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Research Progress on Health Literacy in Patients with Chronic Kidney Disease

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Abstract: Chronic kidney disease (CKD) is characterized by high morbidity, high mortality, and poor prognosis, while health literacy is the goal of health education and an important outcome of health promotion, crucial for improving health outcomes. Therefore, this paper reviews the conceptual evolution, theoretical models, and assessment tools of health literacy, as well as the current status, influencing factors, and intervention strategies of health literacy in CKD patients. The aim is to raise awareness among healthcare professionals regarding health literacy in CKD and to provide a reference for further research on health literacy in CKD patients.

Keywords: Chronic kidney disease; Health literacy; Influencing factors; Measurement tools; Intervention

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1. Introduction

Chronic kidney disease (CKD) is characterized by renal structural or functional abnormalities persisting for more than three months. In the early stages, it often presents with no obvious clinical symptoms. However, as the residual renal units become unable to compensate for the body's needs, it primarily manifests itself in a series of symptoms, including oliguria, proteinuria, anemia, endocrine and metabolic disorders, and is characterized by high

morbidity, high mortality, poor prognosis, and high medical costs [1].

According to statistics, there are 697.5 million CKD patients worldwide, accounting for 9.1% of the global population. China has the largest number of CKD patients, accounting for 19% of the global total [2]. World Health Organization (WHO) statistics indicate that the incidence of CKD in China is as high as 10.8%, and the number of individuals affected by the disease is approximately 150 million [3]. As renal function gradually declines, patients may develop various complications, such as water-electrolyte disorders, metabolic acidosis, and cardiovascular disease, leading to a significantly increased risk of adverse outcomes [4]. When the disease progresses to end-stage renal disease, renal replacement therapy, such as hemodialysis, peritoneal dialysis, and kidney transplantation, becomes the last resort for patients to maintain their lives, imposing a heavy financial burden on patients, families, and society.

CKD treatment primarily focuses on slowing the decline of renal function and preventing complications [5]. Previous studies have demonstrated that CKD patients with poor knowledge of the disease, limited health information support, and poor disease management skills experience faster disease progression and are more likely to have adverse outcomes [6]. Therefore, improving patients' ability to acquire, understand, and utilize health information is essential for enhancing health behaviors and delaying disease progression, a concept known as health literacy. Health literacy is the goal of health education and an important outcome of health promotion, significantly contributing to improved health outcomes. This paper reviews the conceptual evolution, theoretical models, and measurement tools of health literacy, the current status, influencing factors, and intervention strategies of health literacy in CKD patients, aiming to provide references for further research on health literacy in CKD patients. The ultimate goal is to improve the level of health literacy in CKD patients, enhance their ability to self-manage their diseases, delay disease progression, improve health outcomes, and enhance their quality of life.

2. Conceptual evolution of health literacy

In 1974, the American scholar Simonds was the first to introduce the term "health literacy" in *Health Education as Social Policy* [7]. In 1998, the World Health Organization (WHO) defined health literacy as "a cognitive and social skill that determines an individual's motivation and ability to acquire, understand, and utilize information to promote and maintain health" [8]. In 1999, the American Medical Association (AMA) defined functional health literacy as "a set of interacting competencies such as performing basic reading and numeracy in a healthcare setting" [9].

In 2000, Professor Nutbeam defined health literacy as "the personal, cognitive, and social skills of individuals to access, understand, and utilize information to promote and maintain good health" [10]. In 2004, the National Library of Medicine (NLM) defined health literacy as "an individual's ability to access and understand basic health information and services and to use them to make good decisions to maintain and promote one's health" [11]. This definition was adopted by the Healthy People 2010 program in the U.S. In 2005, Guo *et al.* introduced the term "health literacy" to China, and the NLM definition of health literacy was adopted in domestic governmental documents on health literacy [12].

In 2010, McCormack *et al.* defined health literacy as "the extent to which individuals are able to access, process, understand, and communicate health-related information needed to make informed health decisions" [13]. In 2020, the U.S. Healthy People 2030 plan defined health literacy in terms of both individuals and organizations, emphasizing the important role of organizations that provide health-related information and services in improving

health literacy [14].

