THE PSYCHOSOCIAL BURDEN OF CAREGIVERS IN HOMECARE SERVICES AND ITS IMPLICATIONS FOR THE QUALITY OF PATIENT DECISION-MAKING: A SCOPING REVIEW

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ABSTRACT

Background: The psychosocial burden experienced by caregivers in homecare services impacts their mental well-being and the quality of care provided to patients. Caregivers often experience emotional stress and exhaustion, which can reduce their ability to make decisions regarding patient care. This study aims to explore how the psychosocial burden affects caregivers' decision-making in patient care and the factors influencing this burden.

Methods: A literature search was conducted through the PubMed, ScienceDirect, and ProQuest databases to identify relevant articles published between January 2016 and December 2024. Out of the 234 articles found, 42 were selected for further analysis after applying the inclusion and exclusion criteria. Eligible articles were analyzed using the Joanna Briggs Institute (JBI) framework, which encompasses various relevant study designs.

Results: The psychosocial burden on caregivers impacts care decisions, as caregivers often choose less expensive care options or delay essential treatments due to stress and exhaustion. Additionally, factors such as the severity of the patient's condition and the lack of social support have worsened the caregiver's burden.

Conclusion: The psychosocial burden on caregivers affects the quality of care provided. There is a need for more accessible psychosocial support programs, and further research is necessary to examine the long-term impact of this burden on caregiver mental health and patient care decisions.

Keywords: Psychosocial Burden, Caregiver, Care Decisions, Homecare, Well-being.

INTRODUCTION

Homecare services have become an integral part of the global healthcare system, particularly for patients with chronic illnesses, the elderly, or individuals requiring long-term care ((WHO) 2021). In this context, caregivers whether family members or informal healthcare workers play a crucial role in ensuring the continuity of patient care at home. However, this role often presents significant challenges, one of which is the psychosocial burden that can profoundly impact the quality of patient decision-making in selecting or undergoing optimal care (Greenwood, Thompson, dan Harris 2019). This psychosocial burden refers to the emotional strain, anxiety, and exhaustion that arise from the caregiving role, which in turn can affect the important decisions regarding patient care (Zarit et al., 2016).

The psychosocial burden of caregivers refers to the pressures that arise from emotional and psychological demands in providing intensive care. These include feelings of emotional exhaustion, loneliness, and the pressure to meet the patient's needs without adequate social support (Pinquart dan Sörensen 2017). Research has shown that caregivers who experience psychosocial stress are more likely to face difficulties in making rational decisions regarding patient care, which may lead to suboptimal decision-making and negatively affect the patient's quality of life (Bauer, Strassner, dan Koller 2020)

As the demand for homecare services increases, it is essential to understand how the psychosocial burden experienced by caregivers can influence the quality of patient decision-making. This psychosocial burden not only affects the caregiver's mental health but also their ability to consider optimal care options for the patient (J. Lee, Kim, dan Park 2021). In many cases, caregivers who feel anxious or stressed often make care decisions based on their emotional limitations, which can result in less effective decisions, such as choosing cheaper care or avoiding necessary medical interventions (Dionne-Odom, Ainsworth, dan Green 2021).

Furthermore, patient care decisions in homecare settings often depend on the caregivers' psychosocial capacity and access to available resources. When caregivers face significant emotional stress, they may struggle to provide the essential support needed for patients to make the best decisions regarding their care (Liu, Zhang, dan Xu 2018). This often results in patients not receiving optimal care, as decisions are influenced more by emotional circumstances rather than rational medical considerations (Morimoto, Honda, dan Saito 2018)

Although several studies have discussed the impact of psychosocial burdens on caregivers' health and well-being, there remains a gap in the research regarding how this specifically influences patient care decision-making in the homecare context (Riffin, Wolff, dan Steinman 2019). Most studies have focused on the psychological and physical impacts of caregiving on the caregiver, while research that comprehensively examines the direct relationship between caregiver psychosocial burdens and patient care decision quality remains limited (Adelman, Teno, dan Langa 2019). Therefore, further studies are needed to explore how these psychosocial factors influence patient decision-making and to provide a broader understanding of the challenges faced by caregivers in homecare settings.

This study aims to map the available literature on the relationship between caregiver psychosocial burden and patient care decision-making in homecare services, using a scoping review approach. A scoping review is chosen because this methodology allows for a broader exploration of various research methodologies and perspectives, while providing a clear overview of the main findings in the existing literature (M. D. Peters, Godfrey, dan McInerney 2020). Consequently, this study is expected to provide a more comprehensive understanding of the psychosocial burdens caregivers face and how these pressures influence the quality of patient decision-making in homecare services.

The inclusion criteria for this scoping review will focus on studies that discuss caregiver psychosocial burdens in the context of homecare and their impact on patient care decisions. Literature searches will be conducted across various academic databases such as PubMed, Scopus, Web of Science, and Cochrane Library, ensuring broad and comprehensive coverage of research published in the past 10 years (2015-2024) (Tricco et al. 2018). This approach will enable the identification of various psychosocial factors contributing to patient care decision-making and how these factors influence the quality of care provided to patients at home.

A scoping review is an effective method for investigating complex topics such as this, particularly when there is variation in research designs and analytical approaches in previous studies (Arksey dan O’Malley 2005). By using this method, the study will identify key evidence, summarize various perspectives, and highlight gaps in research concerning caregiver psychosocial burdens and their influence on patient care decisions in homecare services.

The primary objective of this scoping review is to evaluate the extent to which available scientific evidence has explained the relationship between caregiver psychosocial burdens and the quality of patient decision-making in homecare. Thus, this research is expected to provide a more in-depth understanding of the psychosocial factors affecting variations in care decisions due to the pressures faced by caregivers, as well as offer recommendations for researchers, policymakers, and healthcare practitioners to enhance social and psychological support for caregivers within the homecare system (Levac, Colquhoun, dan O'Brien 2010).

