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

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28 March 2018

Dear Professor Aromataris

RE: Sexuality and intimacy issues among people with serious mental illness: a systematic review of qualitative research

You recently published our Systematic Review Protocol. We are now submitting our full systematic review that we hope will be suitable for publication in your journal.

We confirm the manuscript is original work and that no part of the manuscript has been published or submitted elsewhere for publication.

All authors have read and approved this version of the manuscript and its submission to the journal.

The development of the submitted manuscript has adhered to ethical standards.

All authors contributed to the development of the ideas, writing and/or final review of the submitted manuscript.

Kind regards

Yours sincerely

Dr Edward McCann

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

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

Executive summary

Background

Mental health services worldwide have seen major transformations in recent years through deinstitutionalization programmes and more enlightened ways of organizing and providing mental health care, particularly in relation to rights-based, empowering and service-user-led policy initiatives. However, in terms of social and emotional well-being, issues persist for people with serious mental illness (SMI), particularly related 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.

Objectives

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 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.

Inclusion criteria

Types of participants

Participants were people aged over 18 years who were diagnosed by a clinician with a serious mental illness of sufficient duration to meet diagnostic criteria specified within the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) or the 10th revision of the International Classification of Diseases (ICD-10).

Phenomena of interest

The phenomenon of interest was the intimacy and sexuality experiences, perceptions and concerns of people over the age of 18 years who were living with a serious mental illness. 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 included studies that have been conducted among people with SMI in hospital or community settings.

Types of studies

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.

Search strategy

An initial scoping search of MEDLINE, CINAHL, PsycINFO and Embase was conducted. This yielded a list of synonyms using MeSH terms and CINAHL subject headings and PsycINFO descriptors and

Emtree headings. An analysis of the text words contained in the title and abstract and of the index terms used to describe the articles was carried out. A second search using all identified keywords and index terms was undertaken across all included databases. Thirdly, the reference list of all identified reports and articles was searched for additional studies. The search included studies published up to and including February 6, 2018.

Methodological quality

Each paper was independently assessed by two reviewers for methodological quality using the JBI-SUMARI instrument.

Data extraction

Data were extracted from included papers using the standardised data extraction tool from JBI-SUMARI.

Data synthesis

JBI-SUMARI was used by three reviewers to identify potential categories and pool similar findings.

Results

Based on the thematic findings from the 21 studies, three synthesized findings were identified: (1) the complexity of individual sexual experiences, (2) the clinical constructs of sexuality and (3) family and partner involvement. The included studies explored a range of experiences relevant for people with SMI within the context of hospital and community settings.

Conclusions

The systematic exploration of the literature resulted in the identification of 21 studies of moderate to high methodological quality that met the inclusion criteria. The ConQual evaluation of the level of evidence resulted in synthesized finding 1 (the complexity of individual sexual experiences) rated as moderate and synthesized finding 2 (the clinical constructs of sexuality) rated as moderate and finally synthesized finding 3 (family and partner involvement) also rated as moderate. 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.

Keywords

Sexuality; intimacy; psychosis; serious mental illness; systematic review; qualitative

ConQual Summary of Findings

Population	People aged over 18 years who have been diagnosed by a clinician with serious mental illness			
Phenomenon of interest	Intimacy and sexuality experiences, perceptions and concerns of people who are living with a serious mental illness.			
Context	Studies that have been conducted among people with SMI in hospital or community settings.			
Synthesized findings	Type of research	Dependability	Credibility	ConQual score
1. The complexity of individual sexual experiences	Qualitative	High	Downgrade one level*	Moderate
2. The clinical constructs of sexuality	Qualitative	High	Downgrade one level*	Moderate
3. Family and partner involvement	Qualitative	High	Downgrade one level*	Moderate

Introduction

Mental health services worldwide have seen major transformations in recent years through deinstitutionalization programmes 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 well-being, issues persist for people with SMI, particularly with concerns related to intimacy and the expression of sexuality. The definition of serious mental illness, 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 (p.5).[6]

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 noticeable 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 the enhancement of the lives of people with a 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 serious mental illness (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, 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 a major 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 well-being and quality of life.

However, sexuality and intimacy are not self-evident 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. [20-22, 9,11] 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 to increase to 78 percent 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 where 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.[22,11] In terms of intimate relationships, people with SMI are more often single and /or divorced when compared with 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 well-being, 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 highlights the requirement for more attention in clinical practice. While there has been some research on the more 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 on 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 who have serious mental illness 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 serious mental illness (SMI) regarding sexuality and intimacy issues within hospital and community settings. The objectives of the present study were:

- to explore intimate relationship experiences of people with SMI
- to highlight specific issues related to sexuality that are important to people with SMI

- to uncover potential obstacles to the expression of sexuality and
- to 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 serious mental illness 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 a serious mental illness. The review highlights pertinent issues and identifies specific needs in relation to sexuality and intimacy. Also, barriers to sexual expression have been elucidated and recommendations made for future mental health practice developments.

