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Scoping Review of Research on the Preparedness of Family Caregivers for Patients with Chronic Diseases

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Abstract

Objective: To conduct a scoping review of studies on the level and influencing factors of preparedness among family caregivers of patients with chronic diseases, and to provide evidence for developing targeted interventions to improve the quality of family care. **Methods:** Guided by the scoping review methodological framework, a systematic search was conducted in 9 databases including CNKI, Wanfang Data, VIP, CBM, PubMed, Embase, Web of Science, CINAHL, and Cochrane Library from inception to April 2025. Two researchers independently screened the literature, extracted data, and synthesized the findings. **Results:** A total of 17 articles (8 in Chinese, 9 in English) were included. The results showed that the overall preparedness level of family caregivers for chronic disease patients was moderate to low. The Caregiver Preparedness Scale was the most commonly used assessment tool. Influencing factors were categorized into three domains: caregiver-related factors (e.g., demographic characteristics, caregiving experience, knowledge level, psychological status), patient-related factors (e.g., disease severity, self-care ability), and social support and environmental factors (e.g., co-caregivers, social support, healthcare accessibility). **Conclusion:** Caregiver preparedness is a key variable affecting the quality and outcomes of care for chronic disease patients, and is influenced by multi-level factors. Future research should develop more disease-specific assessment tools, conduct longitudinal and interventional studies to build an evidence-based systematic support system, thereby effectively enhancing caregiver preparedness, alleviating burden, and improving patient prognosis.

Keywords

Chronic Disease, Family Caregivers, Preparedness, Influencing Factors,

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Scoping Review

1. Introduction

Chronic diseases have a protracted course, require long-term management and care, and have become the primary source of the global disease burden [1]. With the accelerating population aging, chronic disease patients are becoming increasingly dependent on their families, and family caregivers play an indispensable role in patients' disease management, rehabilitation, and maintenance of quality of life [2]. However, family members who assume primary caregiving responsibilities often face immense pressure due to a lack of essential knowledge, skills, and psychological preparation. This leads to a heavy caregiver burden, diminished quality of life, and ultimately impacts the quality of patient care and health outcomes [3].

Caregiver preparedness refers to the perceived level of preparation that caregivers have to fulfill their roles across multiple aspects, including physical care, emotional support, service coordination, and stress coping [4]. Higher levels of preparedness are considered key protective factors in alleviating caregiver burden, improving care quality, and enhancing patient prognosis.

In recent years, scholars both domestically and internationally have conducted a series of studies on the preparedness of family caregivers in various chronic disease domains. However, these research findings still require integration, and the influencing factors are complex and multifaceted. As a methodology that systematically maps the scope of research in a field, key concepts, and types of evidence, a scoping review is well-suited for the initial organization and synthesis of this topic [5].

Therefore, this study aims to systematically integrate the current research status on the preparedness of family caregivers for chronic disease patients using a scoping review approach. It will analyze assessment tools, influencing factors, and their interrelationships, with the goal of providing a theoretical foundation for the clinical identification of caregivers with low preparedness and the development of targeted support interventions, while also offering recommendations for future research directions.

2. Materials and Methods

2.1. Determining Research Questions

This study primarily addresses the following questions: 1) What is the overall level of preparedness among family caregivers of patients with chronic diseases? 2) What tools are used to assess the preparedness of family caregivers? 3) What are the main factors influencing the preparedness of family caregivers?

2.2. Search Strategy

The system searched the following databases: China National Knowledge Infrastruc-

ture (CNKI), Wanfang Data, VIP, China Biomedical Literature Database (CBM), PubMed, Embase, Web of Science, CINAHL, and Cochrane Library. The search period covered the entire database history up to April 2025. A combination of subject terms and free-text terms was used. Chinese search terms included: "chronic disease/cancer/cardiovascular disease/hypertension/diabetes/stroke/chronic obstructive pulmonary disease", "caregiver/carer/family caregiver/family member", and "preparedness/caregiver preparedness/preparedness for caregiving". English search terms included: "chronic disease/cancer/cardiovascular disease/hypertension/diabetes/stroke/COPD", "caregiver/carer/family caregiver/partner", and "preparedness/caregiver preparedness/preparedness for caregiving", etc.