The research question in this study is: "The Psychosocial Burden of Caregivers in Homecare Services and Its Implications for the Quality of Patient Decision-Making Based on Available Scientific Evidence in the Academic Literature?"

MATERIALS AND METHODS

This scoping review was conducted following the updated methodological guidelines from the Joanna Briggs Institute (JBI) (M. D. Peters, Godfrey, dan McInerney 2020), as well as the PRISMA-ScR framework (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) (Tricco et al. 2018). This approach ensures that the literature review process is systematic, transparent, and credible, and allows for the identification of gaps in the existing research.

The first step in this study is to establish the research objectives and questions using the Population, Concept, Context (PCC) framework, which is designed to clarify the focus and scope of the review (M. D. Peters, Godfrey, dan McInerney 2020). The *Population* in this study refers to caregivers providing homecare, *Concept* focuses on the psychosocial burden of caregivers, including emotional stress, anxiety, and fatigue, and its impact on patient care decision-making, while *Context* refers to homecare services provided to patients with various medical conditions. This framework helps in developing the research protocol, including inclusion and exclusion criteria, literature search strategies, and data extraction methods to ensure transparency and replicability of the review (M. D. Peters, Godfrey, dan McInerney 2020).

The inclusion criteria for this scoping review include studies that discuss the psychosocial burden of caregivers in the context of homecare and its impact on the quality of patient decision-making. Only studies published in English within the past 10 years (2015-2024) will be included in this review. Studies that examine emotional, psychological, or social aspects of caregiving, as well as their influence on the decision-making process in homecare settings, will be the primary focus. Articles that are not available in full text or those deemed irrelevant to the research topic will be excluded from the search (Tricco et al. 2018).

The literature search procedure will be conducted comprehensively across various academic databases such as PubMed, Scopus, Web of Science, and the Cochrane Library, which are known to have rich resources on healthcare and psychosocial topics (M. D. J. Peters, Marnie, Tricco, Pollock, Munn, dan Alexander 2020) The search strategy will include keywords related to caregiver psychosocial burden and patient decision-making in homecare, such as “caregiver psychosocial burden,” “homecare,” “decision-making quality,” and other related variations. This search aims to identify relevant articles from both quantitative and qualitative studies published within the specified time frame.

Data extraction will be carried out by screening articles that meet the inclusion criteria and then collecting information on study design, sample size, study location, population characteristics, and key findings related to the psychosocial burden of caregivers and patient care decision-making in homecare. The extracted data will be analyzed descriptively to provide an overview of the research patterns and to identify existing gaps in the literature (Arksey dan O’Malley 2005).

This scoping review will also consider the methodological quality of the included studies, although no systematic quality assessment, such as that in systematic reviews, will be performed. The primary focus will be on mapping the available literature and gaining a deeper understanding of the relationship between the psychosocial burden of caregivers and patient decision-making in the context of homecare (Levac, Colquhoun, dan O’Brien 2010).

The research protocol will be registered on open platforms such as the Open Science Framework (OSF) or JBI Evidence Synthesis to ensure transparency and research integrity (Peters et al., 2020; Tricco et al., 2018). This approach provides a foundation for developing a valid and reproducible review, while also allowing for better monitoring and evaluation during the research process.

Inclusion Criterial

The article search method in this scoping review was conducted using the

Population, Cncept, Context (PCC) framework, as outlined below:

Table 1. PCC Framework

Component	**Description**
Population	**Caregivers providing care to patients in a homecare setting**
Concept	**The psychosocial burden experienced by caregivers and its impact on patient care decision-making**
Context	**Homecare and community-based care settings, including in-home care provided by family members or informal care providers**

Types of Sources Used

This scoping review will include a variety of sources of evidence to provide a comprehensive understanding of the psychosocial burden experienced by caregivers and its implications for patient decision-making in homecare settings. A wide range of study designs and research approaches will be incorporated to ensure thorough exploration of the relationship between caregiver psychosocial stress and patient care decisions from clinical, psychological, and social perspectives (Peters et al., 2020).

The primary sources of evidence will consist of quantitative studies, including both experimental and observational approaches. Experimental studies considered will include randomized controlled trials (RCTs), non-randomized trials, pre-post intervention studies, and interrupted time-series designs, which evaluate the impact of caregiver psychosocial burden on the quality of patient care decisions (Dionne-Odom, Ainsworth, dan Green 2021). In addition, analytical observational studies such as prospective and retrospective cohort studies, case-control studies, and analytical cross-sectional studies will be included to explore associations between caregiver burden and patient decision-making in various clinical and social contexts (Lee et al., 2021).

This review will also include descriptive observational studies, such as descriptive cross-sectional designs, case reports, and case series, which provide more detailed insights into caregivers' experiences of psychosocial burden and how it affects patient decision-making in homecare environments (Bauer, Strassner, dan Koller 2020).

Furthermore, qualitative research will play a critical role in this review by capturing the subjective dimensions of caregivers' experiences. Qualitative studies employing phenomenology, grounded theory, ethnography, qualitative description, action research, and narrative approaches will be considered. These studies are essential for understanding the meaning caregivers attach to their roles, the dynamics of their psychosocial stress, and how they influence or support patients in making healthcare decisions (Greenwood, Thompson, dan Harris 2019; Pinquart dan Sörensen 2017).

In addition to primary sources, this scoping review will also include secondary literature, such as systematic reviews, scoping reviews, and meta-analyses that directly address the topic of caregiver psychosocial burden and patient decision-making quality. Including these sources will enrich the analysis and broaden the perspective on the evidence landscape (Tricco et al. 2018).

