

# BMJ Open Positive experiences of family caregivers of patients with chronic heart failure: protocol for a qualitative systematic review and meta-synthesis

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## ABSTRACT

**Introduction** Previous studies have highlighted the experiences of caregivers for patients with chronic heart failure (CHF), specifically focusing on their negative experiences. There are few systematic reviews on the topic to synthesise the positive experiences of family caregivers for patients with CHF. This study will examine how experiences such as developing new skills, strengthening their relationships (between caregivers and recipients) and receiving appreciation from the care recipient assist to improve caregivers' perception of their circumstances.

**Methods and analysis** This review will be conducted in accordance with the Joanna Briggs Institute (JBI) methodology for qualitative systematic reviews. Qualitative and mixed methods studies related to the positive experiences of family caregivers for patients with CHF, reported in English or Chinese and published from inception in the following databases will be included: PubMed, MEDLINE, Embase, Cochrane Library, Web of Science, PsycINFO, CINAHL, Wan Fang Data, China National Knowledge Infrastructure, Chongqing VIP, Chinese Biomedical Literature Database, Open Grey and Deep Blue Library databases. The standard JBI Critical Appraisal Checklist for Qualitative Research will be used by two independent reviewers to appraise the quality of the included studies, and the standardised JBI Qualitative Data Extraction Tool for Qualitative Research will be applied to extract data. The final synthesised findings will be graded according to the ConQual approach for establishing confidence in the output of qualitative research synthesis.

**Ethics and dissemination** Ethical approval is not required as no primary data are being collected. The results will be made available through a peer-reviewed publication.

**PROSPERO registration number** CRD42021282159.

## INTRODUCTION

Heart failure (HF) is a global public health problem. According to data from the *Journal of the American Medical Association* in 2020, HF affects approximately 40 million people worldwide.<sup>1</sup> The 2022 statistics of the American Heart Association suggest that 9.9% of Americans die because of HF.<sup>2</sup> Additionally, the rise in HF cases is placing an increasing

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Two independent reviewers will screen studies for inclusion, extract data and assess quality to avoid personal biases.
- ⇒ This systematic review will be guided by the Joanna Briggs Institute methodology for qualitative systematic reviews to ensure a high level of rigour.
- ⇒ A limitation is that the synthesis findings rely on the data presented in each of the included studies, which may not reflect the full analysis of the original data.

burden on healthcare systems, with total expenditures ranging between 1% and 2% of the total healthcare budget in developed countries.<sup>3 4</sup>

Patients with chronic HF (CHF) often need to receive daily unpaid care from family caregivers to help manage their symptoms because of age, cognitive decline and comorbidities.<sup>5</sup> A family caregiver, also known as an informal or unpaid caregiver, is defined as an individual who cares for a loved one with a short-term or long-term disability or illness.<sup>6</sup> These people play a key role in the management of CHF by monitoring complex medical and self-care regimens, encouraging medication adherence and managing sleep disturbances.<sup>7</sup> The value of the 'free' services provided by family caregivers is estimated at US\$306 billion per year. This figure is almost two times as much as that spent on home care and nursing home services combined.<sup>8</sup> Thus, family caregivers are important resources for patients with CHF in managing and coping with the disease.<sup>9</sup>

In 2018, the 'Research Priorities in Caregiving Summit' convened by the Family Caregiving Institute at the Betty Irene Moore School of Nursing at UC Davis called for increased awareness of informal caregivers and conducting needs assessment, especially for the subjective experience of caregiving.<sup>10</sup>

Some tools tailored to caregivers' positive experiences assessment were developed at least 20–30 years ago, such as Caregiving Appraisal Scale,<sup>11</sup> Caregiver Reaction Assessment,<sup>12</sup> Benefit Finding Scale<sup>13</sup> and Positive Aspects of Caregiving,<sup>14</sup> which mainly focused on experiences of satisfaction, mastery, ideology, finding meaning, personal growth, self-affirmation and outlook on life. However, these tools are dated and fail to yield the appropriate situational or contextual data.<sup>15</sup> In comparison, qualitative approaches are a legitimate way to provide extensive data on how people interpret and act on their needs or symptoms.<sup>16</sup>