2.3. Inclusion and Exclusion Criteria

Inclusion criteria: 1) The study participants are family caregivers of patients with chronic diseases. .Chronic diseases include but are not limited to cancer, cardiovascular diseases, diabetes, stroke, chronic obstructive pulmonary disease, schizophrenia, and other conditions requiring long-term management and care; 2) The research topic involves the measurement of caregiver preparedness levels or the analysis of influencing factors; 3) The study type is original research (including cross-sectional studies, cohort studies, qualitative studies, etc.); 4) The language is Chinese or English.

Exclusion criteria: 1) Full text is unavailable; 2) Duplicate publications; 3) Non-original research or gray literature, such as conference abstracts, reviews, commentaries, and dissertations.

2.4. Literature Screening and Data Extraction

NoteExpress software was used to manage the literature. The screening process was independently completed by two researchers trained in evidence-based methodology. They first read the titles and abstracts, then obtained and read the full texts. Disagreements were resolved through discussion or by arbitration from a third researcher. A standardized form was designed to extract data, including: first author, publication year, country, study design, sample size, patient disease type, assessment tools, caregiver preparedness score (or main conclusions), and reported influencing factors.

3. Results

3.1. Literature Search and Screening Results

The initial search yielded 2019 articles. After a multi-stage screening process, 17 articles were finally included [6]-[22]. The literature screening process is shown in **Figure 1**.

3.2. Basic Characteristics of the Included Literature

The included literature was published between 2018 and 2025, with research locations spanning 7 countries, including China, Türkiye, the United States, and

