REVIEW

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Health literacy in patients undergoing hemodialysis: literature review

Berlian Ayu Rahmawati[1], Erna Rochmawati[2*]

[1]Students of Master Nursing Program, Postgraduate Program, Universitas Muhammadiyah Yogyakarta, Indonesia;
[2]School of Nursing, Faculty of Medicine and Health Sciences, Universitas Muhammadiyah Yogyakarta, Indonesia;

*Corresponding author:
Erna Rochmawati;
Lecturer Master of Nursing, Post Graduate Program, Universitas Muhammadiyah Yogyakarta, Daerah Istimewa Yogyakarta, Indonesia;
erna.rochmawati@umy.ac.id

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ABSTRACT

Background: Patients with end-stage chronic kidney disease require hemodialysis treatment to maintain kidney function. The patients should be prepared to manage symptoms that may arise and cope with physical, psychological and financial changes. In addition, the patients are expected to be able to make their own decisions on how to manage the disease and adhere to treatment. This situation requires good health literacy skills. Little is known about the synthesis of health literacy among patients with chronic kidney disease.

Goal: To summarize the available evidence on benefits and factors that affect health literacy in patients undergoing hemodialysis from the available literature.

Method: The study reviewed health literacy among patients undergoing hemodialysis. A literature search using a database was conducted in Ebsco, PubMed, Science Direct, Scopus, and Emerald in December 2021 using the terms *health literacy, hemodialysis, dialysis, CKD, and ESRD.* We included studies from 2010-2021 that involved adult patients. Screening title, abstract, and full text were conducted to check each study's eligibility.

Results: A total number of eight of 1223 articles were included, with 2,036 respondents. Most included studies found that patients had a low level or inadequate health literacy (n = 5). In contrast, one study shows moderate health literacy (n = 2), and one article found a good level of health literacy. Higher health literacy was shown can improve patients' quality of life. The review summarizes several factors influencing health literacy, such as education, health care providers, life experiences, happiness and anxiety.

Conclusion: The review shows that most studies found lower health literacy levels. It is expected that nurses and healthcare professionals can improve health literacy which could positively impact patients' quality of life.

Keywords: *chronic kidney disease; end-stage renal disease; health literacy; hemodialysis; quality of life.*
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INTRODUCTION

Chronic kidney disease (CKD) is one of the major health problems globally. CKD refers to a progressive and irreversible decline in kidney function.[1] According to data from the National Health and Nutrition Examination Survey (NHANES), the prevalence of Chronic Kidney Disease (CKD) among adults in the United States is estimated at 15%, and it is predicted that over 30 million American adults may have CKD.[2] Chronic kidney disease is estimated to be 8-16 % worldwide.[3] Hemodialysis has become an alternative treatment in the final stage of renal disease.[4] However, the death rate from hemodialysis remains high. In the United States and developed, the annual mortality rate is as much as 23%.[5]

Patients with end-stage kidney disease require renal replacement therapy to maintain kidney function. The therapy includes hemodialysis. Patients undergoing hemodialysis should understand the symptoms of the disease, how to manage the diet, and be able to cope with changes in the body, changes in daily activities (ADLs) and economic burdens.[6] The situation requires substantial health literacy that affects patients' quality of life undergoing hemodialysis.[6]

Health literacy is a skill and competency that allows a person to gain access to, understand and apply health information and positively influence their health and the health of others around their social environment.[7] Health literacy can improve more comprehensive options for health support.[8] Health literacy has been recognized as an important factor in providing health services.[9] Health literacy is a multidimensional concept consisting of various cognitive, affective, social and personal skills that determine motivation and the ability to gain access to, understand and use health information.[10]

Patients with lower health literacy will generally affect their ability to comprehend their healthcare and make important decisions regarding their disease.[11] Lower health literacy will also lead to lower involvement in health promotion, lower therapy adherence, higher hospitalization rates with readmission within 30 days of discharge from the hospital and an overall poorer health status.[9]

A literature search found no studies synthesizing available evidence on hemodialysis patients' health literacy.

