

# BMJ Open Living experiences of patients with advanced cancer with low socioeconomic status: protocol for a systematic review of qualitative evidence

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## ABSTRACT

**Introduction** The number of patients with advanced cancer is rapidly increasing, and the disease burden among those with low socioeconomic status (SES) has accordingly become a global concern. Low SES can adversely impact patients with advanced cancer. The purpose of this systematic review is to shed light on the life experiences of patients with advanced cancer with low SES to help provide targeted and effective strategies to improve their quality of life.

**Methods and analysis** We will include the following English databases: Cochrane Library, Cumulative Index to Nursing and Allied Health Literature, PubMed, MEDLINE, Embase, Web of Science, Joanna Briggs Institute (JBI) Database of Systematic Reviews, PsycINFO and OpenGrey, and the following Chinese databases: China National Knowledge Infrastructure, VIP Database for Chinese Technical Periodicals and Wanfang Data Knowledge Service Platform. A comprehensive search of qualitative studies on the experiences of patients with advanced cancer with low SES will be conducted from the above databases, with no age limit. Quality assessments of the studies will be independently performed by two reviewers using the JBI Critical Assessment Checklist, and any disagreements will be resolved through a discussion with a third reviewer. Relevant data will be extracted using the JBI standardised data extraction tools. The JBI meta-aggregation tool will be used to compare, analyse and summarise the original results. The reliability and credibility of the overall quality of the studies included will be evaluated using the JBI ConQual approach.

**Ethics and dissemination** This study is based on existing public literature and therefore does not require a formal ethics review. The results of the study may be presented in peer-reviewed international journals and presented at scientific conferences.

**PROSPERO registration number** CRD42021250423.

## INTRODUCTION

Cancer remains the leading cause of death worldwide, and an estimated 10 million cancer deaths occurred in 2020.<sup>1</sup> The global burden of cancer-related diseases is also increasing.<sup>2</sup> Patients with advanced cancer are those with metastatic or controlled but incurable cancer.<sup>3</sup> Although novel treatment

## Strengths and limitations of this study

- There is an urgent need for qualitative evidence regarding the life experiences of patients with advanced cancer with low socioeconomic status (SES) to help formulate appropriate interventions.
- This study is the first qualitative systematic review to focus on the living experiences of patients with advanced cancer with low SES.
- This study will include a systematic review of empirical evidence based on qualitative research conducted across multiple regions and cultures that will contribute to the dissemination of care practices for patients with advanced cancer with low SES.
- The findings of this qualitative systematic review are limited by the context and background of the included original studies.

modalities and the quality of care strategies have improved the overall 5-year survival rate of patients with advanced cancer,<sup>4 5</sup> no curative cancer modality has been developed.<sup>6</sup> Patients with advanced cancer experience adverse health outcomes, and majority do not recover.<sup>7</sup> Within the limited survival period of patients with advanced cancer, the long-term consequences of cancer and its treatment often result in higher symptom loads,<sup>8 9</sup> including moderate to severe cancer pain,<sup>10</sup> depression,<sup>11</sup> malnutrition<sup>12</sup> and cancer-related fatigue.<sup>13</sup> These, in turn, result in a significantly decreased quality of life,<sup>14</sup> with severely impaired overall physical, psychological, and social functions and a higher risk of suicidal intentions.<sup>15</sup>

Patients with advanced cancer with low socioeconomic status (SES), that is, those generally either with residence in a deprived regional status or with low income,<sup>16</sup> face more complex problems.<sup>17</sup> Despite their varying types of cancer, patients with advanced cancer with low SES have similar concerns and issues. They often experience

delays in perceiving non-specific symptoms of certain cancers (eg, fatigue or unexplained weight loss) until the time of diagnosis.<sup>18 19</sup> Further, active clinical treatment is often associated with higher out-of-pocket costs in these patients than their high SES counterparts.<sup>20–22</sup> A systematic review by Iraragorri *et al*<sup>21</sup> showed that patients with cancer residing in low-income areas spent 42% of their annual income on cancer-related out-of-pocket expenses. This was approximately 2.6 times higher than the out-of-pocket expense-to-annual income ratio for patients with cancer in high-income areas. Moreover, the debilitating effects of late illness often lead to unemployment for both patients and their caregivers,<sup>23 24</sup> further lowering the total household income. In addition, the economic cost of advanced cancer treatment is only partially covered by the social security system.<sup>22</sup>