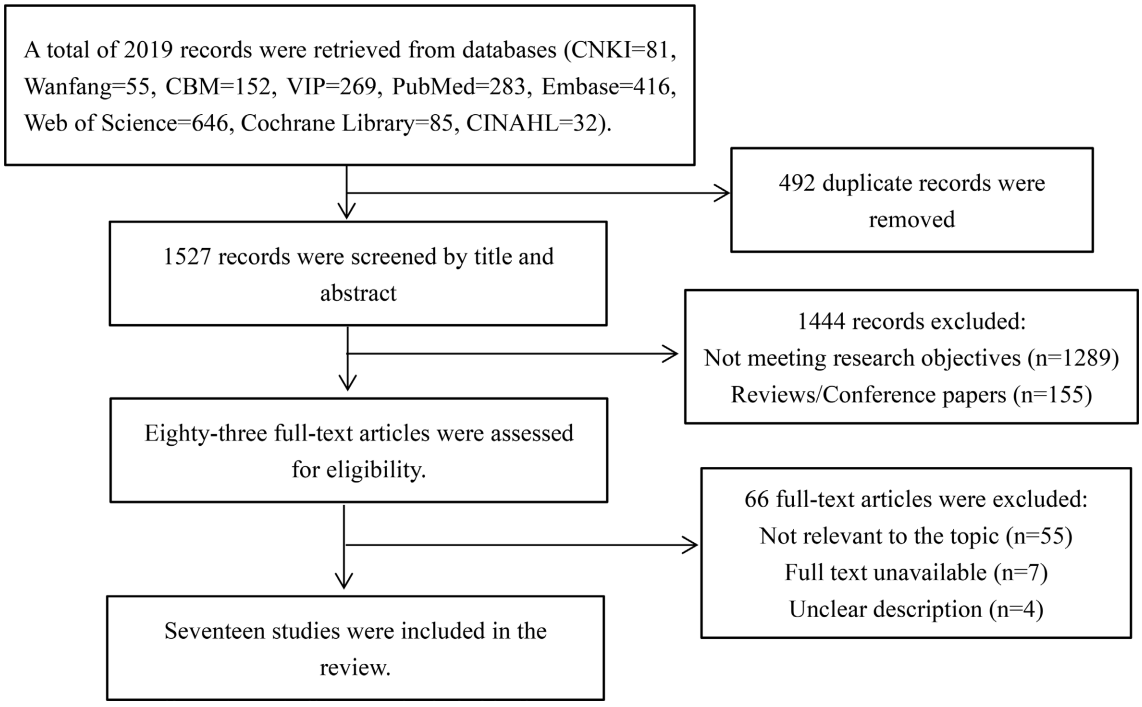

Figure 1. Flowchart of literature screening.

Sweden. The research designs were primarily cross-sectional surveys (n = 16), with 1 qualitative study. Sample sizes ranged from 12 to 337. The disease types involved included schizophrenia, stroke, cancer, heart failure, hemodialysis, and others. Specific characteristics are shown in **Table 1**.

Table 1. Basic characteristics of the included literature (n = 17).

Included Study (Year)	Region	Disease Type	Study Design	Sample Size	Assessment Tool	Reported Main Influencing Factors
Teng Weiyu *et al.* [6], 2018	China	Schizophrenia	Cross-sectional	201	Caregiver Preparedness Questionnaire	Education level, caregiving experience, mental health and psychological healthcare knowledge, patient's number of hospitalizations, social support
Liu Juanjuan *et al.* [7], 2018	China	Stroke	Cross-sectional	200	Caregiver Preparedness Scale	Age, education level, occupation, relationship to the patient, caregiving experience, number of other caregivers, disease uncertainty
Yakar H K *et al.* [8], 2020	Türkiye	Cancer	Cross-sectional	203	Preparedness for Home Caregiving Scale	Duration of caregiving, financial status, caregiving experience
Liu J *et al.* [9], 2020	China	Stroke	Cross-sectional	320	Caregiver Preparedness Scale	Age, gender, education level, occupation, caregiving experience, stroke knowledge, caregiver's level of uncertainty

Continued

Geng Xinxin *et al.* [10], 2020	China	First-Episode Stroke in the Elderly	Cross-sectional	231	Chinese Version of the Preparedness for Home Caregiving Scale	Age, occupation, caregiving experience, perceived stress of caregiving, monthly household income per capita, presence of other caregivers, accessibility to hospitals in the residential area
Dionne-Odom J N *et al.* [11], 2021	USA	Advanced Cancer	Cross-sectional	112	Preparedness for Caregiving Scale	Occupation, family role, psychological status
Li Baiyu *et al.* [12], 2021	China	ICU Transfer Patients	Cross-sectional	142	Primary Caregiver Preparedness Scale	Previous caregiving experience, caregiver's perceived stress, patient's type of medical insurance, caregiver's own chronic conditions, empowerment capacity
Owoo B *et al.* [13], 2022	Ghana	Prostate Cancer	Qualitative	12	Colaizzi's Data Analysis Method	Education and training needs (unpreparedness for the caregiving role, lack of understanding about the condition, misconceptions about the condition), resources (financial hardship, lack of accommodation), caregiver-nurse relationship (poor communication between caregivers and nurses, negative attitudes toward caregivers)
Winterling J *et al.* [14], 2022	Sweden	Patients undergoing allogeneic hematopoietic stem cell transplantation	Cross-sectional	86	Preparedness for Caregiving Scale	Education level, family role, caregiving competence, self-efficacy, psychological status, caregiver burden
Roslin, H *et al.* [15], 2023	Oman	Acquired Brain Injury	Cross-sectional	119	Preparedness for Caregiving Scale	Physical and mental health status, time since injury, symptom severity
Uhm K E *et al.* [16], 2023	South Korea	Individuals with Disabilities (Stroke, Spinal Cord Injury, or Traumatic Brain Injury)	Multicenter Cross-sectional	151	Preparedness for Caregiving Scale	Caregiver burden, depression, health-related quality of life
Wang Danni *et al.* [17], 2023	China	Breast Cancer	Cross-sectional	220	Caregiver Preparedness Scale	Gender, caregiving experience, presence of co-caregivers, self-efficacy, social support
Wang G *et al.* [18], 2024	China	Hemodialysis Patients	Cross-sectional	237	Preparedness for Caregiving Scale	Total duration of caregiving, caregiver burden, whether the family caregiver has chronic diseases, and positive aspects of caregiving