Therefore the study aimed to synthesize the available studies on health literacy. The questions for the review are: (a) "what are the benefits of high health literacy in patients undergoing hemodialysis?" and (b) what factors influence health literacy? The review aimed to identify the level of health literacy among patients undergoing maintenance hemodialysis and the advantages of health literacy in hemodialysis patients. The authors use a narrative review approach to describe CKD patients' health literacy.

METHOD

The methodology used is a narrative review. Available literature was searched from the following databases: Ebsco, PubMed, Science Direct, Emerald and Scopus. We combined the following keywords: 'hemodialysis', 'chronic kidney disease', 'ESRD', 'health literacy', and hemodialysis'. Boolean AND and OR were used to combine the keywords.

The author (BAR) conducted a literature search. The inclusion criteria used in the database search are as follows: Literature published from 2010 to 2021, quantitative and qualitative studies published in English involving adults undergoing hemodialysis, and studies conducted in hospitals and clinics. The articles were checked for duplication to eliminate similarities using EndNote 20. The studies were screened by title, abstract, and full text by both authors (BAR, ER). The authors reviewed the included paper independently and then discussed it to gain agreement. Article selection uses PRISMA guidelines. Figure 1 provides an overview of the process of identifying and screening searches and the results of selected articles.

RESULTS

A total of 1,223 articles were found. Following removing duplicates and screening, 30 articles were reviewed for the full text. A total of 8 studies were included in the review with 2.036 participants. Four studies were conducted in hospitals and another four in clinics. Six studies had a cross-sectional design, one study had a prospective cohort, and the other was a qualitative study with in-depth interviews. Most studies explain the benefits of high health literacy in hemodialysis patients. In addition, several studies also discuss the relationships between health literacy and the quality of life of hemodialysis patients and general health. Several other articles discuss factors that affect health literacy.

Moreover, several other articles discuss factors that affect health literacy. Furthermore, one article discusses the experience of hemodialysis patients related to health literacy. Characteristic explanations of the article included in the review include the average age, national origin, length of hemodialysis, benefits of health literacy and factors that affect it, samples, design and measuring instruments (table 1).

a. Characteristics of studies.
Two studies were conducted in Iran[12,6]; Slovakia[13,14]; Norwegia.[15,10] The other study was conducted in Australia[16] and the United States of America.[17] Six studies had a cross-sectional design[6,1,16,15,13,14], one study had a prospective cohort[17], and the other was a qualitative study with in-depth interviews.[10]

b. Characteristic of participants
Based on the eight included studies, the median age of respondents was an adult with the age of 30 years to 68 years with more than 50% gender of participants on six studies is males[1,17,16,15,13,14] and one study is female[6] and in qualitative studies, 50% on female and males. The

