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Sexuality and intimate relationships of people with Ostomies: a qualitative metasynthesis

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Review question / Objective: To conduct a systematic review and meta-synthesis of qualitative research about sexuality and intimate relationships among patients with intestinal ostomy, to highlight and summarise the overarching dimensions of this clinical issue – to identify key elements, assess our qualitative knowledge on this topic to then identify implications for care and help define a future research agenda.

Condition being studied: (a) Research theme was about sexuality and intimate relationship experience of people with Ostomies; (b) Qualitative methodology was used in studies, data needed to be collected via customary qualitative approaches (e.g., interview, focus group, open-ended survey questions) with sufficient data (i.e., patients' or partners' quotations) reported to support the study findings; (c) Primary study is mixed-methods Studies employing both qualitative and quantitative methods were eligible if qualitative data could be extracted for analysis; (d) Focusing on patients who were or more than 18 years old; (e) Published in Chinese and English.

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INTRODUCTION

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intestinal ostomy, to highlight and summarise the overarching dimensions of this clinical issue – to identify key elements, assess our qualitative knowledge on this topic to then identify implications for care and help define a future research agenda.

Rationale: Stomas are formed surgically, by exteriorising the bowel to the abdominal surface, as a new system for patients who are undergoing stoma surgery, serves as a new route for bowel waste or urine disposal (Son & Kang, 2021). The exact global incidence and prevalence of ostomy surgery is unknown. One report stated that there are approximately 725,000-1 million people with an ostomy in the USA. (United Ostomy Association of America (UOAA, 2019)). This number in China has exceeded 1 million, and with an annual increase of about 100,000, in 2005. (DeHong, 2005). And the worldwide increase in the incidence of colorectal cancers and inflammatory bowel diseases has led to an increase in ostomy creation surgeries (Hubbard et al., 2017). Although abdominal ostomies are considered a part of treatment for physical traumas, several intestinal and urethra diseases, such as: colorectal cancer, inflammatory bowel diseases, urinary obstruction or Crohn's disease. (Martin & Vogel, 2012; Hausegger & Portugaller, 2006). But, production of an intestinal stoma, on one hand, leads to uncontrolled elimination of liquid and stool (Paula, Takahashi, & Paula, 2012), on the other hand, radical pelvic surgery applied in Pelvic cancer such as Bladder cancer or Bowel cancer causes erectile dysfunction because it causes severe structural damage in sympathetic and parasympathetic nerves. And, as for females, total cystectomy by damaging the vascular flow might cause decrease in vaginal lubrication (Kandemir & Oskay, 2017). These could cause people to experience not only physiological, psychological, and social but also sexual problem (Mohamed et al., 2021). For many years, health professionals (HPs) have often avoided addressing sexual health with their patients – especially issues related to intimate relationships and sexual fulfillment within those relationships – regarding these issues as a private and challenging matter (Gott, Galena, Hinchliff, & Elford, 2004). In addition, HPs often report that they lack the skills to manage sexual related problems with their patients – compounded by patients being too embarrassed to raise the topic (Bauer,

McAuliffe, & Nay, 2009; Saunamäki, Andersson, & Engström, 2010). This has created a significant amount of difficulties with patients often having to manage the sexual dimensions of their illness without any support (Barisone et al., 2020). Fortunately, in recent years, there has been an increase in clinical qualitative research related to sex and sexuality in patients living with Stomas. However, these studies consist mainly of very context-related work and are relatively small studies. There is a need to conduct a meta-synthesis to highlight and summarise the overarching dimensions of this clinical issue – to identify key elements, assess our qualitative knowledge on this topic to then identify implications for care and help define a future research agenda.

Condition being studied: (a) Research theme was about sexuality and intimate relationship experience of people with Ostomies; (b) Qualitative methodology was used in studies, data needed to be collected via customary qualitative approaches (e.g., interview, focus group, open-ended survey questions) with sufficient data (i.e., patients' or partners' quotations) reported to support the study findings; (c) Primary study is mixed-methods Studies employing both qualitative and quantitative methods were eligible if qualitative data could be extracted for analysis; (d) Focusing on patients who were or more than 18 years old; (e) Published in Chinese and English.