At present, the international definition of health literacy has not been fully unified [15]. Scholars have elaborated on it from different perspectives. To summarize, health literacy extends beyond basic reading, writing, and numeracy, encompassing a comprehensive skill set for acquiring, understanding, and utilizing health information.

3. Theoretical models of health literacy

3.1. The health literacy model

In 2000, Professor Nutbeam proposed a health literacy model based on a public health perspective, which divides health literacy into three levels: functional health literacy, interactive health literacy, and critical health literacy [10]. Functional health literacy refers to the basic reading and writing skills needed by individuals in everyday situations, including general medical knowledge such as safety, nutrition, medication, and first aid. This level primarily focuses on individuals' mastery of health knowledge. Interactive health literacy is a more advanced cognitive ability that emphasizes an individual's willingness to improve health, motivation, and confidence to implement health actions. This level focuses on the development of personal skills, including the ability to access health information, utilize media, and communicate effectively. Critical health literacy represents the highest level of cognition and skills, involving the use of critical thinking to analyze health information. Individuals with critical health literacy are better equipped to utilize health information and have greater agency, control, and decision-making power over life events and health conditions compared to those at the first two levels.

3.2. The health literacy skills conceptual framework

In 2012, Squiers *et al.* developed the health literacy skills (HLS) conceptual framework, which describes the relationship between health literacy and health-related outcomes [16]. This framework explains how health literacy operates at the individual level while recognizing the influence of external factors such as family, environment, community, culture, and media. Health literacy is considered a multidimensional and dynamic construct, divided into four main components: (1) factors influencing the development and use of health literacy skills; (2) health-related stimuli; (3) health literacy skills required to understand stimuli and perform tasks; and (4) mediating variables between health literacy and health outcomes. Additionally, the framework identifies four dimensions of health literacy: print literacy, numeracy, communication, and information-seeking skills. Demographics, personal resources, competencies, and prior knowledge are several interrelated contextual factors that influence an individual's health literacy skills. According to an ecological perspective, health-related behaviors and outcomes are influenced by multiple dimensions, including individual, system, and societal levels, and these factors interact at different levels.

3.3. Integrated conceptual model of health literacy

In 2012, Sørensen *et al.* argued that most existing health literacy models, despite recognizing the multidimensional nature of health literacy, are incomplete, static, and lack clear causal pathways of action [17]. In response to these shortcomings, an integrated conceptual model of health literacy was proposed, drawing upon medical and public health perspectives. At the core of the model are competencies related to the processes of accessing, understanding, evaluating, and applying health information, each representing a dimension of health literacy.

These competencies require specific cognitive skills and depend on the quality of the information provided. Access to health information depends on comprehension, time, and credibility. Comprehension of information depends on expectations, perceived utility, individualization of outcomes, and interpretation of causality. Processing and evaluation of information depend on complexity, terminology, and partial comprehension of information. Effective communication and utilization depend on understanding of information. This process generates knowledge and skills that enable patients in healthcare settings, individuals at risk for disease, and those involved in health promotion to apply their general literacy, digital skills, and health literacy skills to obtain, understand, critically analyze, evaluate, and independently act on health information.

3.4. The health literacy intervention model

In 2018, Geboers *et al.* concluded that existing models provide valuable insights into the potential determinants of health literacy and the mediating role between health literacy and health outcomes but offer limited guidance for developing comprehensive interventions [18]. To address this gap, they developed the health literacy intervention model. The interventions in the model target both individuals with low health literacy and health service professionals, encompassing the following strategies: (1) strengthening social support systems for individuals; (2) empowering individuals with low health literacy; (3) improving communication between individuals and health professionals and strengthening interactions between individual characteristics and health system needs; (4) enhancing healthcare professionals' health literacy capacity; and (5) improving health system communication and accessibility, reducing care barriers to enhance quality of care or patient safety. The model emphasizes the dynamic interaction between low-health literacy individuals and health professionals, highlighting the synergistic effect of combined interventions.

