BMJ Open Patient-centred infertility care: a scoping review protocol

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ABSTRACT

Introduction Patient-centred infertility care (PCIC) is one of the quality indicators of effective fertility care. The application of this indicator requires a clear definition from the patient's perspective. This proposed scoping review aims to explore the extent and nature of published scientific literature on PCIC in the past decade, identify gaps in the literature and define PCIC from infertile patients' perspectives.

Methods and analysis We will conduct the proposed scoping review following the method of Arksey and O'Malley. The literature search will include studies published from 2009 to 2019, and will be conducted on the MEDLINE, PsycINFO, Scopus, Cochrane Library, and Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases; reference lists will be mined for literature not contained on these databases. A grey literature search will also be conducted. To be included in the review, studies should have been conducted on people with a history of infertility, with a focus on patient-centred fertility care. Studies that have not been published in full text and studies published in languages other than English will be excluded. After study selection, data will be charted in a prepared form. We will analyse the data using descriptive numerical and qualitative thematic analyses to answer the research questions. NVivo V.12 will be used for data extraction.

Ethics and dissemination This work does not warrant any ethical or safety concerns. This scoping review will synthesise existing literature on PCIC, and the results will be published to be readily available for clinical audiences and policymakers. These findings may support clinicians and decision-makers in applying PCIC, thereby promoting high-quality healthcare in the concerned population.

INTRODUCTION

Patient-centred care (PCC), defined as 'providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions', has been described as one of the six important determinants of healthcare quality.¹ While PCC has been defined in various ways, there is currently no universally accepted definition for the concept.² PCC generally takes a holistic view of individuals, considering a range of biopsychosocial aspects.^{3 4} A 1993 Picker Institute study identified eight elements of PCC: the

Strengths and limitations of this study

- Our scoping review will map literature on patient-centred infertility care (PCIC), thereby identifying gaps for future research.
- The proposed review may provide an updated definition of the concept of PCIC to support its implementation in fertility care.
- The current broad definition of PCIC has made the formulation of focused research questions and comprehensive search terms, which cover all aspects of PCIC, difficult.
- This review may miss important literature published in languages other than English.

patient's preferences; integrated and coordinated care; education and information; the patient's physical comfort; emotional support for the patient; the involvement of family and friends; continuity and transition of care; and access to healthcare.⁵

PCC has been proven to have a positive impact on healthcare, including enhanced health outcomes and increased patient satisfaction.^{6 7} These benefits are of paramount importance, especially for patients who are expected to have a long treatment journey, such as infertility patients, who are known to have long, recurrent and emotional healthcare visits.⁸

Infertility and subfertility are a significant health problem affecting around 10% of women.⁹ Infertility is associated with high social and financial burdens, which can severely affect quality of life, especially for women.¹⁰ Different treatment modalities are used to manage infertility, including assisted reproductive techniques such as intrauterine insemination; in vitro fertilisation, which includes zygote intrafallopian transfer and gamete intrafallopian transfer; intracytoplasmic sperm injection; assisted hatching; donor eggs and sperm; gestational carrier; and adoption.¹¹ Many of these modalities are, however, associated with significant comorbidity, like ovarian hyperstimulation after ovulation induction,

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and obstetrics complications.¹² Infertility and its treatment can be a stressful life experience, and a multidisciplinary and multidimensional approach is of paramount importance in the treatment of both men and women, including addressing their social, emotional, psychological and cultural needs.¹³

Previous studies have identified 12 elements of patient-centred infertility care (PCIC): privacy, communication, accessibility, information provision, staff competence, physical comfort, patient involvement, partner involvement, provision of emotional support, coordination and integration of care, continuity and transition of care, and attitude of and relationship with staff.^{14 15} A systematic review of 51 papers published up to October 2008 explored how patients' perspectives on fertility care had been examined in the research; it also examined the perspective of patients in developed countries on fertility care.¹⁵ The review identified significant methodological limitations in the reviewed studies, including failure to clearly define study outcomes and/or study methodologies. The studies further provided limited consideration of patients' perspective on fertility care, as most covered only some PCIC dimensions.¹⁵ In addition, all the reviewed papers were from developed countries, concentrated in Europe. To the best of our knowledge, the extent and nature of PCIC literature have not been reviewed beyond this date.

In this scoping review, we aim to explore the extent and nature of scientific literature on PCIC, published in the past decade, to identify gaps in the literature and to define PCIC from infertile patients' perspectives. These wide research objectives, especially the mapping of previous literature work, are best achieved through a scoping review. This work will be useful in guiding future research to improve our understanding of the concept and dimensions of PCIC, thereby helping in its application.

METHODS AND ANALYSIS

This protocol conforms to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) checklist¹⁶ (see online supplementary file 1). We will follow the method of Arksey and O'Malley and its clarification by Colquhoun *et al*¹⁷ in conducting the scoping review. A stepwise description of the procedure follows.

Identifying the research questions

We aim to answer the following research questions:

1. How is the concept of PCIC presented in the available literature?
2. What are the dimensions of PCIC?
3. What are the gaps in the extent and nature of published scientific literature on PCIC?

The review output will be highlighting the dimensions and definition of PCIC, the mapping of PCIC literature

in the past decade, and defining the research gaps in this area.

Identifying relevant studies

To find relevant studies, we will conduct an iterative literature search using different databases in October 2019. The search strategy will be refined until we obtain the most relevant search results. The search will be conducted using the MEDLINE, PsycINFO, Scopus, Cochrane Library, and Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases. The reference lists of the included articles will be mined for additional relevant studies, and a grey literature search will also be conducted. We will use text words and medical subject heading (MeSH) terms to develop our search terms.