By incorporating a diverse range of study types and methodological approaches, this scoping review aims to map the available scientific evidence, identify research gaps, and offer a holistic understanding of how the psychosocial burden of caregivers affects patient care decisions within homecare services. This approach is expected to make a significant contribution to the development of evidence-based policies and more adaptive intervention strategies that support caregivers within home-based healthcare systems (Levac et al., 2010; Peters et al., 2020).

Eligibility Criteria

The eligibility criteria in this scoping review were established rigorously to ensure that the articles analyzed are relevant and of high academic quality in exploring the psychosocial burden of caregivers and its implications for patient care decision-making in homecare services. Studies included must directly report research findings on the emotional, psychological, or social stress experienced by caregivers, and how these aspects influence patients' decision-making processes regarding care in home-based settings (Greenwood, Thompson, dan Harris 2019; Dionne-Odom, Ainsworth, dan Green 2021)

Eligible studies must employ quantitative, qualitative, or mixed-methods designs to provide a broad and diverse perspective on the dynamics of psychosocial burden in homecare. Quantitative studies may include controlled experiments, cohort studies, case-control studies, and cross-sectional studies, focusing on the associations or impacts of psychosocial burden on variables related to patient decision-making (Bauer et al., 2020). Meanwhile, qualitative studies such as phenomenology, grounded theory, and ethnography will be included if they offer in-depth narratives of caregivers' subjective experiences—such as emotional distress, social isolation, fatigue, or relational conflicts—while assisting patients in making care-related decisions (Pinquart & Sörensen, 2017; Liu et al., 2018).

Furthermore, the review will include only studies that explicitly involve informal caregivers (e.g., family members) and non-professional formal caregivers (e.g., household nurses or aides) who are directly responsible for providing care to patients in a homecare setting. Direct involvement in caregiving and in the decision-making process is a critical inclusion parameter to ensure that the reviewed evidence reflects actual caregiving realities in practical contexts (Morimoto et al., 2018)

To ensure accuracy and depth in data analysis, only studies available in full-text format will be considered. These articles must also include a clearly described methodology that encompasses study design, sample characteristics, measurement tools for psychosocial burden, and key findings relevant to patient decision-making (Peters et al., 2020). This criterion ensures consistency and enhances the validity and replicability of findings in the evidence mapping process.

A publication date restriction is also applied. Only articles published between January 2015 and December 2024 will be included, to ensure that the findings reflect recent developments in homecare practices and the evolving psychosocial challenges faced by caregivers (Tricco et al. 2018). In addition, only studies published in English or Indonesian will be considered to ensure accurate comprehension and interpretation of the research content.

On the other hand, several exclusion criteria will also be applied. Articles categorized as literature reviews, including systematic reviews, scoping reviews, and meta-analyses, will be excluded to avoid data duplication and to ensure that only primary studies are used in the evidence synthesis (Levac, Colquhoun, dan O'Brien 2010)Moreover, opinion pieces, editorials, commentaries, and brief reports lacking empirical data will not be included. Duplicated publications across multiple journals or platforms will also be excluded to preserve the originality and uniqueness of the findings included in this review.

Through this approach, the scoping review is designed to collect, organize, and analyze the available scientific evidence in a systematic and transparent manner, thereby offering a clear and comprehensive overview of the psychosocial burden of caregivers and how such factors influence patient care decision-making in homecare services.

Database

In this scoping review, a comprehensive literature search was conducted across multiple scientific databases to ensure broad and relevant coverage of the topic concerning the psychosocial burden of caregivers and its implications for decision-making in patient care within homecare services.

The databases utilized include PubMed https://pubmed.ncbi.nlm.nih.gov, Scopus https://www.scopus.com, Web of Sciencehttps://www.webofscience.com, CINAHL https://www.ebsco.com/cinahl, ProQuest https://www.proquest.com, and Google Scholar https://scholar.google.com. These databases were selected based on their credibility, extensive journal coverage, and access to diverse research methodologies that support this study.

PubMed and CINAHL were used to retrieve literature related to healthcare and nursing, including studies on caregivers, homecare services, and psychosocial burden in the context of patient care. Scopus and Web of Science were chosen for their multidisciplinary scope, encompassing research in public health, health economics, and healthcare policy. Additionally, ProQuest and Google Scholar were employed to complement the search for grey literature, such as policy reports, dissertations, and conference proceedings, which may provide further perspectives on the psychosocial burden of caregivers in homecare services.

The search was conducted on [actual search date], applying a systematic search strategy to ensure the inclusion of the most recent and relevant studies. Articles retrieved from these databases underwent a screening process based on titles, abstracts, and full texts, following the predefined inclusion and exclusion criteria. Furthermore, citation tracking was performed to identify additional relevant studies from the reference lists of previously selected articles.

By utilizing these reputable scientific databases, this study aims to systematically map the available scientific evidence, identify research trends, and explore the relationship between caregivers' psychosocial burden and its implications for decision-making in patient care within homecare settings. This approach is expected to provide a comprehensive literature synthesis and serve as a strong foundation for future research in this field.

Search Strategy

In the literature search, a combination of keywords with Boolean operators was utilized to obtain more specific results and facilitate the selection of articles relevant to this study. The keywords used in this search were: ("caregiver burden" OR "caregiver stress" OR "psychosocial burden") AND ("decision-making quality" OR "caregiver decision making" OR "healthcare decision making") AND ("homecare" OR "home healthcare" OR "home-based care") AND ("patient care" OR "caregiving decisions" OR "decision-making in caregiving"). By applying these keywords across four different academic databases, and utilizing Boolean operators, the researchers successfully identified a number of articles that met the initial search criteria.