The negative impact of long-term and costly treatment and low income on the patients' quality of life is often multidimensional.<sup>25</sup> Some studies have shown patients' higher drug non-compliance to save costs (eg, reducing drug use, delaying prescriptions, using alternative therapies) in patients with advanced cancer with low SES.<sup>26 27</sup> Further, these patients are forced to interrupt or abandon treatment.<sup>28 29</sup> Lower treatment compliance can have significantly negative health-related consequences, including increased hospitalisations<sup>30</sup> and higher mortality rates.<sup>17</sup> A large National Health Survey found that patients who reported having financial problems because of cancer care costs were not only more likely to report lower health conditions, but also had worse mental health status.<sup>31</sup> Severe symptoms of anxiety and depression lead to poorer quality of life,<sup>32 33</sup> which increases the need for palliative care.<sup>34</sup>

Despite these adverse effects of low SES, the care plan for patients with advanced cancer with low SES has not been clearly defined. Only a few quantitative studies have explored effective nursing strategies for patients with advanced cancer, including symptom management<sup>35</sup> and psychosocial care.<sup>36 37</sup> However, these methods often do not meet the daily care needs of patients with advanced cancer with low SES.<sup>38</sup> For example, symptom management is continuous and dynamic, and regular medication use is better for symptom control. However, patients with advanced cancer with low SES often adjust or delay medication due to their limited financial resources.<sup>26 27 39</sup> These patients also often lack access to adequate and continuous psychosocial care services because of socioeconomic restrictions.<sup>40</sup> Some qualitative studies have found more life difficulties in patients with advanced cancer with low SES. Van Roij *et al* reported that patients in their study felt overwhelmed but were embarrassed when seeking financial support.<sup>25</sup> These patients also often experience stronger feelings of social exclusion and isolation than their high SES counterparts.<sup>25</sup> In addition, their strategies for accepting and managing behavioural changes under such economic hardship may be unique.<sup>41</sup> For instance, the more effective strategies of pain management among these patients were found as the sensory experience of

pain and the meaning of pain, rather than prescribed analgesics.<sup>39</sup>

Therefore, this qualitative review aims to shed light on the life experiences of patients with advanced cancer with low SES, in a detailed manner, including disease distress, barriers and strategies in coping with the disease distress. Ultimately, the synthesised qualitative evidence helps provide targeted and appropriate care strategies to improve patients' quality of life.

## METHODS AND ANALYSIS

This is a qualitative systematic review protocol that follows the Preferred Reporting Items for Systematic Reviews and Meta-analysis Protocols checklist to ensure that the research plan is robust (online supplemental material 1).

### Inclusion criteria

#### Participants

We will review all studies that include patients with advanced cancer, without limitations on the country or type of cancer.

#### Phenomenon of interest

This review will include studies that describe the life experiences of patients with advanced cancer, including disease distress, barriers and strategies in detail.

#### Context

The context will consider the life experiences of patients with advanced cancer with low SES. According to literature review, most previous studies identified low income as a feature of low SES.<sup>16 17 19</sup> Therefore, low income will be considered as low SES in this study. Also, due to the varying standards of low income in different locations, patients with advanced cancer who are identified as having a low-income economic status in the original research will be included in this study.