METHODS

Search strategy: Given our review question, we used the PEO (Population, Exposure, Outcome) mnemonic tool (Moola et al., 2015). The population was found by searching 'Ostomies -related' terms, exposure by 'sexuality-related' terms, and outcomes (namely patients' experience) were defined by 'qualitative research-related' terms. The search terms are summarised as: 1. Population (patients) 'Ostomies -related' terms: "ostomy" OR "urostomy" OR "ileostomy" OR "colostomy" OR "duodenostomy" 2. Exposure (intimate relationships)

'Sexuality-related' terms "Sexual Behaviour" OR "Reproductive Behaviour" OR "Sexuality" OR "Orgasm" OR "Pleasure" OR "Sex" OR "Interpersonal Relations" OR "Sexual Dysfunction, Physiological" OR "Sexual Dysfunctions, Psychological" OR "Family Relations" 3.Outcome (experiences, perspectives, feelings, etc.) Qualitative Research "Qualitative Research" OR "Grounded Theory" OR "Empirical Research" OR "Qualitat*" OR "Interview*" OR "Observation*" OR "Behaviour Observation Techniques" OR "Narrat*" OR "Focus Groups". Database searching for published studies and reports was conducted in may 2021 in PubMed, Embase, Web of Science Core Collection, Cochrane Library, EBSCO hos, China National Knowledge Infrastructure, Wanfang , VIP ,SinoMed. With no publication date limits. We also checked the articles' references to identify other potential studies.

Participant or population: (a) people with Ostomies; (b) 2.patients who were or more than 18 years old.

Intervention: Not applicable.

Comparator: Not applicable.

Study designs to be included: (a) Qualitative methodology was used in studies, data needed to be collected via customary qualitative approaches (e.g., interview, focus group, open-ended survey questions) with sufficient data (i.e., patients' or partners' quotations) reported to support the study findings;(b) Primary study is mixed-methods Studies employing both qualitative and quantitative methods were eligible if qualitative data could be extracted for analysis.

Eligibility criteria: (a) Research theme was about sexuality and intimate relationship experience of people with Ostomies; (b) Qualitative methodology was used in studies, data needed to be collected via customary qualitative approaches (e.g., interview, focus group, open-ended survey questions) with sufficient data (i.e., patients' or partners' quotations) reported

to support the study findings; (c) Primary study is mixed-methods Studies employing both qualitative and quantitative methods were eligible if qualitative data could be extracted for analysis; (d) Focusing on patients who were or more than 18 years old; (e) Published in Chinese and English.

Information sources: Database searching for published studies and reports was conducted in may 2021 in PubMed, Embase, Web of Science Core Collection, Cochrane Library, EBSCO hos, China National Knowledge Infrastructure, Wanfang , VIP, SinoMed. With no publication date limits. We also checked the articles' references to identify other potential studies.

Main outcome(s): Not applicable.

Data management: We tabulated the data to form a single matrix that supported the fusion of the narratives. We identified relationships between the study findings, discerned whether data corresponded or contrasted, and established commonalities in themes and subthemes. Two researchers read and reread the articles independently to gain insight from data, extracted and reflected on the emerging themes and subthemes, resolved disagreement, and achieved consensus through ongoing discussion.

Quality assessment / Risk of bias analysis: We performed a quality appraisal of the studies included in the review using the validated Critical Appraisal Skills Program qualitative checklist (CASP) (CASP UK 2013, <http://www.casp.uk.net>), The CASP tool assesses the quality and usefulness of research studies with a ten question survey. During the quality assessment process, two researchers independently appraise all the including papers. Disagreements among the reviewers were resolved through discussion. Using a score of 1 for yes or 0 for no, then summed up the scores to obtain the final scores. The higher scores indicate more excellent methodological quality.

Strategy of data synthesis: A thematic synthesis approach was used to gather information and identify all themes. It is the most appropriate approach for qualitative meta-synthesis. The inductive analysis by Sandelowski and Barroso (Sandelowski & Barroso, 2007) was adapted and used 3 stages: (1) extraction of findings and coding of findings for each article; (2) grouping of findings (codes) according to their topical similarity to determine whether findings confirm, extend, or refute each other; and (3) abstraction of findings (analyzing the grouped findings to identify additional patterns, overlaps, comparisons, and redundancies to form a set of concise statements that capture the content of findings).

Subgroup analysis: Not applicable.

Sensitivity analysis: Not applicable.

Language: Chinese and English.

Country(ies) involved: China.

Keywords: Meta-synthesis, qualitative research, Ostomies, sexuality, intimate relationships, nursing.

Contributions of each author:

Author 1 - Xia Chen - Made substantial contributions to conception and design, acquisition of data, analysis of data and drafting the manuscript.

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Author 5 - Tianyun Zhao - data collection; data management; analysis of data; interpretation data,Involved in drafting the manuscript.

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Author 7 - Ying Wang - data collection; data management; analysis of data; interpretation data.

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