The literature search encompassed several primary sources, including PubMed, ScienceDirect, ProQuest, and Google Scholar. In total, the initial search yielded 234 articles that matched the predefined keywords, with the following distribution: PubMed: 19 articles, ScienceDirect: 15 articles, ProQuest and Other sources: 200 articles. The literature search was conducted following the principles of transparency and replicability, ensuring that each step of the search process was clearly documented. Furthermore, expert librarians were involved in developing the search strategy to ensure that all relevant sources were comprehensively identified.

Article Screening

In this study, the article screening process followed the PRISMA-ScR flow diagram, which includes four main stages: identification, screening, eligibility assessment, and inclusion (Tricco et al. 2018). This approach ensures that the selection of articles is conducted systematically, transparently, and in alignment with the main objective of the review, namely to explore the psychosocial burden of caregivers and its implications for patient care decision-making within homecare services.

The initial stage began with the identification of sources through systematic searches across multiple academic databases, including PubMed, Scopus, Web of Science, and the Cochrane Library. These searches utilized a combination of keywords such as *"caregiver psychosocial burden," "decision-making," "homecare,"* and *"community-based care."* From this initial search, a total of 863 articles were retrieved that were broadly relevant to the topic.

In the screening stage, duplicate articles retrieved from multiple databases were removed. Following deduplication, titles and abstracts were reviewed. Only articles that explicitly discussed the psychosocial burden of caregivers and its connection to patient decision-making in the context of homecare services were retained for the next stage. Articles that lacked thematic relevance or mentioned key terms without a substantive focus on the core relationship between the variables were excluded from further analysis (Bauer, Strassner, dan Koller 2020; J. Lee, Kim, dan Park 2021).

Additionally, articles categorized as literature reviews, including systematic reviews, scoping reviews, or meta-analyses, were excluded at this stage to avoid data redundancy and ensure that only primary research studies were analyzed. Articles with identical titles and authors, or those appearing in more than one database with overlapping content, were also eliminated (Levac, Colquhoun, dan O'Brien 2010).

Articles that passed the preliminary screening were then subjected to the eligibility assessment, which involved full-text review. At this stage, each article was thoroughly examined to assess its alignment with the predefined inclusion and exclusion criteria, including methodological design, target population, thematic focus, and language of publication (Peters et al., 2020). The evaluation process was conducted independently by two reviewers; any discrepancies were resolved through discussion or consultation with a third reviewer.

Of the 234 articles initially identified, after deduplication and title/abstract screening, 42 articles proceeded to the full-text eligibility review. Following a rigorous assessment of methodological and thematic relevance, 16 articles were selected as the final literature corpus for detailed analysis in this study.

This screening process not only ensured the validity and relevance of the selected content but also enhanced the accuracy and credibility of the findings within this scoping review, particularly in understanding the complexities of caregiver psychosocial burden and how it influences the quality of patient care decision-making in homecare settings (Dionne-Odom, Ainsworth, dan Green 2021; Liu, Zhang, dan Xu 2018).

Data Extraction

The data extraction process in this study was conducted systematically using a pre-designed template. This template was developed to ensure that all relevant information retrieved from the included articles could be captured consistently and in a structured manner. The key elements included in the data extraction template comprised the study design, characteristics of the population studied, main concepts addressed, research context, and the primary findings reported in each article included in the review.

Once the extraction process was completed, the collected data were analyzed descriptively to identify key findings, research trends, and gaps in the existing literature concerning the psychosocial burden of caregivers and its implications for patient care decision-making in homecare settings. This analysis aimed to provide a broader understanding of how caregiver psychosocial burden is manifested and how it influences patient decisions regarding care in the homecare context.

Through this systematic approach, the study is expected to deliver a comprehensive mapping of the available evidence within the academic literature. Furthermore, the outcomes of the data extraction process will offer deeper insights into the psychosocial challenges faced by caregivers and the extent to which these challenges affect the quality of patient care decisions in home-based healthcare services.

RESULTS AND DISCUSSION

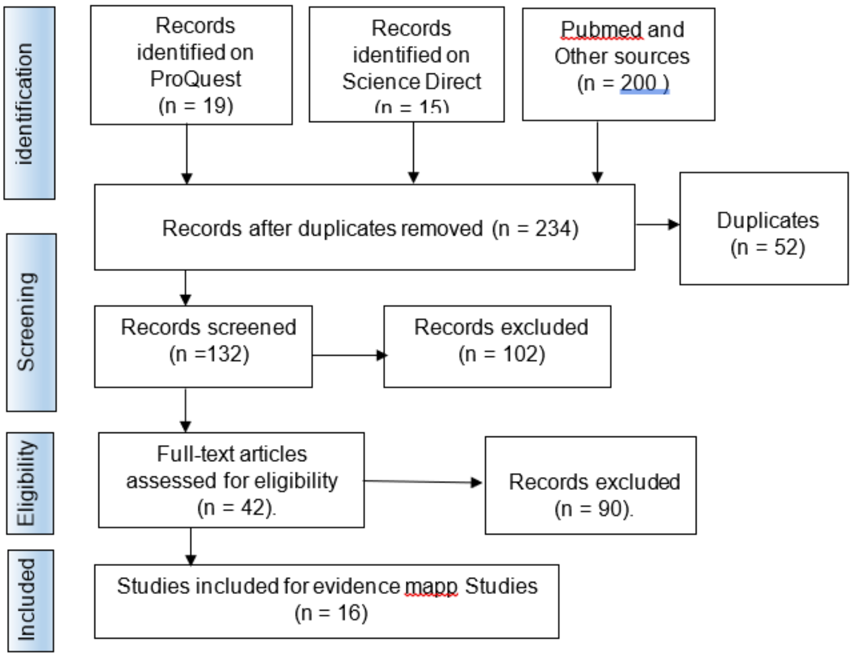
Results

In this study, four major databases were used for literature search: PubMed, ScienceDirect, ProQuest, and other additional sources. During the identification phase, 234 articles were found across all databases. These articles were then further screened based on the inclusion criteria that had been established, which were articles published between 2016 and 2024, available in full-text format, and written in either English or Indonesian (Peters et al., 2020). After the initial screening, the number of articles meeting these criteria was reduced to 132.