Continued

Özkan T F [19], 2024	Türkiye	Stroke	Cross-sectional	127	Preparedness for Caregiving Scale	Gender, education level, patient dependency level
Ye Fan *et al.* [20], 2024	China	Stroke	Cross-sectional	132	Caregiver Preparedness Scale	Gender, caregiver's education level, household income per capita, patient's coping ability
Wang Chaoqun *et al.* [21], 2024	China	Elderly Patients with Chronic Heart Failure	Cross-sectional	160	Caregiver Preparedness Scale	Age, education level, duration of caregiving, caregiver's disease uncertainty, presence/absence of co-caregivers
Liu Zhixia *et al.* [22], 2025	China	ICU-Discharged Severe Stroke Patients	Cross-sectional	337	Caregiver Preparedness Scale	Education level, patient's ICU treatment duration, level of understanding of the patient's condition, monthly family income, comprehensive caregiving ability

3.3. Preparedness Levels and Assessment Tools for Family Caregivers of Patients with Chronic Diseases

The included studies generally reported that the preparedness of family caregivers for chronic disease patients was at a moderately low level. Differences existed between disease groups; for example, caregivers of cancer [8] and hemodialysis [18] patients had relatively higher preparedness scores, while those of stroke [7] [10] and ICU discharge [12] [22] patients had lower scores.

Regarding assessment tools, most included studies employed the Caregiver Preparedness Scale (CPS), developed by Archbold *et al.* [23] and adapted into Chinese by Liu Yanjin *et al.* [24]. This scale is currently the most widely used instrument for measuring caregiver preparedness, comprising 8 items scored on a 5-point Likert scale, with total scores ranging from 0 to 32. It demonstrates good reliability and validity but has strong generalizability with limited disease-specific applicability [25]. A few studies utilized other tools, such as the Preparedness for Family Caregiving Scale [10].

3.4. Factors Influencing the Preparedness of Family Caregivers of Patients with Chronic Diseases

Based on the synthesis of the studies included, the factors influencing the preparedness of family caregivers of patients with chronic diseases can be integrated into three levels:

3.4.1. Caregiver's Personal Factors

This is the most crucial level of influence, encompassing caregiver demographics and resource factors, caregiving-related abilities, and psychological and health status. 1) Demographic and Resource Factors: These include the age, gender, education level, occupation, relationship with the patient, and family economic situation of caregivers for chronic disease patients. Two studies [7] [10] indicated dif-

ferences in preparedness scores among caregivers of different ages, with younger caregivers exhibiting higher preparedness levels. However, other studies [9] [21] found that increasing age among caregivers is more conducive to adequate preparation. Results from four studies [9] [17] [19]-[20] showed that female caregivers had higher preparedness. Eight studies [6]-[7] [9] [14] [19]-[22] suggested that education level can positively predict caregiver preparedness, with higher education correlating to higher preparedness levels. Four studies [7] [9]-[11] indicated that, compared to full-time working caregivers, retired or unemployed caregivers are less impacted by work obligations and can devote more energy to patient care. Two studies [11] [14] found that family caregivers who are spouses had higher levels of caregiving preparedness, though one study [7] reported that spouses facing a sudden stroke in the patient experienced lower preparedness due to role maladaptation and greater emotional dependency on the caregiver. Five studies [8] [10] [13] [20] [22] demonstrated that caregivers with better economic conditions had higher preparedness, as those with higher monthly incomes often possess greater psychological resilience and better financial support for acquiring caregiving knowledge. The contradictory findings regarding the impact of caregiver age and relationship on preparedness may be related to disease type, cultural context, family structure, and role adaptation processes. For example, in sudden-onset conditions like stroke, spouses may exhibit lower preparedness due to abrupt role changes, whereas in progressive diseases, older age may correlate with accumulated experience and higher preparedness.