#### Types of studies

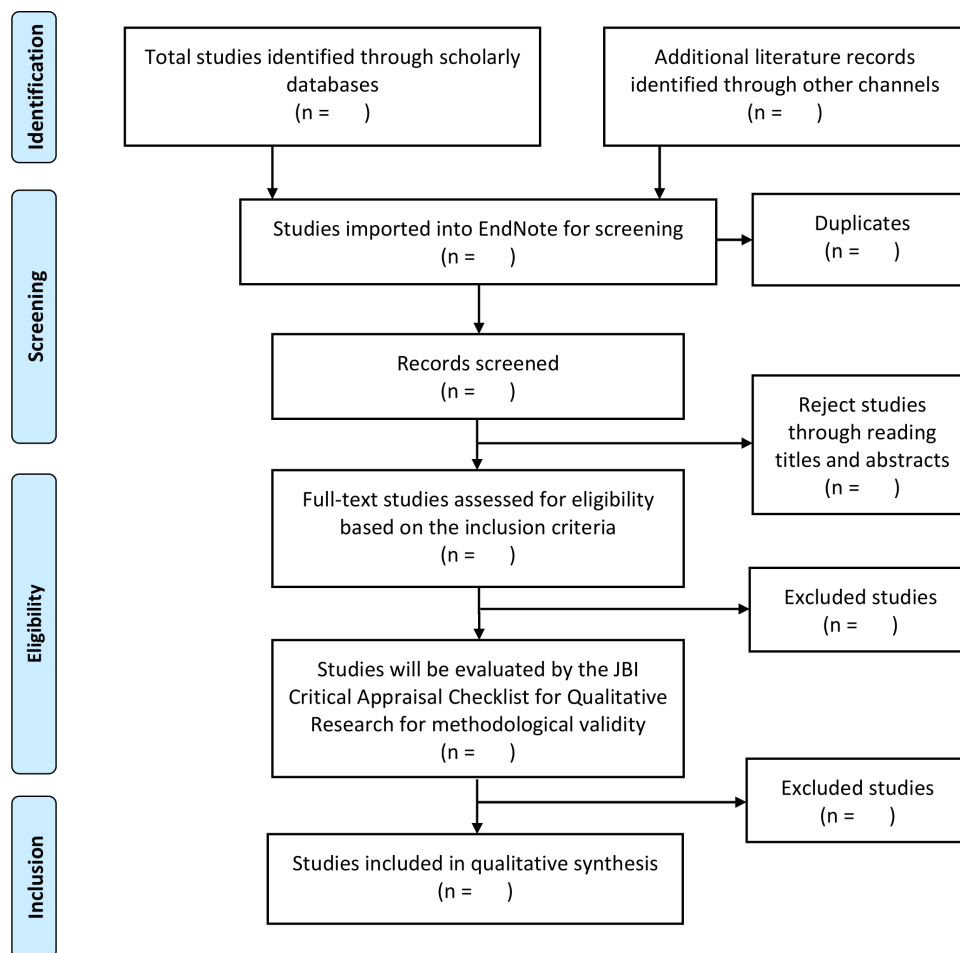
The review will consider qualitative studies, including, but not limited to, personal narratives, grounded theories, ethnographies and feminist research. Only English and Chinese literature will be included, and there will be no restrictions on the year of publication.

#### Patient and public involvement

No patient will be involved in the design, planning and conception of this study.

#### Search strategy

The search strategy aims to find both published and grey literature. An initial search will be conducted using the PubMed and Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases. This will be followed by an analysis of MeSH (Medical Subject Headings) terminologies included in the title and abstract and index terminology terms used to describe the articles. A comprehensive search will also be performed, using



**Figure 1** PRISMA flow diagram of the study process. JBI, Joanna Briggs Institute; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analysis.

the relevant MeSH terminology and index terminology terms, in the following databases: the Cochrane Library, CINAHL, PubMed, MEDLINE, Embase, Web of Science, Joanna Briggs Institute (JBI) Database of Systematic Reviews, PsycINFO, China National Knowledge Infrastructure, VIP Database for Chinese Technical Periodicals, Wanfang Data Knowledge Service Platform and OpenGrey. The complete search strategy for the customisations used in PubMed is presented in online supplemental material 2.

### Study selection

All the identified studies will be collated and uploaded to EndNote V.X9 software; duplicate studies will be eliminated. Two independent reviewers (ZA and XM) will screen the titles and abstracts according to the inclusion criteria. Articles that do not meet the inclusion criteria will be excluded, and the reason for exclusion will be attached as supplemental material in the final systematic review report. To maintain the credibility of the screening process, all included studies will be screened according to a rigorous process, and any disagreements will be resolved through discussion with a third reviewer (HY).