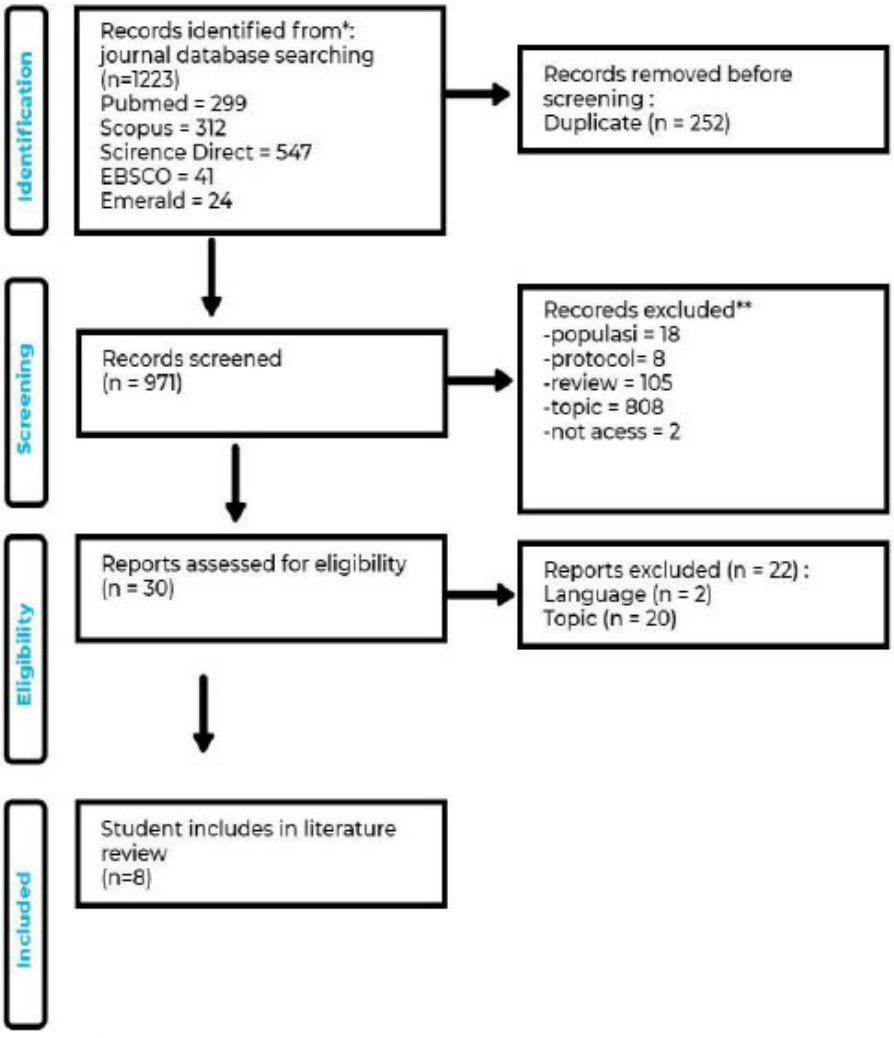

Figure 1. PRISMA (Search and Screening Strategy) of literature review.
From: Page MJ. Mckenzie JE. Bossuyt PM. Boutron I. Hoffman TC. Mulrow CD. et al. The PRISMA 2020.
statement: an Updated guidline for reporting systematic reviews, BMJ 2021:372n71 doi10.1136/bmjn71.

literature explained that the minimum dialysis limit is three months[6,10,14], more than two years[12,16], more than 90 days[17,13] and more than one month.[15]

c. Health Literacy Measuring instruments

Table 1 shows instruments used to measure health literacy in the review. The cross-sectional research design used in the literature obtained as many as six articles with a sample of 2,036 respondents, which aimed to assess the relationship between health literacy and quality of life[6], general health[12], psychological conditions[16], adherence to therapy, and adherence to dietary fluid intake.[15] One article used a prospective design of a cohort of 480 patients using the Rapid Estimate of

Table 1. The summary of the included eight studies.