4. Measurement tools for health literacy

There is a wide variety of health literacy measurement tools, with a predominance of universal measurement tools. Early health literacy measurement tools focused solely on the functional health literacy dimension and had limitations, such as the Rapid Estimate of Adult Literacy in Medicine (REALM) [19] and the Short Test of Functional Health Literacy in Adults Scale (S-TOFHLA) [20]. As research has progressed, the understanding of health literacy has broadened, and the demand for comprehensive health literacy measurement tools has increased. In recent years, scholars have developed specific measurement tools for chronic disease populations, such as diabetic patients [21] and cancer patients [22]. In 2016, Shih *et al.*, a Taiwanese scholar in China, developed a specific measurement tool for health literacy in hemodialysis patients, which demonstrated good reliability and validity but limited use [23]. In 2021, Wei *et al.* developed a specific measurement tool for health literacy in CKD patients, available in both Taiwanese and Mandarin versions, and validated for good reliability and validity [24].

4.1. Health Literacy Management Scale (HeLMS)

In 2013, Professor Jordan *et al.* developed the HeLMS based on in-depth interviews and a conceptual framework [25]. The scale assesses individuals' competencies and their broader social and environmental contexts, encompassing eight dimensions: attitudes to health, knowledge of health information, social support, socioeconomic factors, access to GP healthcare services, communication with health professionals, proactivity, and use of health information. The scale consists of 29 items rated on a 5-point Likert scale, with higher scores indicating higher

levels of health literacy. The Cronbach's alpha coefficient for each dimension of the scale ranged from 0.82 to 0.89, demonstrating good reliability.

4.2. Health Literacy Questionnaire (HLQ)

In 2013, Osborne *et al.* developed the HLQ to address the limitations of the HeLMS and assess the health literacy needs of a broader range of individuals and organizations [26]. The scale comprises nine subscales with 44 items, covering: perceived understanding and support from healthcare providers, having enough information to manage health, actively managing one's own health, health-related social support, the ability to assess health information, the ability to interact with healthcare providers, the ability to navigate the healthcare system, the ability to find health information, and the ability to understand and utilize health information. The Cronbach's alpha coefficient of the scale is 0.77. In recent years, the HLQ has become one of the most widely used health literacy instruments in public health and health services research, and it has been translated into various languages, including Korean [27], Arabic [28], and Portuguese [29].

4.3. The European Health Literacy Survey Questionnaire (HLS-EU-Q)

Sørensen *et al.* concluded that existing health literacy measurement tools had limitations and redefined the meaning and conceptual framework of health literacy [17]. In 2013, the HLS-EU-Q was developed to measure health literacy in European populations [30]. The scale assesses the ability to access, understand, evaluate, and utilize health-related information in three domains: healthcare, disease prevention, and health promotion. It consists of 47 items rated on a 4-point Likert scale, with higher scores indicating higher levels of health literacy. In 2017, Duong *et al.* validated the scale in six Asian countries, and Cronbach's alpha coefficients of the translated scales exceeded 0.90, demonstrating good reliability and validity [31]. In 2018, Finbråten *et al.* developed a simplified version, the 12-item European Health Literacy Questionnaire (HLS-Q12) [32]. In 2023, the HLS-Q12 was validated in patients with chronic diseases, confirming its good reliability [33].

4.4. The Health Literacy Scale for Chronic Disease Patients

Based on the HeLMS developed by Professor Jordan, Chinese scholar Sun compiled the Health Literacy Scale for Chronic Disease Patients in 2012, tailored to China's national conditions and population characteristics [34]. The scale includes four dimensions and 24 items: information acquisition ability, communication and interaction ability, willingness to improve health, and willingness to provide financial support. The Likert 5-point scale is used, with higher scores indicating higher levels of health literacy. Scores of 96 or more are considered indicative of good health literacy, while scores below 96 suggest a lack of health literacy. The Cronbach's alpha coefficient of the scale is 0.894, indicating good reliability.