### Assessment of methodological quality

Quality assessments prior to inclusion in the review will be performed by two independent reviewers (ZA and XM) according to the 10-item checklist of the JBI Qualitative Assessment and Review Instrument for methodological validity.<sup>42</sup> The checklist assesses different domains, including research methodology, philosophical foundation, data collection, analysis method and result validity (online supplemental material 3). All studies will be evaluated based on whether or not the study being evaluated fulfils the checklist item for each domain. Items in the checklist will be marked as 'yes' if the study fulfils the domain criteria, 'no' if it does not and 'unclear' if the study's adherence to certain domain criteria cannot be conclusively proven. The result of the evaluation will be determined based on the number of domain items (of a total of 10) that the study fulfils, with a rating of  $\leq 6$  considered weak, 7–8 considered moderate and 9–10 considered high quality. Any disagreements will be resolved through a discussion with the third reviewer (HY) until a consensus is reached. For studies that are evaluated as moderate and above, data will be extracted and integrated for analysis.

## Data collection

Two independent reviewers (ZA and XM) will collect qualitative data related to the research questions and objectives using the JBI qualitative assessment and review instrument from the JBI System for the Unified Management, Assessment and Review of Information.<sup>43</sup> The extracted data will include details regarding the populations, contexts, methods, culture, geographical location, study methods and the phenomena of interest (online supplemental material 4). All information obtained will be grouped into tables.

## Data synthesis

The collected data will be organised and synthesised using the JBI meta-aggregation method.<sup>44</sup> Before integration, two independent reviewers (ZA and XM) will read the articles to understand the full text. They will then summarise the quality of the results and divide them into three levels: unequivocal, equivocal and unsupported. These results will then be further classified to arrive at a set of meaningful concepts that are consistent with those of the original manuscript. These similar categories are eventually integrated to produce a comprehensive set of findings that can improve the living experiences of patients with advanced cancer with low SES.

## Assessing the accuracy of results

Ultimately, the accuracy of the findings will be evaluated based on the JBI ConQual approach,<sup>45</sup> which evaluates the reliability and credibility of the findings. The confidence level of the final study results will be classified into four scales of high, moderate, low or very low (online supplemental material 5). The process will be completed by two independent reviewers (ZA and XM), and any disagreement will be resolved through a discussion. The entire protocol process is illustrated in figure 1.

## Reporting of protocol

The findings of the comprehensive review in this qualitative study will be reported in accordance with the Enhancing Transparency in Reporting the Synthesis of Qualitative Research<sup>46</sup> guideline to ensure that the review and research is robust (online supplemental material 6).

## ETHICS AND DISSEMINATION

This systematic review will identify and integrate the life experiences of patients with advanced cancer with low SES to understand the other issues and needs of such a vulnerable population, apart from financial barriers, to provide targeted care to improve patients' quality of life. The findings will be published in a peer-reviewed journal or presented at scientific conferences.

**Contributors** ZA and XM contributed equally to this work. ZA and XM contributed to the conception and design of the study. The introduction was written by ZA and XM. The methods, including literature retrieval, data extraction and appraisal, risk offset assessment and data synthesis, were drafted by HY and LY. In addition, PF, LY and HY assisted in clarifying differences to avoid errors. All authors contributed to the final manuscript and agreed with its publication.

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**Competing interests** None declared.

**Patient consent for publication** Not required.

**Provenance and peer review** Not commissioned; externally peer reviewed.

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# Reporting checklist for protocol of a systematic review and meta-analysis.

Based on the PRISMA-P guidelines.

## Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the PRISMA-Reporting guidelines, and cite them as:

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		Reporting Item	Page Number
<b>Title</b>			
Identification	<a href="#">#1a</a>	Identify the report as a protocol of a systematic review	1
Update	<a href="#">#1b</a>	If the protocol is for an update of a previous systematic review, identify as such	n/a
<b>Registration</b>			
	<a href="#">#2</a>	If registered, provide the name of the registry (such as PROSPERO) and registration number	2
<b>Authors</b>			
Contact	<a href="#">#3a</a>	Provide name, institutional affiliation, e-mail address of all protocol authors; provide physical mailing address of corresponding author	1
Contribution	<a href="#">#3b</a>	Describe contributions of protocol authors and identify the	13

guarantor of the review

## Amendments

<a href="#">#4</a>	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments	n/a
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## Support

Sources	<a href="#">#5a</a>	Indicate sources of financial or other support for the review	13
Sponsor	<a href="#">#5b</a>	Provide name for the review funder and / or sponsor	13
Role of sponsor or funder	<a href="#">#5c</a>	Describe roles of funder(s), sponsor(s), and / or institution(s), if any, in developing the protocol	13

## Introduction

Rationale	<a href="#">#6</a>	Describe the rationale for the review in the context of what is already known	4,5
Objectives	<a href="#">#7</a>	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)	6

## Methods

Eligibility criteria	<a href="#">#8</a>	Specify the study characteristics (such as PICO, study design, setting, time frame) and report characteristics (such as years considered, language, publication status) to be used as criteria for eligibility for the review	6
Information sources	<a href="#">#9</a>	Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature sources) with planned dates of coverage	6
Search strategy	<a href="#">#10</a>	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated	6
Study records - data management	<a href="#">#11a</a>	Describe the mechanism(s) that will be used to manage records and data throughout the review	7
Study records -	<a href="#">#11b</a>	State the process that will be used for selecting studies (such	7

selection process		as two independent reviewers) through each phase of the review (that is, screening, eligibility and inclusion in meta-analysis)	
Study records - data collection process	<a href="#">#11c</a>	Describe planned method of extracting data from reports (such as piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators	7
Data items	<a href="#">#12</a>	List and define all variables for which data will be sought (such as PICO items, funding sources), any pre-planned data assumptions and simplifications	7
Outcomes and prioritization	<a href="#">#13</a>	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale	n/a
Risk of bias in individual studies	<a href="#">#14</a>	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis	7
Data synthesis	<a href="#">#15a</a>	Describe criteria under which study data will be quantitatively synthesised	n/a
Data synthesis	<a href="#">#15b</a>	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data and methods of combining data from studies, including any planned exploration of consistency (such as I <sup>2</sup> , Kendall's $\tau$ )	n/a
Data synthesis	<a href="#">#15c</a>	Describe any proposed additional analyses (such as sensitivity or subgroup analyses, meta-regression)	n/a
Data synthesis	<a href="#">#15d</a>	If quantitative synthesis is not appropriate, describe the type of summary planned	8
Meta-bias(es)	<a href="#">#16</a>	Specify any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies)	n/a
Confidence in cumulative evidence	<a href="#">#17</a>	Describe how the strength of the body of evidence will be assessed (such as GRADE)	8

Notes:



- 1b: n/a. This is a protocol for a new systematic review.
- 4: n/a. This protocol will be published for the first time.
- 15a, 15b, 15c,16: n/a. This is an integration of qualitative evidence, and the criteria for quantitative synthesis do not apply.

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## Supplement material 2: Search strategy

### Example search strategy for PubMed

#1 "Neoplasms"[Mesh] OR "tumor"[Title/Abstract] OR "cancer" [Title/Abstract] OR "carcinoma"[Title/Abstract]

#2 "terminal"[Title/Abstract] OR "advanced"[Title/Abstract] OR "late stage"[Title/Abstract] OR "end stage"[Title/Abstract] OR "end of life"[Title/Abstract] OR "metastatic"[Title/Abstract]

#3 "Social Class"[Mesh] OR "socioeconomic status"[Title/Abstract] OR "socioeconomic"[Title/Abstract] OR "social environment"[Title/Abstract] OR "social support"[Title/Abstract] OR "economic"[Title/Abstract] OR "poor"[Title/Abstract] OR "income"[Title/Abstract] OR "low income"[Title/Abstract] OR "poverty"[Title/Abstract] OR "unemployment"[Title/Abstract] OR "employment"[Title/Abstract]

