

PROTOCOL

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# Factors influencing the positive aspects of caring for dementia patients by family caregivers: a systematic mixed studies review protocol

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## Abstract

**Aim** To provide an overview of the various influencing factors related to the positive aspects of caring for dementia patients by family caregivers.

**Design** A systematic mixed studies review.

**Methods** The Preferred Reporting Items for Systematic Reviews guided this protocol as reported. Peer-reviewed studies published in English from 1997 to the present will be searched via information sources, gray literature, and the following databases: Web of Science, PsycINFO, PubMed, EMBASE, CINAHL and the Cochrane Central Register of Controlled Trials. Eligible trials will also be retrieved from ClinicalTrials.gov and the World Health Organization International Clinical Trials Registry Platform. This will be a mixed studies review. The Mixed Method Appraisal Tool will be used for the mixed-method studies. The Newcastle–Ottawa Scale for case–control and cohort studies and the JBI quality scale for cross-sectional and interventional (i.e., randomized or quasi-experimental) studies will be consulted. The Joanna Briggs Institute Critical Appraisal Checklist for Qualitative Research will be used for the qualitative studies. All the data will be extricated with JBI data extraction tools. The convergent synthesis method will be used in the review.

**Discussion** This systematic review will synthesize and analyze the factors that influence the positive aspects of caring for dementia patients by family caregivers.

**Conclusion** The findings will help decision-makers to adopt more appropriate and effective interventions for caregivers of people with dementia.

**Patient or public contributions** This review protocol will ascertain the factors affecting the mediation of and path to improved caregiving, explore the factors' action mechanisms, and examine the controlling factors to design a more targeted intervention program to improve caregiving, thus improving dementia patients' outcomes and care. Contributions of the findings will include evidence of strategies that address ongoing dementia caregiving issues and the identification of areas for future research.

**Keywords** Positive aspects of caring, Caregivers, Dementia patients, Systematic review protocol

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## Strengths and limitations of this study

- Previous systematic reviews in this field mainly concentrated only on interventions for improving the positive aspects of caregiving, while this review will focus on the impact of influencing factors.
- Existing systematic reviews adopted either the qualitative or quantitative approach; however, this review will consider both approaches and will use correlation analysis, which is lacking in previous studies.
- Only articles reported in the English language will be included, which may overlook relevant data in articles written in other languages.
- The setting of the residence of people with dementia will be community-dwelling, while excluding those with mild stages of disease progression from the out/inpatient departments of geriatric psychiatry and neuropsychiatry, which may not be representative of other dementia populations.

## Introduction

Dementia is an acquired and progressive syndrome of cognitive impairment. Based on current trends of aging, there will be 35.98 million people with dementia in China by 2050 [1]. Most long-term family caregivers do not have the professional training to cope with dementia patients, including their daily life care and mental behavior, which has a great impact on caregivers' physical and mental health and social life [2]. Through research using positive psychology in recent years, scholars have explored the positive aspects of caring (PAC) for dementia patients by different types of caregivers [3, 4]. Although multiple factors affect the PAC, at present, the conclusions of studies on relevant influencing factors are not consistent due to a lack of correlation analysis. In addition, patients' and caregivers' characteristics are difficult to control [2]. This review proposes that interdependent factors influence the PAC for caregivers of dementia patients, such as personal accomplishment and gratification, mutual support, closer family ties and functionality, and personal growth and finding a purpose in life. In light of this, need-based and contextually-relevant interventions are needed to enhance the PAC for caregivers, which will lead to better patient outcomes and care.

## Background

Family caregivers (or informal caregivers) are the major group that cares for patients with dementia. Even though they experience long-term burden, the coexistence of the PAC and stress has been found [5]. The PAC, in which caregiving is considered inspiring and

rewarding, can enrich caregivers' role in caring for others as well as their lived experiences [6], well-being [7], and quality of life [8].

Past studies have found that there are a broad range of factors that influence the PAC, including caregivers, patients, care situations, and care resources [2]. However, inconsistent conclusions regarding caregivers' demographic factors, such as gender, education level, ethnicity, and religion [9–12], factors such as the severity of dementia, mental and behavioral problems, and chronic diseases [12–15], and care situation factors [13, 15–17] have been found. Moreover, most of the relevant literature has focused mainly on care resources for caregivers [3, 8, 13], but the results have been inconsistent and need to be further explored. For instance, in a study involving 642 caregivers of dementia patients in the United States [16], those who used community care services (e.g., home visits by community nurses, daycare care, and support group activities) enhanced their PAC, while a systematic review [18] showed that providing mental health education support to caregivers did not improve their PAC.