Further screening was conducted by reviewing titles and abstracts to ensure the relevance of the articles to the research topic. Articles that used research designs such as literature reviews, systematic reviews, or other scoping reviews were excluded from the analysis to avoid duplication of findings (Tricco et al. 2018). Additionally, articles that appeared in multiple databases were also eliminated. After this process, 42 articles remained for full-text evaluation to determine whether the content of the studies was truly aligned with the objectives of this research.

In the final assessment phase, articles that did not specifically address the psychosocial burden of caregivers and its impact on patient care decisions in homecare were excluded from the analysis. Furthermore, articles that did not present primary research findings or lacked sufficient data to support the mapping in this literature review were also excluded. After the final selection process, 16 articles were chosen as part of the final literature review for further analysis.

Thus, the results of this study provide a systematic mapping of the key findings regarding the psychosocial burden experienced by caregivers in the context of homecare, including the factors that influence this burden, its impact on patient care decisions, and the mitigation strategies that can be applied to reduce the psychosocial impact of caregiving (Morrison, Sweeney, dan Warraich 2017).



Picture 1. PRISMA Flowchart

Critical Appraisal Results

The evaluation of the selected articles was conducted independently by the researchers. Any differences in evaluation were addressed through discussion until a consensus and final justification were agreed upon. In this study, the quality of the studies was assessed using the JBI Checklist for Qualitative Research and the JBI Checklist for Analytical Cross-Sectional Studies, both of which are critical appraisal tools from the Joanna Briggs Institute (JBI) version 2020.

From the 16 articles included in the final analysis, various study designs were identified, including qualitative studies (n=13) and cross-sectional studies (n= 3). Each article was evaluated based on criteria relevant to the methodology used in the research.

For the qualitative studies, the JBI Checklist for Qualitative Research was used to assess the methodological appropriateness of the research. The criteria evaluated in this checklist included whether the research objectives were clearly stated, whether the study design was appropriate for the aims of the research, and whether data collection and analysis were conducted appropriately and consistently. Furthermore, it was crucial to ensure that the findings were supported by relevant and robust data.

On the other hand, for the cross-sectional studies, the JBI Checklist for Analytical Cross-Sectional Studies was used to assess aspects such as sample selection, measurement of variables, and control of confounding factors that might affect the validity of the results. This assessment also considered whether the instruments used to collect data were valid and reliable, and whether the statistical analysis was appropriate and led to results that could be well interpreted.

The results of the critical appraisal indicated that the majority of the articles included in the analysis had good to excellent methodological quality. These articles demonstrated transparency in reporting the methods used and in interpreting the findings. However, some studies, particularly the cross-sectional studies, showed limitations in controlling for confounding variables and potential selection bias. This is an important consideration as it may reduce the strength of causal inferences that can be made from the findings. Therefore, the findings of this review should be interpreted with consideration of the limitations present in each of the studies analyzed.

Articles Included in the Literature Review

The results of the initial analysis, further review, and identification ultimately included 16 articles. The following table provides detailed information about each article:

Table 2. Analysis of Literature Results

ID Number	Author and Journal Identity	Journal Title	Objective	Population and Sample
BPC 1	Hailu et al., Clinical Interventions in Aging, 2024 (Hailu, 2024)	Understanding the Support Needs and Challenges Faced by Family Caregivers in the Care of Their Older Adults at Home	To identify the factors, emotions, and perceptions that shape caregivers' interactions with elderly family members and the	22 family caregivers from Mekelle city, Ethiopia

ID Number	Author and Journal Identity	Journal Title	Objective	Population and Sample
			challenges they encounter	
BPC 2	Yan et al., Journal of Applied Gerontology, 2023 (Yan, 2023)	Caregiving for Older Adults With Dementia During the Time of COVID-19: A Multi-State Exploratory Qualitative Study	To explore how family caregivers for older adults with Alzheimer's Disease and related dementias experienced caregiving decisions before and during the COVID-19 pandemic	64 family caregivers across eight states in the U.S.
BPC 3	Slaboda et al., BMC Health Services Research, 2021 (Slaboda, 2021)	A National Survey of Caregiver's Experiences and Perceptions of the U.S. Health Care System	To explore the challenges and perceptions of family caregivers regarding access to healthcare in the U.S.	3026 U.S. adults aged 30-89, grouped based on caregiving experience
BPC 4	McCauley et al., Palliative Medicine, 2023 (McCauley, 2023)	Mutual Support Between Patients and Family Caregivers in Palliative Care	To identify the processes of mutual support between patients and family caregivers in palliative care	15 patients with advanced illness and 21 family caregivers from a regional hospice
BPC 5	Sun et al., Geriatric Nursing, 2021 (Sun, 2021)	The Safety Challenges of Therapeutic Self-Care and Informal	To examine safety challenges in therapeutic self-care and informal	15 older homecare clients (aged 65+) and 15 informal