4.5. All Aspects of Health Literacy Scale (AAHLS)

In 2013, Chinn *et al.* developed the AAHLS, a short health literacy measurement tool, based on Nutbeam's health literacy model [35]. The scale includes four dimensions and 14 items: ability to use written health information, communication with healthcare providers, ability to evaluate and apply health information, and individual autonomy. The first 12 items are scored on a 3-point Likert scale, and items 13 and 14 are two-category multiple-choice questions. Higher total scores indicate higher levels of health literacy. The Cronbach's alpha coefficient of the total scale is 0.75. In 2017, Chinese scholars Wu *et al.* adapted the scale for Chinese contexts, resulting

in the Chinese version of the Comprehensive Health Literacy Scale (C-AAHLS) [36]. The C-AAHLS includes three dimensions and 11 items, scored on a 4-point Likert scale, and it has demonstrated good reliability with a Cronbach's alpha coefficient of 0.811.

5. Research status of health literacy among CKD patients

In 2009, Devraj *et al.* suggested that health literacy plays a crucial role in kidney disease, pioneering a new research direction in health literacy for CKD [37]. Subsequently, related studies have flourished, encompassing cross-sectional studies, qualitative studies, intervention studies, and systematic evaluations. In 2019, a cross-sectional study conducted in Norway revealed that health literacy among patients with CKD stages 3 to 5 was moderately high, with the highest scores on the subscale "feeling understood and supported by healthcare providers" and the lowest scores on the subscale "ability to assess health information" [38]. The results indicated that gender, education, type of prescription medication taken, and depressive symptoms were associated with health literacy. In 2024, Singaporean scholar Ho *et al.* surveyed 289 CKD patients and found that 31.1% had limited health literacy, and health literacy was associated with gender and level of self-care [39].

A longitudinal qualitative study conducted in-depth interviews with 24 CKD patients, revealing that these patients had insufficient health literacy, barriers to self-management, and inadequate support from healthcare professionals [40]. The study emphasized the need for further optimization measures to improve patients' health literacy and the support capacity of healthcare professionals.

Research on health literacy in CKD patients in China began relatively late, with most existing studies focusing on status quo surveys, analysis of influencing factors, and correlation analysis with other variables. Qualitative studies and interventional studies are relatively scarce. In 2013, a questionnaire survey conducted by Sun *et al.* on 80 CKD patients hospitalized in Beijing, China, found that 71.2% of the CKD patients had low health literacy [41]. Around 2019, cross-sectional studies in Sichuan and Hunan provinces, China, revealed that the health literacy of CKD patients was moderately low, with CKD stage 5 patients exhibiting even greater deficiencies [42-44]. Cross-sectional studies from 2021 onward indicated that the health literacy of CKD patients had improved to a moderately high level [45-47]. In conclusion, although the health literacy of CKD patients in China has shown improvement in recent years, the overall situation remains suboptimal.

6. Factors influencing health literacy in CKD patients

6.1. Demographic factors

Age [42], literacy [46,48], occupation [45,46], mode of residence [46], per capita monthly household income [42,48], mode of payment for healthcare [42], and smoking status [49] have been found to be associated with the level of health literacy in CKD patients. Demographic factors can help healthcare professionals identify CKD patients with limited health literacy, providing a foundation for effective interventions.

6.2. Disease-related factors

Some studies have shown that the number of hospitalizations [46], frequency of hemodialysis [44], number of prescribed medications [38], and severity of comorbidities [48] are important factors influencing health literacy in CKD patients. Additionally, Chen investigated the correlation between nutrition and health literacy in CKD

patients, finding that better nutritional status was associated with higher levels of health literacy [43].

6.3. Psycho-cognitive factors

Zhang *et al.* found a negative correlation between fear of disease progression and health literacy [45], indicating that CKD patients with lower levels of fear were better able to utilize information to address their health concerns. Studies have also shown a positive correlation between health literacy and self-efficacy, with higher self-efficacy associated with higher health literacy [50]. This mutual reinforcement is consistent with the findings of Kazak *et al.* [51] and Ho *et al.* [39]. Stømer *et al.* pointed out a correlation between health literacy and depressive symptoms in CKD patients [38]. These findings highlight the importance of psychological and cognitive factors in influencing health literacy among CKD patients and emphasize the need for their improvement.

6.4. Family and social support

Family and social support play a crucial role in the health literacy of CKD patients, providing information, resources, and emotional support to help patients better manage their disease and improve their quality of life. A qualitative study revealed that family understanding and support were facilitators of health literacy in CKD patients [52]. Studies have shown a positive correlation between social support and health literacy, with higher social support associated with better access to health information and improved self-management abilities [53]. Kita *et al.* demonstrated a link between health literacy and socialization activities in CKD patients [54]. Additionally, research has indicated a correlation between health literacy and disease burden in CKD patients [55].