2) Care-Related Abilities: In examining the relationship between care-related abilities and caregiver preparedness, nine studies [6]-[10] [12] [14] [17] [22] indicated that caregivers with prior caregiving experience typically exhibit better preparedness and are better equipped to cope with various challenges during the caregiving process. Caregivers with experience may be more familiar with changes in the patient's condition, enabling them to prepare adequately in advance and take timely measures [26]. Moreover, the longer the cumulative caregiving duration, the greater the preparedness [8] [18] [21]. The level of understanding of disease knowledge is one of the key factors influencing caregiver preparedness. Four studies [6] [9] [13] [22] found a positive correlation between the level of disease knowledge and caregiver preparedness. When caregivers have a thorough understanding of the disease, they can better comprehend changes in the patient's condition, develop reasonable care plans, and implement effective nursing measures [27].

3) Psychological and Health Status: Relevant studies have found that lower levels of negative emotions among caregivers [10]-[12] [16] [18] and higher self-efficacy [14] [17] are positively correlated with their preparedness. When caregivers experience physical and mental exhaustion, they struggle to adequately prepare for and cope with caregiving tasks, thereby reducing their preparedness levels [28] [29]. In contrast, caregivers with high self-efficacy can alleviate negative emotions, manage stress and challenges during caregiving, and better prepare for their role

[30]. Caregivers' own health issues can limit their caregiving capacity and increase difficulties and risks in the process [21]. Studies [12] [15] [18] indicate that caregivers who suffer from chronic diseases have relatively lower preparedness. The better a caregiver's own health status and quality of life, the less interference they face from personal health problems during caregiving, enabling them to prepare for and respond more effectively to tasks.

3.4.2. Patient-Related Factors

Patient-related factors influencing the level of preparedness of family caregivers include the number of hospitalizations, level of self-care ability, level of dependence, and duration of treatment. Studies have shown [6] that caregivers of patients hospitalized more than once have significantly higher levels of preparedness than those of patients hospitalized for the first time, possibly due to the accumulation of more nursing experience and greater familiarity with the hospital environment and nursing procedures. Two studies [15] [20] suggest a positive correlation between patient self-care ability and caregiver preparedness; the higher the patient's self-care ability, the lighter the psychological and physical burden on the caregiver, and the higher the level of preparedness. Patient dependence level [19] and treatment duration [15] [22] are also important factors affecting caregiver preparedness. Patients who are highly dependent on caregivers require more time and energy for care, which may lead to excessive stress for caregivers and reduced preparedness. Patients undergoing long-term treatment require continuous support from caregivers, who may face more challenges and stress during the long-term care process, thus affecting their level of preparedness.

3.4.3. Social Support and Environmental Factors

The presence of co-caregivers, broad social support, and effective patient-caregiver communication can provide caregivers with substantive and emotional support, serving as key resources for enhancing preparedness. Four studies [7] [10] [17] [21] showed that co-caregivers can help share caregiving tasks, alleviate the burden on individual caregivers, and offer emotional support, resulting in higher preparedness levels for family caregivers with assistance from others. Results from two studies [6] [17] indicated a positive correlation between social support (material or spiritual) from family, friends, and healthcare professionals and caregivers' preparedness scores. Such support provides caregivers with essential resources and emotional backing. Effective patient-caregiver communication contributes to improving caregivers' preparedness levels [13], as it helps reduce anxiety and uncertainty stemming from information asymmetry, enabling better understanding of the patient's condition and care needs. Additionally, high accessibility to medical resources in the living area—such as geographic proximity, transportation convenience, affordable costs, service availability, and short appointment waiting times—is an important influencing factor for elevating caregiver preparedness. Convenient medical resources can minimize the time and energy caregivers expend on patient medical visits [10], allowing them to focus more ef-

fectively on caregiving tasks.