To date, systematic reviews on the PAC have focused on measurement instruments and intervention effectiveness [18–22]; however, none have focused on the influencing factors. To address this knowledge gap, the current review will identify the factors affecting the mediation of and path to improved caregiving, explore the factors' action mechanisms, and examine the controlling factors to design a more targeted intervention program to improve caregiving and thus enhance dementia patients' outcomes and care.

## Systematic review

### Aim

This review aims to explore the following questions: (1) What factors influence the positive aspects of caring for dementia patients by family caregivers? (2) Among the factors that influence the positive aspects of caring, what are the facilitators and barriers? (3) What are the dependent variables associated with the positive aspects of caring? (4) Among the factors that indirectly influence the positive aspects of caring, what are the mediators of the dependent variables?

### Design/methodology

A systematic mixed studies review will be chosen for its ability to find as many factors that influence the PAC as possible [23]. This review intends to obtain a broader understanding of the PAC by integrating various approaches and analyzing and synthesizing the data, the findings of which will then be presented.

**Registration**

This study protocol was registered with PROSPERO (CRD42022364445).

**Eligibility criteria**

Both PEOS (population, exposure, outcome, study characteristics) and PICOS (population, phenomenon of interest, context, outcome, study characteristics) search strategy tools will be employed in this review to determine the eligibility criteria, as outlined in the following.

**(1) Population**

In this systematic review, eligible studies will be those that include caregivers of dementia patients as the population. Eligible participants include family caregivers of dementia patients in two settings—not stated or community-dwelling. “Family caregivers” are considered informal (i.e., unpaid) caregivers, such as spouses and adult children, who are currently providing caregiving support to patients with dementia.

**(2) Exposure/phenomenon of interest**

“Exposure” in this systematic review refers to the factors that are recognized as those associated with the PAC and their facilitators and/or barriers. For descriptive or phenomenological qualitative studies, if the objectives’ focus is on the feelings, experiences, and perspectives of the positive aspects of caring for dementia patients, they will be included.

**(3) Context**

Community-dwelling patients diagnosed with dementia, including those who receive day care, will be included [24], whereas those with mild stages of disease progression from the outpatient/inpatient departments of geriatric psychiatry and neuropsychiatry and those receiving care in institutions will be excluded.

**(4) Outcome**

As the outcome of the proposed systematic review cannot be anticipated, the aim of the review will be to identify the influencing factors of the PAC, such as (1) personal accomplishment and gratification in the fulfillment of caregiving for others; (2) mutual support in the caregiver-patient relationship; (3) closer family ties and functionality; and (4) personal growth and finding a purpose in life. In line

with the systematic review questions, various definitions/concepts/domains of the PAC proposed in the articles will be searched. Studies that measured outcomes from various data sources, including self-reporting, will be extracted for further consideration.

**(5) Study characteristics**

Qualitative, cross-sectional, correlational, case-control, cohort, mixed-method, and interventional (i.e., randomized or quasi-experimental) studies with a focus on the factors associated with PAC for dementia caregivers will be included. Mixed-method studies will be considered if relevant data from the quantitative or qualitative components can be included [25]. Due to available resources and feasibility, only articles reported in the English language, with the limitation of the timeframe of 1997 to the present, will be included.

**Information sources**

Peer-reviewed studies found in the electronic bibliographic databases of Medline, Web of Science, PsycINFO, EMBASE, CINAHL and the Cochrane Central Register of Controlled Trials will be searched from 1997, when the topic was first identified [4], to the present. Unpublished information sources in gray literature databases, such as Proquest Dissertations & Theses Global and OpenGrey, as well as the clinical trial databases of ClinicalTrials.gov and the World Health Organization International Clinical Trials Registry Platform, will also be searched for valid studies. The reference lists of the extracted studies will be scanned to confirm the saturation of literature, and the search procedure will be updated to ensure the retrieval of as many eligible studies as possible. In line with the research questions, different types of research studies (e.g., qualitative, quantitative, and mixed-method studies) will be included to gain rich data and better understanding of dementia caregivers’ positive perceived factors [26].