No	Researcher name, Year, Title	Method	Result
1.	Alemayehu et al, 2021, Relationship between health literacy and quality of life among hemodialysis patients, Tehran, Iran, 2019	**Purpose:** To assess the relationship between health literacy and quality of life in patients undergoing hemodialysis at hospitals affiliated with the Tehran University of Medical Sciences **Design:** Cross-sectional **Sample:** 133 Patients who underwent hemodialysis for more than 3 months Have the ability to read and write No vision and hearing problems. The mean age of participants between 35 to 60 years old. Gender 52,6% female. **Instrument:** HELIA dan KDQOL SF **Country of Origin:** Iran	Based on research there is a significant relationship between health literacy and the quality of life of patients undergoing hemodialysis.
2.	Bahadori et al, 2018, The Relationship between Health Literacy and General Health Level of Hemodialysis Patients: A Case Study in Iran	Purpose This study aims to find out the relationship between health literacy and general health in hemodialysis patients. **Design**: Descriptive-analytic **Sample**: 130 Patients undergoing hemodialysis. The mean age of participants was 30 at 60 years old. Gender 63% males. **Instruments:** sociodemographics, HELIA and GHQ – 12 **Country of origin:** Iran	Health literacy affects various aspects of health General patients undergoing hemodialysis
3.	Cavanaugh et al, 2010, Low Health Literacy Associates with Increased Mortality in ESRD	**Purpose:** The purpose of this study was to characterize the prevalence of limited health literacy and test the cause of death based on literacy rates in patients undergoing hemodialysis. **Design**: Prospective cohort **Sample**: 480 patients. The mean age of participants was 62 years old. Gender 56 % males. **Instrument**: REALM **Country of origin:** United States	Limited health literacy in patients undergoing Hemodialysis is common and is associated with a higher risk of death.
4.	Dodson et al, 2016, Multifaceted Assessment of Health Literacy in People Receiving Dialysis: Associations With Psychological Stress and Quality of Life	**Purpose**: The purpose of this study was to describe health literacy in patients undergoing dialysis and look for factors related to health literacy. **Design**: cross-sectional **Sample**: 76 people who received hemodialysis in the dialysis unit, 16 people received peritoneal dialysis at home, and 8 people who received hemodialysis at home. The mean age of participants was 68 years old. Gender 57% males. **Instrument**: HLQ KDQOL-36 DASS-21 **Country of origin:** Australia	A low health literacy profile in patients undergoing hemodialysis is strongly associated with poorer quality of life. Depression and anxiety factors also increased in patients with low health literacy.
5.	Stømer, Wahl, Gøransson, Urstad et al, 2020, Health Literacy In Kidney Disease: Associations With Quality Of Life And Adherence	**Purpose**: This study aims to explore the relationship between multidimensional health literacy, quality of life (QoL) and adherence to long-term therapy in CKD patients **Design**: A descriptive single-centre cross-sectional study **Sample**: 187 Patients. The mean age of participants was 67 years old. Gender 65 % males. **Instrument**: HLQ QoL SF-12 VAS-QoL MARCH-5 **Country of origin:** Norway	Patients who have high health literacy have a significantly higher quality of life and better than patients with medium and low health literacy. Health literacy is essential for improving quality of life and long-term therapeutic adherence.

No	Researcher name, Year, Title	Method	Result
6.	Stømer, Wahl, Gøransson, & Urstad,2020, Exploring health literacy in patients with chronic kidney disease: a qualitative study	**Purpose:** To find out the level of knowledge about health literacy and explore the experiences of CKD patients **Design:** a qualitative study utilized individual in-depth interview **Sample:** 12 Patients. The mean age of participants was 66 years old. Gender 50% male and 50 % female. **Instrument:** HLQ **Country of origin:** Norway	- The existence of variations in patient attitudes and behaviors as a health information seeker The existence of fragmented health care problems in the context of multimorbidity - good relationship with health care providers
7.	Skoumalova et al,2019, Is Health Literacy of Dialyzed Patients Related to Their Adherence to Dietary and Fluid Intake Recommendations?	**Purpose:** To assess the relationship between multidimensional health literacy and non-compliance with dietary recommendations and fluid intake in patients undergoing hemodialysis **Design**: cross-sectional **Sample**: 452 patients Over the age of 18 who is diagnosed with stage 5 chronic kidney disease and undergoes hemodialysis for at least 90 days. Criteria for exclusion of dementia, severe acute illness and psychiatric diagnosis. The mean age of participants was 63 years old. Gender 60,7% males. **Instrument**: -SES -NADFIR self reported -HLQ **Country of origin:** Slovakia	There is a relationship between health literacy and non-compliance. Higher NADFIR found in patients with less health management ability - so that health literacy affects the adherence of patients undergoing hemodialysis
8.	Skoumalova et al, 2020, Does Depression and Anxiety Mediate the Relation between Limited Health Literacy and Diet Non-Adherence?	Purpose The aim of the study was to assess the relationship between health literacy, depression and anxiety with dietary non-compliance and to assess whether anxiety and depression mediated the relationship between health literacy and dietary non-compliance in patients undergoing hemodialysis. **Design**: cross-sectional **Sample**: 542 patients. The mean age of participants was 63 years old. Gender 60,7% males. **Instrument**: -questionnaire dietary non-compliance -Slovakian version of HLQ -Hospital Anxiety and Depression Scale (HADS) **Country of origin**: Slovakia	Patients with low health literacy are more likely to be disobedient to diet than patients with high health literacy. Patients with low and moderate health literacy are more likely to report depression or anxiety. Patients who report depression or anxiety are more likely to be disobedient to diet.