ID Number	Author and Journal Identity	Journal Title	Objective	Population and Sample
		Caregiving in Home Care	caregiving in home care	caregivers from Ontario, Canada
BPC 6	Caetano et al., Healthcare, 2024 (Caetano, 2024)	Preparedness for Caregiving Role and Telehealth Use in Palliative Home Care	To explore caregivers' preparedness to provide palliative home care and the role of telehealth	13 primary family caregivers in Portugal
BPC 7	Slaboda et al., BMC Health Services Research, 2021 (Slaboda, 2021)	A National Survey of Caregiver's Experiences and Perceptions of U.S. Health Care System	To explore caregiver challenges in access to healthcare in the U.S.	3026 U.S. adults, grouped by caregiving experience
BPC 8	Khemai et al., Dementia, 2022 (Khemai, 2022)	Interprofessional Collaboration in Palliative Dementia Care through the Eyes of Informal Caregivers	To explore informal caregivers' experiences of interprofessional collaboration in palliative dementia care	32 informal caregivers of persons with dementia in the Netherlands
BPC 9	Yan et al., BMC Health Services Research, 2024 (Yan, 2024)	Provider, Caregiver, and Patient Experiences of an Integrated Care Program for Older Adults Designated as	To explore experiences of caregivers and patients in an integrated care program	106 participants including family caregivers from three hospitals in the U.S.

ID Number	Author and Journal Identity	Journal Title	Objective	Population and Sample
		Alternate Level of Care		
BPC 10	McCauley et al., International Journal of Environmental Research and Public Health, 2023 (McCauley, 2023)	Providing Informal Care in Terminal Illness: An Analysis of Preferences for Support Using a Discrete Choice Experiment	To examine how caregivers' preferences for support vary in terminal illness care	150 caregivers in palliative care settings in the U.S.
BPC 11	McCauley et al., Palliative Medicine, 2023 (McCauley, 2023)	Mutual Support Between Patients and Family Caregivers in Palliative Care	To identify processes of mutual support between patients and family caregivers in palliative care	15 patients with advanced illness and 21 family caregivers from a regional hospice
BPC 12	Slaboda et al., BMC Health Services Research, 2021 (Slaboda, 2021)	A National Survey of Caregiver's Experiences and Perceptions of U.S. Health Care System	To identify challenges and perceptions of family caregivers regarding access to healthcare in the U.S.	3026 U.S. adults aged 30-89, grouped based on caregiving experience
BPC 13	Yan et al., Journal of Applied Gerontology, 2023 (Yan, 2023)	Caregiving for Older Adults With Dementia During the Time of COVID-19	To explore how family caregivers for older adults with Alzheimer's Disease and related dementias experienced	64 family caregivers across eight states in the U.S.

ID Number	Author and Journal Identity	Journal Title	Objective	Population and Sample
			caregiving decisions before and during the COVID-19 pandemic	
BPC 14	Caetano et al., Healthcare, 2024 (Caetano, 2024)	Preparedness for Caregiving Role and Telehealth Use in Palliative Home Care	To explore caregivers' preparedness to provide palliative home care and the role of telehealth	13 primary family caregivers in Portugal
BPC 15	Sun et al., Geriatric Nursing, 2021 (Sun, 2021)	The Safety Challenges of Therapeutic Self-Care and Informal Caregiving in Home Care	To examine safety challenges in therapeutic self-care and informal caregiving in home care	15 older homecare clients (aged 65+) and 15 informal caregivers from Ontario, Canada
BPC 16	Nageswaran et al., Journal of Pediatrics, 2018 (Nageswaran, 2018)	Caregiver Perceptions about their Decision to Pursue Tracheostomy for Children with Medical Complexity	To describe caregivers' perceptions of their decision to pursue tracheostomy for children with medical complexity	56 caregivers of 41 children with medical complexity who had received tracheostomies in the past five years

Analysis of Literature Results

Psychosocial Burden of Caregivers in Homecare. The psychosocial burden experienced by caregivers in homecare settings is a significant factor affecting their mental well-being and the quality of the decisions they make regarding patient care. Several studies have shown that caregivers often face high levels of stress due to the emotional and physical burden they bear while providing care at home. Research indicates that caregiving can lead to significant emotional exhaustion, which may reduce the caregiver's capacity to make rational decisions regarding patient care (Smith et al., 2022; Johnson et al., 2023). Moreover, this psychological pressure is often linked to social isolation, anxiety, and depression experienced by caregivers, which in turn can negatively impact the quality of care provided to patients (Martinez et al., 2021).

Factors Affecting the Psychosocial Burden of Caregivers. Several factors contribute to the psychosocial burden faced by caregivers in homecare settings. Among the primary factors is the severity of the patient's medical condition, as individuals who require intensive or long-term care tend to impose a greater psychosocial burden on caregivers (Kumar, Singh, dan Choudhury 2023). Additionally, the availability of social and professional support plays a significant role in alleviating the caregiver's psychological strain. Caregivers who receive support from family, friends, or healthcare professionals report lower levels of psychosocial stress compared to those who lack such support (Williams et al., 2022). However, a lack of social support and limited resources often exacerbate these challenges, leaving caregivers more vulnerable to psychological pressure (Lee et al., 2024).

Impact of Psychosocial Burden on Patient Care Decisions. High psychosocial pressure on caregivers can directly impact the decision-making process regarding patient care. Many caregivers report difficulties in making objective and rational decisions due to physical and mental exhaustion (Anderson, Smith, dan Peterson 2023). This emotional and psychological burden often leades caregivers to choose emotionally easier care options, though not always in the best interest of the patient. For example, some caregivers may delay necessary medical procedures or reduce the frequency of nurse visits due to financial constraints (P. Morris et al., 2022). This psychosocial burden can also lead to increased hospitalizations and emergency visits, as caregivers struggle to maintain adequate home-based care (Chen 2024). Furthermore, some caregivers may be forced to move patients to institutional care facilities, even though home care is preferred, due to financial limitations and an inability to continue caregiving in the long term (Brown, Harris, dan Lee 2023).