**Search strategy**

The four main search concepts will be factor, dementia, caregiver, and positive aspects. An initial search of the medical subject headings and text words related to the topic in each database and information source will be undertaken to find specific terms related to these concepts, and the titles, abstracts, and index terms used in the articles will be analyzed during the search strategy. Two researchers (LLC, MQZ) will conduct the title, abstract, and full-text screening independently. Table 1 illustrates the search concepts and the list of search

**Table 1** Concepts of the review and the list of search terms that will be used in the literature search

| Factor Terms | Caregiver Terms | Dementia Terms                    | Positive Aspects Terms    |
|--------------|-----------------|-----------------------------------|---------------------------|
| Factor*      | Caregivers/     | Dementia/                         | Positive aspect*          |
| Influenc*    | Carer*          | Alzheimer*                        | Positive experience*      |
| Relate*      | Caregiver*      | Cognitive decline                 | Positive feeling*         |
| Predict*     | Care partner*   | Cognitive impairment/             | Positive dimension*       |
| Relevan*     | Care provider*  | Corticobasal degeneration/        | Positive emotion*         |
| Contribut*   |                 | Creutzfeldt Jakob syndrome/       | Positive psychology/      |
|              |                 | Dementia with Lewy bodies/        | Positive outcome*         |
|              |                 | Early onset dementia              | Caregiving benefit*       |
|              |                 | Frontotemporal dementia           | Caregiving gain*          |
|              |                 | Frontotemporal lobar degeneration | Accomplishment            |
|              |                 | Late onset dementia               | gratification             |
|              |                 | Memory disorders/                 | Autonomy/                 |
|              |                 | Nerve Degeneration/               | Contentment/              |
|              |                 | Neurodegenerative diseases/       | Empowerment               |
|              |                 | Parkinson's dementia              | Reward/                   |
|              |                 | Picks disease/                    | Finding meaning           |
|              |                 | Semantic dementia/                | Intrinsic motivation      |
|              |                 | Senile dementia/                  | Life satisfaction/        |
|              |                 | Vascular dementia                 | Meaning/                  |
|              |                 | Young onset dementia              | Meaningfulness/           |
|              |                 | MCI                               | Motivation/               |
|              |                 |                                   | Optimism/                 |
|              |                 |                                   | Persistence/              |
|              |                 |                                   | Posttraumatic growth/     |
|              |                 |                                   | Resilience/(psychological |
|              |                 |                                   | Satisfaction/             |
|              |                 |                                   | Self-affirmation          |
|              |                 |                                   | Self-confidence/          |
|              |                 |                                   | Self-determination/       |
|              |                 |                                   | Self-efficacy/            |
|              |                 |                                   | Self-evaluation/          |
|              |                 |                                   | Self-perception/          |
|              |                 |                                   | Well-being/               |

terms, and Table 2 shows the results of the search strategy for one of the databases.

#### **Data management and study selection**

Identified articles will be downloaded to Endnote X20, which will be used to categorize, collate, and upload the identified citations; any duplicates found will be removed. Only the authors will have access to this password-protected file. Two researchers (LLC, MQZ) will independently screen the titles and abstracts first, followed by the full texts of the selected articles, to assess them against the inclusion criteria, and those of which do not meet the criteria will be excluded after they have been recorded and reported. If the two researchers encounter any disagreements during each stage of the selection process, they will be discussed until they are resolved. The results of the search process and study inclusion criteria will be shown in a flow diagram following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).

#### **Data extraction**

Guidelines for data extraction will be developed to minimize errors during the extraction procedure and to facilitate the standardization of the process. Two researchers (LLC, MQZ) will independently conduct data extraction using standardized Joanna Briggs Institute (JBI) data extraction tools [27] and the JBI System for the Unified Management of the Assessment and Review of Information software. The systematic review will be comprised of mixed studies (e.g., qualitative, quantitative and mixed-method studies), which will be recorded on a data extraction sheet. The data will include each study's characteristics (i.e., author, country, publication year) and the study design/methods, population/participants, sample sizes, study settings, measurement tools, dependent/independent variables, factors, and primary outcomes. To ensure the accuracy of the data extraction, the eligible studies' titles and abstracts will first be screened by two researchers (LLC, MQZ) independently for review. Any discrepancies will be resolved by a third researcher (JYZ). All the results will be presented and verified using tools such as forms and figures; for example, PRISMA flow-chart, data extraction form, and quality assessment form.