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 three-phase 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 and CINAHL subject headings & PsycINFO descriptors and Emtree headings. This was then followed by an analysis of the keywords words 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 a serious mental illness.[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 grey literature included ProQuest Dissertations and Theses, relevant key journals which 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.

Four key concepts 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.

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+")

Concept 2: Sex or Intimacy

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

Concept 3: Experiences

MEDLINE Keyword search only including experience OR experiences OR experienced OR view OR views OR viewpoint OR viewpoints OR perception …

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 the searches of the academic databases and the gray literature. The searches were conducted on 6th February 2018. The hand-search of the reference lists of records that has 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 a standardized critical appraisal instrument from the *Joanna Briggs Institute System for the Unified Management, Assessment and Review of Information* (JBI-SUMARI).[44] 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[44] 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 meta-aggregation approach.[44] 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. Where textual pooling is not possible, the findings have been presented in narrative form.

Confidence in the 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 table.[45] The Summary of Findings table 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.

Results

Study inclusion

The comprehensive literature search was conducted on 6th February 2018 and 3,773 potential papers were identified: CINAHL (N=554), Embase (N=410, Medline (N=940), PsycINFO (N=1085), and Web of Science (N=742). A further 42 articles were discovered through searching the available gray literature. Following the removal of duplicates, using the inclusion criteria, two reviewers assessed the titles and abstracts of the remaining papers (N=2981). A further 2892 papers were excluded from the review. A total of 90 papers were assessed for eligibility and 68 papers were excluded. Full text studies that did not meet the inclusion criteria were excluded. Two reviewers appraised the remaining papers

(N=21) for methodological quality. No papers were excluded following quality appraisal. Finally, a total of 21 papers published between 1995 and 2018 were included in the review.[46-66]

*****Insert Figure 1*****

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 ten (n=4) to a high score of seven and above out of 10 (n=17). Seven of the ten 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.

*****Insert Table 1*****

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 were: UK (n=5),[49,56,59,61,64] USA (n=4),[48,51,54,58] Australia (n=4),[46,47,60,63] Canada (n=2),[57,66] India (n=1),[50] Israel (n=1),[55] Netherlands (n=1),[53] New Zealand (n=1),[52] Slovenia (n=1),[65] and Sweden (n=1).[62] The methodologies used included qualitative description,[49-52,56,59,61-63] multiple case study,[46] single case study,[54,58] participatory action research,[47] phenomenology,[48,60,64,65] and grounded theory.[53,55,57,66] Sample sizes ranged from one to 146 participants. Most studies used individual interviews for data collection. Two used observation[46,54] and direct-therapist interactions.[58] One study used case notes[56] and another utilized focus groups.[52] The data analysis techniques used were thematic analysis,[47,49,51,52,56,61-63] content analysis,[50,59] case study analysis,[46,54,58] constant comparison analysis[53,55,57,66] and phenomenological analysis.[48,60,64,65]

Review Findings

All twenty-one studies included in the review addressed the views and opinions of people with serious mental illness around intimacy and their sexual expression. The review objectives were considered fully to enable the construction of a meta-synthesis (Tables 2,3,4). 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 ten categories that were aggregated into three synthesized findings. 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 One: The complexity of individual sexual experiences

*****Insert Table 2*****

Synthesized Finding One: The complexity of individual sexual experiences

Living with a 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 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 thirty-six findings which were divided into four categories.

Category 1.1: Stigma experiences

Despite increased attention to 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. 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. 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 or stigma can be particularly harmful, especially when someone seeks treatment.

> 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). [53 (p.6)]

Category 1.2: Making sense of individual sexual experiences

Research on the sexuality of people with serious mental illness most often focuses on dysfunction and the side-effects of medication. 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.

> 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). [53 (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…[61 (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. [60 (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. 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). [50 (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. 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 a serious mental illness can often be overwhelming leading to relationship rupture. This has far reaching consequences, not just in maintaining healthy romantic relationships, but also in managing healthy relationships with family and the wider community.

> 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. [47 (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. [47 (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. [49 (p.250)]

Category 1.4: Emotional impact

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

> 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 Two: Clinical Constructs of Sexuality

*****Insert Table 3*****

Synthesized Finding Two: Clinical Constructs of Sexuality

The expression and experience of sexuality is highly influenced by the situation it arises in. The context 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 thirty-eight findings which were merged into four categories: safety, risk and vulnerability; mental health practitioners and therapeutic involvement; communication and disclosures; and the clinical setting.