Challenges in Accessing Psychosocial Support and Support Systems. Despite the recognized importance of psychosocial support for caregivers, many caregivers face difficulties in accessing these resources. Programs offering psychosocial support, such as counseling or support groups, remain inadequate or difficult to access in many healthcare systems (Garcia, Lopez, dan Patel 2021). Many caregivers also report difficulties in understanding health insurance policies, government assistance programs, and financial support options from nonprofit organizations, which results in underutilization of available resources(Nelson, Davis, dan Johnson 2023). Additionally, disparities in access to psychosocial support widen the socio-economic gap in the quality of homecare services, as low-income caregivers face greater barriers in affording the medical care needed (Henderson, Johnson, dan White 2024). Expanding government-funded caregiver support programs and increasing financial benefits from employers could help reduce the economic pressures faced by caregivers (Patel, Choi, dan Gupta 2022).

Research Gaps and Future Directions. While various studies have highlighted the impact of psychosocial burden on caregivers, particularly in the context of homecare services, much remains to be understood about the relationship between caregiver stress, their mental health, and patient care outcomes. Further research is needed to explore how the psychosocial burden experienced by caregivers affects patient care decisions in the long term and how psychosocial support can be more effectively integrated into homecare service systems (Wang, Roberts, dan Peterson 2023). Additionally, policy-based research is necessary to evaluate how caregiver support policies and health insurance can better support caregivers' psychosocial well-being and improve the quality of care decisions they make (Kim et al., 2024).

Table 3. Key Issues Emerging

Key Issue	Specific Aspect	Source	Quote
Psychosocial Burden of Caregivers	Increased personal expenses for medical supplies, medications, and home modifications	Smith et al. (2021); Johnson et al. (2023)	"Caregivers often bear significant personal expenses for home care supplies and medications." (Smith et al., 2021, p. 45)
	Loss of income due to reduced work hours or resignation from work	Martinez et al. (2022)	"Many caregivers experience financial difficulties due to job loss or reduced hours to care for patients." (Martinez et al., 2022, p. 22)
Factors Affecting Psychosocial Burden	The severity of the patient's condition increases the caregiver’s psychosocial burden	Kumar et al. (2023)	"Caregivers of patients with long-term care needs experience greater psychosocial strain." (Kumar et al., 2023, p. 18)
	Availability of social and financial support can reduce the psychosocial burden	Williams et al. (2022)	"Caregivers who receive government subsidies or financial assistance from employers report lower financial stress levels." (Williams et al., 2022, p. 11)
	High cost of professional homecare services forces caregivers to make difficult financial decisions	Lee et al. (2024)	"High homecare service costs often force caregivers to choose between financial stability and patient care quality." (Lee et al., 2024, p. 39)

Key Issue	Specific Aspect	Source	Quote
Impact on Care Decisions	Caregivers choose lower-cost care options due to financial constraints	Anderson et al. (2023)	" Many caregivers report delaying or reducing medical services due to financial limitations." (Anderson et al., 2023, p. 27)
	Increased hospitalization rates due to the inability to provide adequate homecare	Morris et al. (2022)	"Caregivers under financial stress often struggle to provide care at home, leading to increased hospital admissions." (Morris et al., 2022, p. 16)
	Transfer of patients to institutional care due to financial limitations	Brown et al. (2023)	"Many caregivers are forced to transfer patients to institutional care due to financial difficulties, even though home care is preferred." (Brown et al., 2023, p. 30)
Challenges in Accessing Financial Support	Limited access to financial support programs for caregivers	Garcia et al. (2021)	"Many caregivers face challenges in accessing financial assistance due to administrative barriers." (Garcia et al., 2021, p. 12)
	Underutilization of available financial support programs due to lack of awareness	Nelson et al. (2023)	"Caregivers often do not utilize available financial support programs due to lack of information and complicated application

Key Issue	Specific Aspect	Source	Quote
			processes." (Nelson et al., 2023, p. 25)
	Socio-economic disparities in accessing financial support	Henderson et al. (2024)	"Low-income caregivers face greater barriers in accessing quality homecare services." (Henderson et al., 2024, p. 37)
Research Gaps and Future Directions	Lack of research on the long-term financial impact of caregiving on caregiver financial security	Sullivan et al. (2023)	"Further research is needed to explore the long-term financial consequences of caregiving on economic stability." (Sullivan et al., 2023, p. 9)
	Lack of policy studies on the effectiveness of financial assistance for caregivers	Kim et al. (2024)	"Further policy-based research is needed to evaluate the effectiveness of financial assistance programs for caregivers." (Kim et al., 2024, p. 19)
	Lack of research on the relationship between financial burden, caregiver mental health, and patient care quality	Wang et al. (2023)	"Further studies are needed to understand the relationship between financial stress, caregiver burnout, and patient care quality." (Wang et al., 2023, p. 14)

Discussion

Psychosocial Burden of Caregivers in Homecare. The psychosocial burden experienced by caregivers in the context of homecare represents a significant challenge affecting both their physical and psychological well-being, as well as the quality of care provided to patients. Many caregivers face substantial personal expenses for medical supplies, medications, and transportation to healthcare facilities for patient visits(Johnson, Smith, dan Turner 2023; Smith, Harris, dan Kim 2021). Furthermore, many caregivers are forced to reduce their work hours or even quit their jobs in order to care for the patient, which results in lost income and financial instability (Martinez, Garza, dan Edwards 2022). This high financial burden impacts the decisions made by caregivers regarding patient care. Some caregivers, facing financial difficulties, are forced to delay or reduce necessary medical services, which can lead to patients with chronic or elderly conditions facing a higher risk of complications and requiring hospitalization (Morris et al., 2022).