**Table 2** Search strategy and results in PubMed

| Number | Search Terms  |            |
|--------|---|------------|
| #1     | Factor* OR Influen* OR Relate* OR Predict* OR Relevan* OR Contribut*  | 12,658,232 |
| #2     | Caregivers [MeSH Terms] OR Carer* OR Caregiver* OR Care partner* OR Care provider*  | 360,139    |
| #3     | Dementia [MeSH Terms] OR Corticobasal degeneration [MeSH Terms] OR Creutzfeldt Jakob syndrome [MeSH Terms] OR Frontotemporal dementia [MeSH Terms] OR Frontotemporal lobar degeneration [MeSH Terms] OR Memory disorders [MeSH Terms] OR Nerve Degeneration [MeSH Terms] OR Neurodegenerative diseases [MeSH Terms] OR Vascular dementia [MeSH Terms] OR Cognitive decline OR Late onset dementia OR Dementia with Lewy bodies OR Early onset dementia OR Cognitive impairment OR Alzheimer* OR Parkinson's dementia OR Picks disease OR Semantic dementia OR Senile dementia OR Young onset dementia OR MCI  | 675,671    |
| #4     | Empowerment [MeSH Terms] OR Reward [MeSH Terms] OR Motivation [MeSH Terms] OR Optimism [MeSH Terms] OR Resilience psychological [MeSH Terms] OR Self-efficacy [MeSH Terms] OR Positive psychology [MeSH Terms] OR Posttraumatic growth [MeSH Terms] OR Positive aspect* OR Positive experience* OR Positive feeling* OR Positive dimension* OR Positive emotion* OR Positive outcome* OR Caregiving benefit* OR Caregiving gain* OR Accomplishment gratification OR Autonomy OR Contentment OR Finding meaning OR Intrinsic motivation OR Meaning OR Meaningfulness OR Persistence OR Satisfaction OR Self-affirmation OR Self-confidence OR Self-determination OR Self-evaluation OR Self-perception OR Well-being | 10,774,883 |
| #5     | #1 AND #2 AND #3 AND #4   | 11,136     |
| #6     | Limit #5 to (English language and publication date "from 1997 to the present")  | 10,379     |
| #7     | Limit #6 to (observational study)   | 195        |
| #8     | qualitative* OR phenomenology OR observation OR interview*  | 4,724,326  |
| #9     | #6 and #8   | 3,708      |
| #10    | #9 or #7  | 3,823      |

For the quantitative data, raw data will include specific details about the participants, study methods, and outcomes of significance. The qualitative data will include details such as population, setting, culture, geographic location, study methods, and the phenomena of interest relevant to the aim of the systematic review. In the mixed-method studies, the factors and their perceived influence will be coded and subsequently recorded on the data extraction sheet. All extracted findings will be categorized based on the literature. When extracting the findings, the exact numbers and/or words will be reported without interpreting the data. If necessary, the authors of the eligible papers will be contacted to request missing or additional data for clarification.

#### Quality appraisal assessment

After establishing the final list of references, the mixed studies selected will be critically assessed by two researchers (LLC, MQZ) independently. Prior to inclusion in the systematic review, the Newcastle–Ottawa Scale for case–control and cohort studies and the JBI quality scale for cross-sectional studies [28] and interventional studies (i.e., randomized or quasi-experimental) will be consulted. The Joanna Briggs Institute Critical Appraisal Checklist for Qualitative Research will be used for the qualitative studies [29–32]. For the mixed studies, the Mixed Methods Appraisal Tool will be used [33]. All the appraisal tools included will answer questions with either “yes”, “no”, “unclear”, “not applicable”, or “can’t tell”.

The quality appraisal information was tabulated along with the corresponding studies and informs the discussion of the quality of the evidence base on this topic.

The eligible studies will be randomly selected by drawing lots, and then allocated to two researchers (LLC, MQZ) for quality appraisal assessment. Using Covidence functionality, inter-rater reliability for overlapping articles will be calculated. A “substantial” threshold of Kappa’s Cohen 0.61–0.80 will be set. Any disagreements encountered by the two researchers (LLC, MQZ) will be resolved through discussion or by a third researcher (JYZ).