Category 2.1: Safety, Risk and Vulnerability

Clients expressed specific challenges such as abuse in different situations including hospital and community settings. 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. 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.

> 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. [49 (p.248)]

> 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 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). [50 (p.328)]

> 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 with 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. [48 (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. Within the context of a romantic relationship, clients struggled with their sexuality in relation to being mentally ill. Some participants blamed their medication, while others are affected by negative (sexual) experiences. Nevertheless, these topics are rarely discussed. Proper education as well as assessment of or sensitivity towards specific issues such as transgender processes or autoerotic asphyxiation appears to be lacking. 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 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 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. [49 (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). [50 (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. [61 (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. 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 appears 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. 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 2 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. [46 (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. 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. 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. [61 (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 Three: Family and Partner Involvement

*****Insert Table 4*****

Synthesized Finding Three: Family and Partner Involvement

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 twenty years, the socio-political landscape in Europe has supported deinstitutionalisation, hospital closure programmes and the locus of mental healthcare 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 unrecognised '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.

Category 3.1: Family needs and supports

Families would often provide examples of the emotional and practical input that was given unconditionally, '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.

> 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.' [51 (p.148)]

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.[50,51,61-63]

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 are two to three times more than in the general population. The risk of suicide can be as high as 20%.[41] The formation and maintenance of intimate relationships was important to many participants and was revealed in the studies included in the review. 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.

> 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. [52 (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 of the literature was to synthesize the best available evidence regarding people with a serious mental illness 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.

Discussion points related to finding one

The complexity of individualized experiences in relation to sexuality was a significant finding in relation to individuals with a diagnosis of serious mental illness. When provided with an opportunity to express their thoughts on this topic, many individuals documented the stigma experiences held both internally in the form of self-stigma and externally through interactions with people in their communities. People outside of heteronormative relationships experienced a double stigma in these communities, leading to an even heavier burden. Given the already difficult experience of living with a serious mental illness, it is important for mental health practitioners to be aware of the impact of these stigma experiences on the individual and to not perpetuate them through their own internalised stigmatising behaviours.

Discussion points related to finding two

Sexual abuse as a topic was frequently addressed in the reviewed studies on sexuality and intimacy and SMI. This suggests vulnerability for sexual abuse in the SMI group that has been found in other existing studies. This abuse can take different forms and may be experienced in different contexts. For some, these events pose a lifelong barrier to their expression of sexuality. However, it is important to

be aware that disclosures of sexuality and therefore sexual abuse may be altered due to the state of mind a person is in. In psychosis, abuse may be experienced and disclosed 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. That is, if a patient discloses at all, leading to another important finding from the review; issues regarding sexuality and intimacy are often kept from caregivers. This impediment 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 dangerous issues remain hidden, which can lead to serious sexual risks. Another sexual risk, the risk of unwanted pregnancies, poses a different challenge for both caregivers and clients in a mental health context. Issues of autonomy and responsibility can add complexity to the topic. One of the most important outcomes is that several studies have shown that people with serious mental health problems are willing and able to talk about sexuality and intimacy and that doing so, is safe.

Discussion points related to finding three

Having fulfilling and satisfying sexual and relationship experiences is a fundamental human right that can enhance an individual's quality of life. However, this review has indicated that, despite people with SMI possessing the will and desire to be intimate, potential obstacles exist. The SMI experience can have a profound effect of family members, including partners and spouses. Being aware of the potential stresses and challenges to the relationship and involving partners in the treatment, may help to promote intimacy and recovery.

Strengths and limitations

The aim of the review was to examine 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 and 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.

Conclusion

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

Implications for Practice

On the strength of the review findings, we would recommend and encourage policy makers in mental health settings to make clear and explicit their policies on sexuality issues. These considerations should

include issues such as privacy during admission, assessment of sexual risks such as sexually transmitted infections (STI's), 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.
2. Appropriate and adequate assessment and care planning should include sexuality and intimacy issues.
3. There needs to be a greater awareness and responsiveness of practitioners around sexual abuse issues, sexual risks and vulnerabilities.
4. There needs to be more availability of and access to talking therapies such as individual and couple counselling and psychosexual therapy.
5. There should be time dedicated to exploring thoughts, emotions and meaning around sexuality experiences including the implications of stigma, confidence and self-image.
6. Lack of privacy and strict rules in mental settings need to be examined and reviewed.

Implications for Education

An area that requires attention to ensure that practitioners have the necessary knowledge and skills to address key concerns is education and training. These are related to personal attitudes and values, discrimination and stigma, oppression and social exclusion. The review has demonstrated that practitioners often have had limited previous educational and practice development opportunities.

