

INPLASY PROTOCOL

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A Meta-synthesis on Perceptions of Sexuality in People with Dementia

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None declared.

Review question / Objective: What are the perceptions and experiences of people with dementia from different populations that include people with dementia, family members, caregivers and healthcare providers?

Condition being studied: Perceptions and experience of sexuality in all populations who involved in dementia care as directly or indirectly. It also include sexual experience in people with dementia in all levels including mild, moderate and severe stages. The sexual expressions refer to sexual behavior regardless of appropriate or inappropriate sexual behavior, sexual desire, arousal and feelings in heterosexual or same sex relationships.

INPLASY registration number: This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 12 September 2022 and was last updated on 12 September 2022 (registration number INPLASY202290050).

INTRODUCTION

Review question / Objective: What are the perceptions and experiences of people with dementia from different populations that include people with dementia, family members, caregivers and healthcare providers?

Rationale: Sexuality is defined as 'a central aspect of being human throughout life

encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. (World Health Organization, 2010). The right to access to a sexual life with true consent and mutual desire had been recognised as a fundamental human rights (Peisah et al., 2021). The Convention on Rights of Persons with Disabilities (2006) stated clearly that all persons have the rights to sexual life regardless of age or disability.

However, enjoyment of sexuality among older persons including people with dementia is always being neglected. When civil and criminal laws play a part in ensuring that sexuality activity is consensual, further obstacles are being identified in preventing people with dementia from sexual enjoyment due to lose of capacity to consent to sexual activity (Sorinmade et al., 2021).

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METHODS

Search strategy: We searched the database Academic Search Complete, CINAHL Plus with full text, MEDLINE complete, Psychology and Behavior Sciences Collection, Healthcare Business Elite and Scopus.

Participant or population: People with dementia, spouse, family members and healthcare professionals.

Intervention: Not applicable.

Comparator: Not applicable.

Study designs to be included: Qualitative studies or mixed methods study where qualitative studies will be analyzed

Eligibility criteria: The inclusion criteria for the study were: (i) the studies investigated on sexuality in older person with dementia, (ii) the studies involved people with dementia, family members, caregivers or healthcare professionals, (iii) the studies explored the perceptions or experience of people with dementia, family members, caregivers or family members towards sexuality in dementia; and (iv) qualitative

studies. The exclusion criteria were (i) gray literature, (ii) quantitative studies, (iii) studies published in non-English language, (iv) no full text available, and (v) studies without peer review process.

Information sources: An exhaustive search of articles was performed with the keywords indicated. Manual search was carried out by revising the included citation list and scanning for suitable articles. Electronic search was updated on 30th August 2022. The screening process involved first author independently reviewed all the articles in the title and abstract screening. The screening tasks were carried out based on the inclusion and exclusion criteria set up in the early stage. Duplicates were removed at the stage of title screening. A pair of authors (first author with either second, third or fourth author) performed the quality assessment to the articles independently and compared the scoring subsequently. Mutual agreement towards the scoring eventually achieved through discussion. The final included articles had been confirmed for the next level of data analyses.

Main outcome(s): The results from the synthesis of included articles yielding a rich and holistic understanding of sexuality in dementia among the people from different populations and different cultural background. It also provided a estimation of result to the related research to be conducted in Malaysia.

Quality assessment / Risk of bias analysis: Hawker's Evidence Appraisal Tool (HEAT) was chosen as the instrument to evaluate the quality of the included articles from full text screening. This tool consists of 9 components where each component can be rated as 'good', 'fair', 'poor' or 'very poor'. These nine components refer to (i) abstract and title, (ii) introduction and aims, (iii) method and data, (iv) sampling, (v) data analysis, (vi) ethics and bias, (vii) results, (viii) transferability and generalizability, and (ix) implication and usefulness. Each rating is being given a numerical score of 1 point (very poor) to 4 points (good). It sums up

the minimum score of 9 points and maximum of 36 points in each component. The total scoring of each components contributed to the overall quality grades with the following definitions: high quality (A), 30-36 points; medium (B), 24-29 points; low quality (C), 9-24 points (Hawker et al. 2002).

Strategy of data synthesis: The thematic synthesis began with rereading of each included articles and followed by development of initial codes. These initial codes consist of a list of ideas about the most relevant data from the each paragraph of the results, discussion and conclusion of the studies. Subsequently, we created the themes by grouping the several codes into broader units of analysis with broader meanings. The authors discussed the coding and themes results, cross-checked and harmonized them among the articles. We concluded the analysis by organizing the themes and writing the most significant extracts.

Subgroup analysis: Findings from included articles were analyzed based on the categories of country of origin, populations involved, data collection methods, exposure of sexual education or training and management of sexuality in dementia care.

Sensitivity analysis: At least a pair of authors involved for inter-rater reliability analysis. Inter-rater reliability was evaluated through out the stage of quality assessment on HEAT tool and coding formation for the included articles. All the authors cross checked on the themes, compared the results and harmonized them in parallel.

Language restriction: English.

Country(ies) involved: Malaysia.

Keywords: dementia; sexuality; older person; qualitative; Alzheimer; sexual; cognitive impairment; older adult; senior; aging; veteran; older people; mixed-method; interview.

Dissemination plans: This meta-synthesis paper is expected to be published as journal article and presented in any academic or medical conferences.

Contributions of each author:

Author 1 - Dinnee Kong - Author 1 involved in all the process for this meta-synthesis where it started with drafting the ideas, defining research questions, setting up selection criteria, selecting research articles, screening articles, performing quality assessments for included articles, extracting and critically analyzing the data from the included articles.

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Author 2 - Muhammad Hibatullah Romli - Author 2 provided the expertise advise on selection of study, reviewed the included articles, registered the protocol, verified the data analyzed by author 1, critically analyzed the results, reviewed the manuscript writing and approved the final manuscript.

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Author 3 - Tan Maw Pin - Author 3 verified the data extracted in table, critically analyzed the findings and approved the final manuscript.

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Author 4 - Navin Kumar Devaraj - Author 4 evaluated the quality of included articles by using HEAT tools, decided the included articles, verified the data extracted and approved on the final manuscript.

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