4. Discussions

4.1. The Multidimensional Assessment Framework for Caregiver Preparedness among Chronic Disease Patients Requires Further Development

From the conclusions of the literature included in this study, the overall preparedness of family caregivers for chronic disease patients is not optimistic, and there is heterogeneity across groups [7] [8] [18] [22]. This suggests that in clinical practice, healthcare professionals should routinely and dynamically assess the preparedness status of family caregivers and provide targeted support and interventions for those with low preparedness among chronic disease patient caregivers.

This study found that there are few scales for measuring family caregiver preparedness [23]. Future research could focus on developing or adapting disease-specific preparedness assessment modules, or constructing a multidimensional evaluation index system that integrates demographic factors, caregiving abilities, psychological resources, and social support, to achieve more precise risk stratification and needs identification.

Although CPS is widely used, its items primarily focus on individual caregiving abilities and offer limited coverage of systemic factors such as social support and environmental resources. Future tools should integrate multidimensional factors to provide a more comprehensive assessment of caregiver preparedness.

4.2. Analysis of Influencing Factors on the Preparedness of Family Caregivers for Chronic Disease Patients

This review systematically delineates a multi-level network of factors influencing caregiver preparedness. Among them, caregivers' disease knowledge, caregiving skills, and levels of negative emotions are core targets with substantial evidence and clinical intervenability [6] [9] [21]. For instance, knowledge and skills can be enhanced through structured education programs, while psychological distress can be alleviated via mindfulness-based stress reduction or cognitive behavioral therapy. Improvements in these factors may generate cascading positive effects. For factors with inconsistent evidence (such as age and relationship with the patient) [7] [9] [14], it is suggested that their influences may be moderated by contextual variables like cultural backgrounds and family dynamics, necessitating personalized consideration in specific interventions.

4.3. Future Research Directions on the Preparedness of Family Caregivers for Chronic Disease Patients

This study reveals that social support and environmental factors play crucial roles [9]. Enhancing the preparedness of family caregivers for chronic disease patients cannot focus solely on individuals. Future support strategies should go beyond education and training for individual caregivers, advancing toward an integrated

care model that links "individual-family-medical system-community". This includes: establishing "caregiver-friendly" systems in medical institutions; developing supportive service networks at the community level, such as respite care and peer support; and utilizing digital health technologies to provide accessible information and remote guidance for caregivers. Only by embedding individual empowerment within a robust support system can preparedness be sustainably and effectively improved.

4.4. Limitations

This study is a scoping review, aiming to describe the overall landscape of the research field, and did not include a methodological quality assessment of the included literature. The search was limited to Chinese and English databases, which may introduce language bias. The included studies were primarily cross-sectional in design, making it difficult to determine the causal relationship between influencing factors and preparedness. More high-quality longitudinal and interventional studies are needed for further validation.

5. Conclusion

This scoping review indicates that the preparedness of family caregivers for chronic disease patients is a critical issue affecting care quality and population health. Its level requires enhancement and is influenced by complex multi-level factors, including the caregivers themselves, patient characteristics, and social support systems. Clinical practitioners and policymakers should prioritize the preparedness status of family caregivers, integrating their assessment into routine care processes. Future research and practice must adopt a dual approach: on one hand, deepening scientific evaluation through the development of disease-specific tools; on the other hand, constructing an integrated intervention model that "empowers individuals and strengthens support systems" to comprehensively improve family caregivers' preparedness. This will ultimately achieve the objectives of alleviating caregiver burden and enhancing health outcomes for chronic disease patients.

Authors' Contribution Statement

Liang Chunli was responsible for the research design, literature search and analysis, and manuscript writing; Bai Xue was responsible for research supervision, manuscript review and revision, and funding support.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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