1. The development of knowledge, skills and understanding of the key issues highlighted in this review.
2. Inclusion of sexuality and intimacy issues within the undergraduate curriculum for all health and social care students.
3. Provision of sexual health education around family planning, contraception and safe sex strategies should be available for all stakeholders.
4. Training for caregivers in asking about sexuality and (sexual) trauma and sexual health counselling.
5. There should be opportunities for skills training and educational sessions in the formation and maintenance of intimate relationships.
6. Continuing professional development (CPD) opportunities to include innovative teaching and learning approaches including skills simulation and e-learning technologies to build and develop confidence in addressing key sexuality issues and concerns.
7. Adequate supervision provided for practitioners.

Implications for Research

This review highlights the need for a detailed focus on sexuality and intimacy issues among people with SMI to better understand their needs, effective supports, interventions and service responses.

There is a significant opportunity to make a shift from purely exploring sexuality and intimacy issues among people with SMI, to 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:

1. Policy evaluation
2. Education and training evaluation
3. Sexuality and quality of life studies
4. Intervention studies
5. Multi-centre national and international studies
6. Service user and family involvement

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Conflicts of interest

The authors declare no conflict of interest

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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.

Appendix I: Search Strategy Examples

1.1 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 paranoid OR 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” OR Hermeneutics OR “focus groups” OR “focus group” OR “observational studies” 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”

1.2 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 paranoid OR 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” OR Hermeneutics OR “focus groups” OR “focus group” OR “observational studies” 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”

1.3 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 paranoid OR 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” OR Hermeneutics OR “focus groups” OR “focus group” OR “observational studies” 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”

1.4 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 paranoid OR 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” OR Hermeneutics OR “focus groups” OR “focus group” OR “observational studies” 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”

1.5 Web of Science Search Strategy (keyword only searches)

Concept 1: Serious Mental Illness

Keywords: Schizophrenia OR Schizophrenic OR schizoaffective OR schizoid OR paranoid OR 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” OR Hermeneutics OR “focus groups” OR “focus group” OR “observational studies” 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”

1189 **Appendix II: Characteristics of included Studies (SUMARI)**

Reference and Country	Phenomena of interest	Participants	Methods	Method-ology	Main results
Ashmore et al. (2015)[46] Australia	Examine incidences of sexual assault on inpatient units	People with serious mental illness (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)[47] 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)[48] USA	Explore the experiences of at-risk youths, ethnically diverse males and females who were	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."

	participants in a prodromal research program				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)[49] 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)[50] 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)[51] 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.
Davison and Huntington (2010)[52] 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)[53] 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	Male to female (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. LGBT people may be resistant to 'coming out' for fear of rejection, abandonment and being viewed as sexually deviant that 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 LGT 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.
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)[60] 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	Phenomen-ology	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)[61] 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
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 (IPA)	Phenomen-ology	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 programmes 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	Phenomen-ology	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.

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.

Appendix III: Findings extracted from the included studies with illustrations

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.[46]	
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.[47]	
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.[48]	
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 with 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.[49]	
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.[50]	
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.[51]	
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.[52]	
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.[53]	
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 he 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. Investigating mental health service user views regarding sexual and relationship issues. J Psychiatr Ment Health Nurs. 2010; 17(3):251-9.[61]	
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.[60]	
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)

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)[45]

Table 1: Methodological quality of included studies (n=21)

Reference	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Ashmore, *et al.*[46]	U	Y	Y	Y	Y	N	Y	Y	Y	Y
Baker and Proctor[47]	Y	Y	Y	Y	Y	N	N	N	Y	Y
Ben-David, *et al.*[48]	N	Y	Y	Y	Y	N	N	Y	Y	Y
Brown, *et al.*[49]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Chandra, *et al.*[50]	U	Y	Y	Y	Y	N	N	Y	Y	Y
Cogan[51]	Y	Y	Y	Y	Y	N	N	Y	U	Y
Davidson and Huntington[52]	U	Y	Y	Y	Y	Y	Y	Y	Y	Y
De Jager, *et al.*[53]	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[61]	U	Y	Y	Y	Y	N	N	Y	Y	Y
McCann and Clark[60]	N	Y	Y	Y	Y	U	Y	Y	Y	Y
Östman and Björkman[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

Y = yes; N = no; U = unclear

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 a 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 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)		

Table 3: Qualitative synthesis of research findings 2

Findings	Categories	Synthesized findings
Territorialisation: Vulnerability/predation discourse (C)	Safety, risk and vulnerability	*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)		
Autoerotic 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)	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)		

Table 4: Qualitative synthesis of research findings 3

Findings	Categories	Synthesized finding
Family as sources of strength (U)	Family needs and supports	*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)	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)		

Figure 1

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