacher at RINO Amsterdam, RINO group Utrecht, Forta and PPO
2016	Healthcare psychologist/ researcher at GGZ Noord-Holland-Noord
2014 – 2015	Psychologist in training to healthcare psychologist at FACT GGZ Noord-Holland-Noord
2013	Psychodiagnostic-assistant at FACT Altrecht
2012 – 2013	Psychologist at GGZ Drenthe
2009 – 2012	Project coordinator and nurse SOA/SENSE (sexual health) at GGD Groningen
2007 -2009	Psychiatric nurse at University Centre of Psychiatry, part of UMCG

Volunteer work

2016-2018	Supervisor ‘advieswinkel’
2013- 2018	Chairwoman ‘Wat Doe Jij?’ foundation (www.watdoejij.org)
2011-2017	Boardmember Anan Clinica Foundation in Mozambique (www.ananclinica.com)
2013-2014	Correspondent Psychopraktijk
2011	Project coordinator Anan Clinica Foumdation in Mozambique (on location)

Education

2017- 2020	Clinical psychologist/psychotherapist education at RINO Amsterdam
2015-2018	Cognitive Behavioral Therapist VGCT
2014-2015	Healthcare psychologist education at RINO Amsterdam
2012 - 2013	Master (MSc) Medical Anthropology and Sociology at the Unisersity of Amsterdam
2012	Master (MSc) Clinical Psychology at the Rijksuniversity Groningen
2011	SENSE education to sexual health counselor at RINO Group Utrecht
2007 - 2011	Bachelor (BSc) Psychology at the Rijksuniversity Groningen

2003 – 2007 Bachelor (BSc) of nursing at Hanze University Groningen
1998 – 2003 Senior general secondary education at Dockinga college Dokkum

Courses and other registrations

2019 EMDR Practitioner Europe
2019 Senior schema therapist
2016 Training CBT for Ultra High Risk for Psychosis
2015 CAARMS training

Publications

De Jager, J., Nugter, A., van Os, J. (2021) Sexual trauma, PTSD and sexual dysfunctioning in people with SMI. (under review)

De Jager, J., Topper, M., Ensing, A., Nugter, A., van Os, J. (2021) Sexuality and intimacy in people with SMI; testing a model. (under review)

De Jager, J., Topper, M., Nugter, A., GROUP-investigators, van Os, J. (2021) The impact of childhood sexual trauma on intimacy and sexuality needs among people with psychosis. (under review)

De Jager, J., Greevenbroek, R., Nugter, A., van Os, J. (2018) Sexual Expression and It's Determinants, in People Diagnosed with Psychotic Disorders. Community Mental Health Journal 54(3)

McCann, E., Donohue, G., de Jager, J., van Os, J., Nugter, A., Eustace-Cook, J. (2018) Sexuality and intimacy among people with serious mental illness in hospital and community settings: a systematic review protocol of qualitative research. JBI Database of Systematic Reviews and Implementation Reports 15:1-5

De Jager, J., Cirakoglu, B., Nugter, A., van Os, J. (2017) Intimacy and its barriers: a qualitative exploration of intimacy and related struggles among people diagnosed with psychosis. Psychosis journal Vol. 9, Iss. 4

De Jager, J. & McCann, E. (2017). Psychosis as a barrier in the expression of sexuality and intimacy: an environmental risk? Schizophrenia Bulletin, doi:10.1093/schbul/sbw172

De Jager, J., Wolters, H. A., Pijnenborg, G. H. M. (2016) Jongeren met een psychotische kwetsbaarheid over seksualiteit, intimiteit en relaties. Een exploratief onderzoek middels focusgroepen. Tijdschrift voor Psychiatrie, 58 (3), 223-227

Helmus, K.L. & de Jager, J. (2015) De GGZ als speler in de strijd tegen stigma. Vakblad Sociale Psychiatrie, jaargang 34 (111)

Bookchapters

De Jager, J & Helmus, K.L. (2019) Hoofdstuk Stigmatisering. In Staring T, van der Gaag, M. Handboek psychose. Boom uitgevers, Amsterdam

Swindels, W., Gorter, L., van Goor, L., de Jager, J. (2017) Hoofdstuk Seksualiteit bij mensen met EPA. Hoofdstuk in Handboek Seksualiteit. Coutinho, Bussum

Columns

De Jager, J. (2014) Functionele geesten. Psychopraktijk, 2014/2
De Jager, J. (2014) Verwijzing vanwege bezetenheid. Psychopraktijk, 2014/4
De Jager, J. (2013) Alle gekheid op een Afrikaans stokje. Psychopraktijk, 2013/4
De Jager, J. (2013) Psychotische context. Psychopraktijk, 2013/6

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