To date, qualitative studies<sup>9 17–19</sup> have explored the experiences of family caregivers for patients with CHF. Some<sup>9 17</sup> extracted a few themes of positive experience during caregiving, which were identified to play an important role in buffering the stress of caregivers, promoting caregivers' role adaptation, increasing life satisfaction and enabling individuals to reflect on their situation and seek a sense of 'being' to discover personal ability, talent, strength and courage.<sup>5 20</sup> The limited two qualitative systematic reviews<sup>21 22</sup> focused on the experiences of family caregivers for patients with CHF and were published in 2011 and 2020, respectively. They reviewed studies published from 2003 to 2018 in English databases, and they did not provide clear themes of positive experiences. Therefore, the qualitative information related to positive experiences of family caregivers for patients with CHF is still fragmented and lacks synthesis. Furthermore, two studies<sup>5 23</sup> specifically focused on positive experiences of family caregivers for patients with CHF. They were published in 2019. One<sup>23</sup> was published in a Chinese database, while the other<sup>5</sup> employed a mixed methods design. However, studies about the experience of family caregivers for patients with CHF, either published in Chinese database or designed in mixed methods were not considered in the past qualitative systematic reviews.<sup>21 22</sup>

Therefore, this study will systemically review and synthesise qualitative data in both qualitative and mixed methods studies on positive experiences of family caregivers for patients with CHF in both English and Chinese databases from inception to now. This can offer a bird's eye view of the positive experiences of caregiving and might inform healthcare professionals and policy-makers of targeted guidance or supporting measures for family caregivers.

## METHODS AND ANALYSIS

### Design

The proposed systematic review will be conducted in accordance with the Joanna Briggs Institute (JBI) Methodology for Systematic Reviews of Qualitative Evidence.<sup>24</sup> The review protocol follows the Preferred Reporting Items for Systematic Review and Meta-analysis (PRISMA) Protocols 2015 statement.<sup>25</sup> Any amendments to the protocol will be documented on PROSPERO and in the final manuscript.

### Eligibility criteria

#### Type of participants

Family caregivers of patients with CHF, who are aged  $\geq 18$  years and unpaid, such as sons, spouses, daughters, parents, close friends and other relatives.

#### Phenomena of interest

The positive experiences of family caregivers caring for patients with CHF.

#### Context

In home settings.

#### Types of studies

Qualitative and mixed methods studies in English and Chinese and from databases since inception and designed in the following format: phenomenology, grounded theory, narrative, hermeneutic, action research, field research, feminism, key informant and ethnography. We will only consider the qualitative component of the mixed methods studies. Studies with a quantitative design, case reports, practice guidelines, case series, conference abstracts, expert opinions and book chapters will not be considered.

#### Information sources

The databases to be searched include PubMed, MEDLINE (EBSCOhost), Embase, Cochrane Library, Web of Science, PsycINFO, Cumulative Index to Nursing Allied Health Literature (CINAHL) and four Chinese literature databases: Wan Fang Data, China National Knowledge Infrastructure, Chongqing VIP and Chinese Biomedical Literature Database. Sources of grey literature to be searched include Open Grey and Deep Blue Library databases.

#### Search strategy

The search strategy will aim to locate qualitative studies in English and Chinese, published from inception. First, index terms will be fixed based on an initial search of PubMed and CINAHL databases. Then, a tailored search strategy will be used to search various databases. Reference lists of all included studies will be screened to identify other relevant studies. The PROSPERO registration number is CRD42021282159. The full search strategy is available in online supplemental appendix I.