The search strategy is clarified through an example in online supplementary file 2. A similar search strategy will be used to retrieve relevant studies from other databases. The identified articles will be exported to the EndNote reference management software, and duplications will be removed. The search results will be displayed in a PRISMA flow diagram.

Study selection

We will review the retrieved articles for study inclusion, applying inclusion and exclusion criteria. We (HHW and TATI) will independently review the titles and/or abstracts of the retrieved articles. Then, the full texts of all potentially eligible articles will be reviewed for possible inclusion. In case of disagreement, a third reviewer (NMN or SBI) will assist in determining the final inclusion. Every 20–30 papers identified for possible inclusion will be discussed to resolve any conflict and to ensure consistency between reviewers and within the review research questions.

Inclusion criteria are that the study subjects should be individuals with a history of infertility, the study should be about PCIC, defined as the infertile patient's preferences, needs, expectations, satisfaction and perspectives; and includes all healthcare settings which provide infertility care. The search will include studies published from 2009 until 2019, given that this 10-year period will encompass current evidence. Studies not published in full text will be excluded. Further, only papers written in English will be included. No other limitations will be applied, including participants' characteristics, study design or countries where the studies were conducted.

Charting the data

The variables will be extracted in advance, and include study characteristics (author, year of publication, type of paper, and country); participant characteristics (gender, age, infertility type, infertility cause and type of fertility care received); methodology (study design, sample size and outcome); PCIC definition; and PCIC dimensions. We piloted the charting form on five studies to determine whether it is consistent with the research questions. HHW will continually extract the information from the included

studies using NVivo V.12 and chart the data accordingly. TATI will verify the charted data.

Collating, summarising and reporting the results

We will analyse data using descriptive numerical summary and qualitative thematic analysis to answer the research questions. Thematic construction will be used to provide an overview of the breadth of the literature using NVivo V.12. A thematic analysis will then be conducted to answer the research questions.¹⁷ We will report the results in tables, charts and narrative synthesis. Finally, we will discuss the findings and their implications for future research.

Patient and public involvement

Patients are involved at two levels. Before developing the review proposal, we explored the PCIC concept through a qualitative study, including indepth interviews (IDIs) with 14 infertile women. The IDI transcripts surfaced nine dimensions of PCIC. In interpreting the review findings, we will invite five women who had received infertility care during the preceding 6 months to participate in a telephonic interview to discuss the results and the identified gaps in the literature.

ETHICS AND DISSEMINATION

This work does not warrant any ethical or safety concerns. This scoping review will synthesise existing literature on PCIC, and the results will be published to be readily available for clinical audiences and policymakers. These findings may support clinicians and decision-makers in applying PCIC and developing tools for measuring PCIC in fertility units, thereby promoting high-quality health-care in the concerned population.

Contributors All authors contributed to the objectives, research questions and study design. HHW and TATI wrote the study method and analysis. HHW drafted the manuscript, and NMN and SBI made major revisions. All authors read and approved the final version of the manuscript.

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REFERENCES

- 1 Baker A. Crossing the quality chasm: a new health system for the 21st century: Institute of medicine. *BMJ* 2001;323.
- 2 Scambler S, Gupta A, Asimakopoulou K. Patient-centred care - what is it and how is it practised in the dental surgery? *Health Expect* 2015;18:2549-58.
- 3 Luis Turabian J, Turabian JL. Patient-Centered care and biopsychosocial model. *Trends Gen Pract* 2018;1:1-2.
- 4 Ekman I, Swedberg K, Taft C, et al. Person-centered care--ready for prime time. *Eur J Cardiovasc Nurs* 2011;10:248-51.
- 5 The Picker Institute. Principles of patient centred care. Picker Institute Europe. Available: <https://www.picker.org/> [Accessed 10 May 2019].
- 6 Hansson E, Ekman I, Swedberg K, et al. Person-centred care for patients with chronic heart failure - a cost-utility analysis. *Eur J Cardiovasc Nurs* 2016;15:276-84.
- 7 Bertakis KD, Azari R. Patient-Centered care is associated with decreased health care utilization. *J Am Board Fam Med* 2011;24:229-39.
- 8 Jafarzadeh-Kenarsari F, Ghahiri A, Zargham-Boroujeni A, et al. Patient-Centered fertility care: from theory to practice. *JMRH* 2016;4:712-9.
- 9 World Health Organization. Infertility is a global public health issue. Available: <https://www.who.int/reproductivehealth/topics/infertility/perspective/en/> [Accessed 19 Jul 2019].
- 10 Cui W. Mother of nothing: the agony of infertility. *Bull World Health Organ* 2010;88:881-2.
- 11 Anwar S, Anwar A. Infertility: a review on causes, treatment and management. *Womens Health Gynecol* 2016;5:2-5.
- 12 Kulkarni AD, Jamieson DJ, Jones HW, et al. Fertility treatments and multiple births in the United States. *N Engl J Med* 2013;369:2218-25.
- 13 Liminana Gras RM. Reproductive psychology and infertility. *Acta Psychopathol* 2017;03.
- 14 Dancet EAF, Van Empel IWH, Rober P, et al. Patient-Centred infertility care: a qualitative study to listen to the patient's voice. *Hum Reprod* 2011;26:827-33.
- 15 Dancet EAF, Nelen WLD, Sermeus W, et al. The patients' perspective on fertility care: a systematic review. *Hum Reprod Update* 2010;16:467-87.
- 16 Tricco AC, Lillie E, Zarin W, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med* 2018;169:467-73.
- 17 Colquhoun HL, Levac D, O'Brien KK, et al. Scoping reviews: time for clarity in definition, methods, and reporting. *J Clin Epidemiol* 2014;67:1291-4.