6.5. Healthcare delivery system

Studies have shown a strong relationship between the health literacy of CKD patients and interactions with healthcare providers [49,55]. Effective communication between healthcare providers and patients can improve patient health behaviors, optimize health decision-making, and play a key role in enhancing health literacy. In the context of complex diseases with multimorbidity, decentralized healthcare issues can make it challenging for CKD patients to navigate the healthcare system [56]. Therefore, strengthening communication to improve the accessibility of healthcare services and establishing long-term mechanisms for health literacy improvement is crucial.

6.6. Information and media support

Studies have shown that information navigation biases and media use barriers influence health literacy. Compared to younger CKD patients, older patients may be less receptive to electronic information. Smartphone-based educational methods, such as WeChat and apps, may be less accessible to some older CKD patients. Additionally, the existing health information may be obscure and difficult to comprehend, further hindering patients' access to health information [52]. Therefore, patients should be guided to actively utilize modern media while improving their ability to identify reliable health information.

7. Intervention strategies for health literacy in CKD patients

7.1. Multiform interventions

Huang *et al.* designed a one-on-one health literacy education program involving the distribution of health education brochures and the viewing of health education videos [57]. The results demonstrated that this program

was effective in improving the health literacy of CKD patients and clinical outcomes. Fu *et al.* applied humanized care to CKD patients, and the study results showed that, compared to conventional care, humanized care improved patients' health literacy levels, comfort, and satisfaction, making it worthy of clinical promotion [58]. Deng *et al.* utilized the Feynman-style learning method to enhance patients' health literacy [59]. The results indicated that this method contributed to improved health literacy, self-management behaviors, and quality of life in ESRD patients, demonstrating its clinical value. Nong *et al.* employed the teach-to-fish health education model for CKD patients, effectively improving patients' health literacy and self-management abilities [60]. These findings suggest that healthcare professionals can actively explore diverse intervention models to better meet the health needs of patients.

7.2. Multicomponent intervention

Multicomponent intervention is a strategy that combines multiple approaches to achieve optimal intervention outcomes. Boonstra *et al.* developed a four-component intervention for CKD patients and healthcare professionals based on intervention mapping theory [61]. The intervention included: (1) improving the awareness and knowledge of CKD patients; (2) enhancing patients' motivation for self-management; (3) enhancing patients' self-management ability; and (4) enhancing healthcare professionals' competence. The intervention was delivered through videos and manuals, and the results showed that the multicomponent intervention was feasible and met the needs of healthcare professionals and CKD patients.

7.3. eHealth interventions

With the increasing popularity of the internet and the advancement of information technology, mHealth has gained significant attention. The use of online media for health education and medical services has become a prominent trend. Eneanya *et al.* assisted CKD patients with decision-making through a supportive renal care video, and the results showed a significant improvement in patient knowledge and high levels of patient satisfaction and acceptability of this video decision aid [62]. Muscat *et al.* developed the Success app to support active participation in self-management and decision-making for Australian CKD patients requiring dialysis [63]. The intervention covered diet, fluids, medications, physical activity, mood, and supportive care. The study demonstrated that e-health interventions can improve self-management in CKD patients, optimize healthcare utilization, and enhance patient outcomes.

8. Conclusion

The current state of health literacy among CKD patients is not optimistic. Improving patients' health literacy and enhancing their self-management abilities is crucial for effective disease management. While research on health literacy in CKD patients has been steadily progressing, the focus has primarily been on patients undergoing hemodialysis or peritoneal dialysis. Objective, practical, and specific assessment tools remain limited, and there is a relative scarcity of intervention studies in China.

It is recommended to prioritize attention to patients in the early stages of CKD, as this can significantly contribute to delaying disease progression. Additionally, the development of a scientific and systematic intervention program is essential to enhance the health literacy of CKD patients and improve their overall health outcomes.

Disclosure statement

The authors declare no conflict of interest.

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