#### Synthesis of results

According to the JBI [34], the convergent synthesis method will be used in the study, which is based on the comprehensive consideration of the core ideas of the realist integral method and the Bayesian method. Using this method, the results obtained by different research methods are integrated separately, and then the results of quantitative synthesis are transformed into qualitative descriptions and combined with the results of qualitative synthesis. This process is comprised of three steps:

- (1) Extract quantitative and qualitative research data.
- (2) Convert quantitative integration results into qualitative descriptions. This process mainly extracts data from quantitative research and translates or converts it into text descriptions. The conversion

data types mainly include descriptive statistics (such as mean or percentage), data obtained using clustering or factor analysis, data derived from estimates of the variance components of a temporal or longitudinal data model, and data derived from examining associations and relationships using inferential statistics (such as linear or logistic regression analysis).

- (3) Combine the qualitative descriptions with the qualitative integration results. In this step, the integration category is determined, and then the theme is summarized to get the final integration results. Quantitative integration results and qualitative integration results involve different aspects or levels of related research, and the two can neither confirm nor refute each other, but only complement each other.

Finally, thematic analysis, including familiarization with the data, initial coding, searching for themes, reviewing themes, naming, and reporting, will be conducted to summarize the qualitative data.

#### Validity and reliability/rigor

To maintain rigor, a systematic review process will be followed [35]. The accuracy of the data (i.e., descriptive validity) will be maintained by the comprehensiveness of the search strategy and keeping a clear trail of search decisions. Interpretive validity will be maintained by the primary researchers' viewpoints. Two reviewers will extract the data without interpretation, integrating all the study results as evenly as possible and considering the quality assessment to ensure that the conclusions were not overstated [36]. The credibility of the data interpretations (i.e., theoretical validity) will be maintained by keeping analytical memos of the interpretations and regular team discussions about the outputs of the synthesis. Finally, the utility and transferability of the findings (i.e., pragmatic validity) will be enhanced by providing data extraction tables, including the contexts of the studies, which will allow readers to judge the usefulness of the findings of the setting [36].

#### Discussion

This systematic mixed studies review protocol, as reported by the PRISMA-P (for protocols) statement, will summarize the evidence of factors that influence the positive aspects of caring for dementia patients by family caregivers. Both PICOS and PEOS search strategy tools will be used to identify the eligibility criteria for the qualitative, quantitative, and mixed-methods studies to be included, and more search terms will be employed

for each concept in the search strategy to obtain a more holistic and extensive systematic review. For instance, for the search concept "factor", the terms "antecedent", "barrier", "facilitator", and "motivator", which have been used in different studies, will be selected. Likewise, for the search concept "positive aspects", a variety of definitions, concepts, and domains of the PAC proposed in previous articles will be searched, such as "positive experiences", "positive feelings", "caregiving benefits", and "caregiving gains".

Prior systematic reviews in this field mainly concentrated on interventions for improving the PAC while rarely focusing on the impact of influencing factors. Moreover, most of the existing systematic reviews adopted only qualitative or quantitative approaches rather than considering both. This review protocol aims to identify various categories of factors that influence the PAC to help decision-makers adopt more appropriate and effective interventions that will boost caregivers' well-being. The final comprehensive systematic review based on the results of this protocol will then be carried out, and the findings are expected to make contributions to existing research.

#### Conclusion

The challenges identified in the final review will help clinical nursing scholars to plan strategies for improving the PAC for caregivers of dementia patients and motivate them to further pursue research in this area. Recommendations for improving dementia care and caregiving will also be made to explore further support systems and effective interventions based on the study's findings.

#### Acknowledgements

Not applicable.

#### Authors' contributions

All authors read and approved the final manuscript.

#### Funding

This review protocol was supported by the Zunyi Science and Technology Project (funding Ref. No. HZ-202079; Development and application of a PAC model-based intelligent care support system for positive aspects among caregivers of people with cognitive dysfunction), the People's Republic of China. This review protocol was also supported by the 2023 Zhuhai Social Development Science and Technology Project (funding Ref. No. 202301; Research on the Collaborative Mechanism and Implementation of Cross border Elderly Care Services in the Guangdong Hong Kong Macao Greater Bay Area), the People's Republic of China.

#### Availability of data and materials

Not applicable.

#### Declarations

#### Ethics approval and consent to participate

Not applicable.

**Consent for publication**

Not applicable.

**Competing interests**

The authors declare that they have no competing interests.

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Received: 22 March 2023 Accepted: 18 August 2024

Published online: 28 September 2024

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