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# **Sexuality and intimacy among people with serious mental illness in hospital and community settings: a qualitative systematic review protocol**

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# **Sexuality and intimacy issues among people with serious mental illness in hospital and community settings: a systematic review protocol of qualitative research**

## **Review question/objective**

The aim of this review is to synthesize the best available qualitative evidence on the experiences and support needs of people with serious mental illness (SMI) regarding sexuality and intimacy within hospital and community settings. The objectives of the present study are:

- to explore intimate relationship experiences of people with SMI
- to explore specific issues related to sexuality 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.

## **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.<sup>1-4</sup> 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.<sup>5</sup>

A recognised working definition of sexuality and intimacy 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).<sup>6</sup>

In terms of potential psychosocial supports, the area of human sexuality continues to present challenges to practitioners within the mental health professions.<sup>7,8</sup> Several studies have highlighted issues around unmet needs regarding intimate and sexual relationships among people diagnosed with SMI.<sup>9-11</sup> Where challenges in issues around sexuality and forming intimate relationships exist, some basic psychological needs may also remain unfulfilled. Furthermore, in times of stress there may be no significant other to turn to for support, thus posing an environmental risk.<sup>12</sup>

A recent study has identified key issues related to the experience of sexuality in people with SMI.<sup>11</sup> 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 studies focusing on biological aspects of sexuality and intimacy such as psychotropic side-effects, sexual risks and sexually transmitted infections (STIs).<sup>11</sup> 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. In appreciating 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.<sup>13</sup> This has clear implications for policy, research, education and practice developments.

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.<sup>14</sup> The fact remains that the needs of people with SMI in the field of sexuality and intimacy remains unaddressed. Hence, mental health practitioners need to explore ways that they may better support people in establishing and maintaining satisfying intimate relationships in the full expression of their sexuality.

In order to address the research objectives, we propose conducting a systematic review of evidence generated by qualitative research. A search of the Joanna Briggs Institute Database of Systematic Reviews and Implementations Reports, the Cochrane Library, CINAHL and PubMed databases did not find any current or planned systematic reviews on this topic.

## **Inclusion criteria**

### ***Types of participants***

This qualitative review will include 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 5<sup>th</sup> edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V)<sup>15</sup> or the 10<sup>th</sup> revision of the International Classification of Diseases (ICD-10).<sup>16</sup> 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 review will investigate 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 will highlight pertinent issues and identify specific needs in relation to sexuality and intimacy. Also, barriers to sexual expression will be elucidated and recommendations made for future mental health practice developments.

### ***Context***

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

### ***Types of studies***

This review will consider studies that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

### **Search Strategy**

The search strategy aims to find both published and unpublished studies. A three-step search strategy will be utilized in this review. An initial limited search of MEDLINE and CINAHL will be undertaken followed by an analysis of the text words contained in the title and abstract, and of the index terms used to describe the articles. A second search using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference list of all identified reports and articles will be searched for additional studies.

International studies published in the English language will be considered for inclusion in this review. Also, studies published since 1995 to the present will be included to coincide with the increasing emphasis and public discourse on recovery and related concepts involving people living with a serious mental illness.<sup>17</sup>

The databases to be searched include:

CINAHL

Embase

PsycINFO

MEDLINE

Scopus

The search for unpublished studies will include:

ProQuest Dissertations and Theses

Mednar

Google Scholar

Initial keywords to be used will be:

Serious mental illness OR severe mental illness OR schizophrenia and disorders with psychotic features OR psychosis OR psychoses OR psychotic OR schizophrenia OR schizoaffective OR bipolar disorder\*

AND

Sex\* OR human sex\*

AND

Experience\* OR view\* OR perception\* OR opinion\*

AND

Qualitative OR qualitative and experience OR lived experience OR perception OR perceived OR understanding OR ethnography OR phenomenology OR feminist and research OR critical and research OR action and research OR systematic review

### **Assessment of methodological quality**

Qualitative papers selected for retrieval will be 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).<sup>18</sup> Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer. Full text studies that do not meet the inclusion criteria will be excluded and reasons for exclusion will be provided in an appendix in the final systematic review report. The results of the search will be reported in full in the final report and presented in a PRISMA flow diagram.

### **Data collection**

Qualitative data will be extracted from papers included in the review using the standardized data extraction tool from JBI-SUMARI<sup>18</sup> by two independent reviewers. The data extracted will include specific details about the populations, context, culture, geographical location, study methods and the phenomena of interest relevant to the review question and specific objectives. Primary authors of papers will be contacted for any missing information.

### **Data Synthesis**

Qualitative research findings will, where possible be pooled using JBI-SUMARI<sup>18</sup> with the meta-aggregation approach.<sup>19</sup> This will involve 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 are then 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 will be presented in narrative form.

## **Assessing Confidence**

The final synthesized findings will be graded according to the ConQual approach for establishing confidence in the output of qualitative research synthesis and presented in a Summary of Findings table.<sup>20</sup> The Summary of Findings table includes the major elements of the review and details how the ConQual score is 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 then presented along with the type of research informing it, a score for dependability, credibility, and the overall ConQual score.

## **Conflicts of Interest**

There are no conflicts of interest to declare.

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