#### Study selection

Following the search, all identified citations will be collated and uploaded into a NoteExpress database. Duplicates will be removed. First, the titles and abstracts will be screened and assessed by two independent reviewers (PY and QG) considering the noted inclusion criteria; then, the full text of selected citations will be reviewed. The reasons for exclusion of full-text studies will be noted and reported in the systematic review. Finally, all study reference lists that meet the inclusion criteria will be checked to identify other relevant studies. The results will be reported in full

in the final systematic review and presented in a PRISMA flow diagram.<sup>26</sup>

### Assessment of risk of bias

The methodological quality of eligible studies will be critically appraised with the standard JBI Critical Appraisal Checklist for Qualitative Research (online supplemental appendix II),<sup>24 27</sup> which includes 10 items that assess research methodology, philosophical foundation, data collection, analysis method, result validity and research ethics. All items will be evaluated as follows: 'yes', 'no', 'unclear' and 'not applicable'. The evaluation results will be judged by the number of items that meet the standard requirements. Studies will be considered to have a weak rating if  $\leq 6$  of the items were answered 'yes', to have a medium rating if 7–8 of the items were answered 'yes' and to have a strong rating if 9–10 of the items were answered 'yes'.<sup>28</sup> Only studies with at least a medium rating will undergo data extraction and synthesis. Authors of studies will be contacted to obtain missing or additional data for clarification, when required. The two independent reviewers (PY and QG) will remain unaware of each other's assessment. Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer (YF). The results of critical appraisal will be reported in tabular and narrative forms.

### Data extraction

Data will be extracted by two independent reviewers (PY and MM) from the included studies using the standardised JBI Qualitative Data Extraction Tool for Qualitative Research (online supplemental appendix III),<sup>29</sup> which is part of the JBI Qualitative Assessment and Review Instrument that was developed by the JBI based on relevant literature, a panel of experts and pilot-testing.<sup>30</sup> The author information, year of publication, methodology, method of data collection, geographical location, setting, participants (type and number of family caregivers), data analysis, phenomena of interest and findings (such as the themes, subthemes, authors' analytic interpretations and relevant illustrations under the headings 'Results/Findings' relating to the family caregivers' positive experiences), which are referred in the JBI Qualitative Data Extraction Tool for Qualitative Research, will all be labelled. Only unequivocal and credible findings will be included in the synthesis. Any disagreements that arise between the reviewers will be resolved through discussion or with a third reviewer (YF). Authors of studies will be contacted to request missing or additional data, when required. All extracted data will be presented in tabular and narrative forms.

### Data synthesis

The extracted data will be pooled using the JBI meta-aggregation approach.<sup>24</sup> Two independent reviewers (PY and MM) will read the studies and extract findings and the accompanying illustrations. The quality of the extracted findings will be rated on three levels—unequivocal,

equivocal and unsupported—based on the degree of fit or congruency between the data and the accompanying illustration. Only unequivocal and credible findings will be included and coded line by line. Then, categories will be derived based on similarity in meaning. Finally, the synthesised findings will be based on the similarity of meaning in categories, which can be used as a basis for evidence-based practice. Any disagreements that arise between the reviewers will be resolved through discussion or with a third reviewer (YF).

### Assessing the certainty of findings

The synthesised findings were subjected to an assessment, using the JBI ConQual approach,<sup>31</sup> to determine the level of confidence knowledge users may have in the value of the synthesised findings. The level of confidence for each synthesised finding is scored as high, moderate, low or very low based on the dependability of the primary studies from which the synthesised finding was composed and the credibility of the research findings from those studies.

### Patient and public involvement

None.

### Ethics and dissemination

Ethical approval is not required for secondary data analysis. The results will be disseminated through publication in a peer-reviewed journal.

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**Contributors** PY and YF: Conception. PY, QG, MM and YF: Acquisition, analysis and interpretation of data for the work; drafting the manuscript and revising it critically for important intellectual content; final approval of the version to be published; agreeing to be accountable for all aspects of the work; and ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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