#4 "Qualitative Research"[Mesh] OR "Focus Groups"[Mesh] OR "Interview as topic"[Mesh] OR "Hermeneutics"[Mesh] OR "Grounded Theory"[Mesh] OR "Personal Narrative"[Mesh] OR "Feminism"[Mesh] OR "Life Change Events"[Mesh] OR "Anthropology, Cultural"[Mesh] OR "qualitative"[Title/Abstract] OR "group focus"[Title/Abstract] OR "groups focus"[Title/Abstract] OR "grounded theory"[Title/Abstract] OR "grounded analysis"[Title/Abstract] OR "grounded analyses"[Title/Abstract] OR (stud\*[Title/Abstract] AND "grounded"[Title/Abstract]) OR "narrative analysis"[Title/Abstract] OR "feminist ethics"[Title/Abstract] OR "ethics, feminist "[Title/Abstract] OR (experience\*[Title/Abstract] AND "life"[Title/Abstract]) OR "analysis, event history"[Title/Abstract] OR "event history analysis"[Title/Abstract] OR experience\*[Title/Abstract] OR "Cultural Anthropology"[Title/Abstract] OR ethnograph\*[Title/Abstract]

#5 #1 AND #2 AND #3 AND #4

**Supplemental material 3:****JBI Critical Assessment Checklist**

<b>Methodology</b>	<b>Yes</b>	<b>No</b>	<b>Unclear</b>	<b>Not applicable</b>
1. Is there congruity between the stated philosophical perspective and the research methodology?				
2. Is there congruity between the research methodology and the research question or objectives?				
3. Is there congruity between the research methodology and the methods used to collect data?				
4. Is there congruity between the research methodology and the representation and analysis of data?				
5. Is there congruity between the research methodology and the interpretation of results?				
6. Is there a statement locating the researcher culturally or theoretically?				
7. Is the influence of the researcher on the research, and vice-versa, addressed?				
8. Are participant, and their voices, adequately represented?				
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?				
10. Do the conclusions drawn in the research report flow from the analysis or interpretation, of the data?				
Overall appraisal:	Include			Exclude
Seek further info				
Comments (Including reason for exclusion):				

**Supplemental material 4:****JBI Qualitative Assessment and Review Instrument Data Extraction**

Study (Name and authors)	Methodology	Methods	Phenomenon of interest	Setting	Geographical location	Cultural	Participants	Data analysis	Author conclusion	Comments

## Supplemental material 5:

### JBI ConQual summary of findings

Systematic review title: Living experiences of advanced cancer patients with low socioeconomic status: Protocol for a systematic review of qualitative evidence.				
Population: Patients with advanced cancer, without limitations on the country or type of cancer.				
Phenomena of interest: The life experiences of patients with advanced cancer, including disease distress, barriers, and strategies in detail.				
Context: The life experiences of advanced cancer patients with low SES.				
Synthesised finding	Type of research	Dependability	Credibility	ConQual score

**Supplemental material 6:****Enhancing transparency in reporting the synthesis of qualitative research: the ENTREQ statement**

No	Item	Guide and description
1	Aim	State the research question the synthesis addresses.
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis and describe the rationale for choice of methodology.
3	Approach to searching	Indicate whether the search was pre-planned or iterative.
4	Inclusion criteria	Specify the inclusion/exclusion criteria.
5	Data sources	Describe the information sources used and when the searches conducted; provide the rationale for using the data sources.
6	Electronic Search strategy	Describe the literature search.
7	Study screening methods	Describe the process of study screening and sifting.
8	Study characteristics	Present the characteristics of the included studies.
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion.
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings.
11	Appraisal items	State the tools, frameworks, and criteria used to appraise the studies or selected findings.
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies?
15	Software	State the computer software used, if any.
16	Number of reviewers	Identify who was involved in coding and analysis.
17	Coding	Describe the process for coding of data.
18	Study comparison	Describe how were comparisons made within and across studies.
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.

<b>20</b>	Quotations	Provide quotations from the primary studies to illustrate themes/constructs and identify whether the quotations were participant quotations of the author's interpretation.
<b>21</b>	Synthesis output	Present rich, compelling, and useful results that go beyond a summary of the primary studies.