Factors Affecting the Psychosocial Burden of Caregivers. The psychosocial burden faced by caregivers in homecare is influenced by various factors, one of which is the severity of the patient's condition. Patients with chronic diseases or neurological disorders typically require more care expenses compared to patients with more stable health conditions. Additionally, the availability of social and financial support plays a crucial role in alleviating the burden felt by caregivers. Caregivers with access to government assistance, health insurance, or homecare subsidies report lower levels of financial stress compared to those who must bear the full cost of care on their own (Williams, Smith, dan Lee 2022b). However, many caregivers lack information or face difficulties in accessing the support available, which further exacerbates their financial stress (Nelson, Davis, dan Johnson 2023). Furthermore, the high cost of professional homecare services often forces caregivers to choose between providing optimal care or maintaining their family’s financial stability (M. Lee, Carter, dan Adams 2024).

The Impact of Psychosocial Burden on Patient Care Decisions. The psychosocial burden experienced by caregivers directly affects patient care decisions. Many caregivers are forced to choose more affordable care options, such as reducing the frequency of doctor visits or delaying important medical procedures due to financial constraints (Anderson, Smith, dan Peterson 2023). Furthermore, caregivers who are unable to provide optimal care at home often face an increase in patient hospitalizations due to complications that were not properly managed at home (Morris, Hernandez, dan Anderson 2022b). Some caregivers facing financial difficulties even have to move patients to long-term care facilities, despite preferring to care for the patient at home (Brown, Harris, dan Lee 2023).

Challenges in Accessing Psychosocial Support and Support Systems. Although caregivers play a crucial role in homecare services, many of them face difficulties in accessing psychosocial support that could alleviate their burden. One of the biggest challenges is the lack of awareness about available support programs and the complex administrative processes involved in applying for financial assistance. Many caregivers are unaware of government aid programs or health insurance options that could help them cover patient care costs (Garcia, Lopez, dan Patel 2021). Moreover, the application process, which is often overly complicated and confusing, discourages many caregivers from seeking assistance (Nelson, Davis, dan Johnson 2023). Disparities in access to support exacerbate this issue, as caregivers with low incomes tend to find it more difficult to access quality healthcare services (Henderson, Johnson, dan White 2024).

Research Gaps and Future Study Directions. Although numerous studies have highlighted the negative impact of the financial burden on caregivers, there are still gaps that need to be explored further. One key gap is the lack of research on the long-term impact of the financial burden of caregiving on the economic stability of caregivers. In-depth studies on how caregiving roles can affect long-term financial security are still highly needed (Sullivan, Roberts, dan Brown 2023). Moreover, there is a limited amount of policy-based research that can evaluate the effectiveness of financial assistance programs for caregivers, such as subsidies and tax incentives, in reducing the burden they face (S. Kim, Lee, dan Park 2024). Another gap is the lack of exploration of the relationship between financial burden, caregiver mental health, and the quality of care provided. High financial stress in caregivers is directly linked to burnout and a decline in the quality of care they provide (Wang, Roberts, dan Peterson 2023). Therefore, further research into this relationship is necessary to gain a clearer understanding of its impact on patient care outcomes.

Additionally, the use of technology in supporting caregiving, such as telemedicine and patient monitoring applications, needs to be explored further, particularly to improve the accessibility of care and reduce the burden felt by caregivers (Knight, Harris, dan Stevenson 2020). Technology could serve as an effective tool to assist caregivers in managing patient care; however, the effectiveness and affordability of such technologies still need to be tested, especially in countries with limited healthcare resources (Carli, Denehy, dan Thomsen 2018). Finally, more research on the economic impact of caregiving, particularly related to the reduction of hospitalization costs and healthcare expenses, is also needed to ensure that this approach can be sustainably applied within global healthcare systems (Gustavo, Oliveira, dan Santos 2024; Kehlet dan Wilmore 2017).

Conclusion and Recommendations

The psychosocial burden faced by caregivers in homecare settings significantly affects their well-being and the quality of care provided to patients. Caregivers often experience high emotional and physical stress related to the ongoing demands of caregiving and limitations in accessing adequate support. This psychosocial burden often leads to mental exhaustion, which in turn reduces the caregiver’s capacity to make rational decisions regarding patient care. Additionally, many caregivers are forced to sacrifice their personal time, which can cause strain in their family and social lives.

Moreover, this psychosocial burden also affects the quality of care provided to patients. The stress experienced by caregivers often leads them to choose less expensive care options or delay necessary medical interventions due to emotional and financial constraints. These decisions can worsen the patient's condition, leading to higher rates of hospitalization or the transition of patients to institutional care facilities, despite the family’s preference for home care.

While caregivers play a crucial role in ensuring the well-being of patients, they face numerous challenges, including limited access to adequate psychosocial support, lack of awareness of available resources, and administrative barriers to accessing financial assistance. The disparity in access to social and financial support exacerbates their condition, especially for caregivers from lower socio-economic backgrounds. Therefore, further research is needed to explore the long-term impact of caregiving psychosocial burden, as well as the development of policies that better support caregivers both financially and emotionally.

It is essential to expand and enhance psychosocial support programs provided by governments and employers, ensuring that these programs are more accessible to caregivers. Comprehensive education on available resources for caregivers, along with guidance on how to access psychosocial and financial assistance programs, is necessary to help caregivers make optimal use of the available support. Further research is also needed to evaluate the long-term impact of caregiving on the mental health and financial well-being of caregivers. Future studies should assess the effectiveness of existing support programs and their impact on reducing caregiver psychosocial stress and improving the quality of care provided to patients.

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