Adult Literacy in Medicine (REALM) instrument.[17] In comparison, five article used a sample of patients using the Health Literacy Questionnaire HLQ instrument.[16,15,10,13,14] And two studies use Health Literacy For Iranian Adults (HELIA).[6,12]

d. Level and benefits of health literacy

Most of the included studies found that patients had a lower level or inadequate health literacy6,12,16,10,13, while two studies show a moderate health literacy15,14, and one article found good health literacy.[17] Patients who have higher health literacy is associated with better quality of life.[6,16,15] Patients who have higher health literacy have better general health.[12] Limited health literacy is associated with higher mortality rates in patients with CKD. Patients with high literacy have a higher adherence rate to food and fluid intake.[13] Patients with lower health literacy are more likely to have moderate/severe symptoms of depression.[14]

e. Factors that affect a health literacy

Three articles state that education factors greatly affect the level of health literacy in hemodialysis patients.[6,12,15] The presence of factors related to non-adherence to dietary and fluid recommendations also affects the health literacy level of hemodialysis patients.[13] Two articles state that depression, psychological stress, or anxiety greatly affects the literacy of hemodialysis patients.[16,14] The last factor is good communication or relationships and mutual trust with health care providers that play a role in the level of health literacy in hemodialysis patients.[10]

DISCUSSION

The results showed that the average patient undergoing hemodialysis has lower or inadequate health literacy, even though having good literacy has several benefits for patients undergoing hemodialysis, including improving adherence to therapy[15], improving quality

of life[6,16,15] and also health in general[12]. Several factors affect health literacy in patients undergoing hemodialysis, there are, education[6], health care providers[10], anxiety factors and also happiness of these patients.[16,14] The review results are in line with research from Stømer et al., that female gender, lower education levels, the number of prescribed drugs that impact the economic burden and depressive symptoms are associated with lower health literacy in CKD patients.[18]

In CKD patients with a higher levels of health literacy have a better quality of life and are more obedient to lifestyle recommendations than patients who have lower health literacy.[6] Understanding health information is important for a patient's quality of life. The ability to engage with health care providers and actively manage health appears to play a role in adherence to predetermined therapies[15], adherence to diet, exercise, and home blood pressure monitoring.[19]

A lower health literacy is associated with poorer adherence indicate. Patients with lower health literacy are generally less active in communicating about their symptoms and concerns regarding their health condition. The patients also have issues on their adherence to treatment recommendations. Therefore, it is important to identify the level of health literacy to enable the provision of information about their disease, treatment so that patients will be confident. It is also important to support patient self-management activities and joint decision-making about their health.[13] Further studies identify the causal importance of health literacy respectively on potential to health promotion very required.[20]

Alemayuehu's research identified a statistically significant relationship between health literacy and quality of life. The relationship revealed that as the health literacy of patients undergoing hemodialysis improved, quality of life also improved, HL and QOL ($P<0.01$).[6] Bahadori's research results, et al showed that the good health literacy in 6,2 % do not have problems with general health status which is as much as 10,8 %. It was seen in the study of Aygun et al, that with a higher level health literacy were able to assess their own general health.[21]

The nature of a person's life experiences, comfort, and happiness can be influenced by the extent to which individuals have the potential to acquire, process, and understand the information and health services necessary to make informed health decisions.[6] Patients are dialysis patients who often have lower levels of education and social status that can affect their information literacy[1]. Increased levels of depression and anxiety in patients with limited health literacy may prevent them from using, their capacity to discover, understand, and act on health information, leading to less effective management of their diet and to a decrease in their ability to comply with dietary recommendations.[14] With a decrease in the ability to communicate diet-related problems with relevant health care providers due to feelings of failure, passive or feelings of uncertainty and thus the patient will continue to eat foods that are not recommended.[14]

Consideration of education and continuing health assessment in the subpopulation of patients undergoing hemodialysis can gradually improve the health literacy and quality of life of such patients.[6] Educational background that affect health literacy are in line with previous study, where age, education level and higher income are associated with domains having sufficient information.[22]

Stømer's study, Wahl, Göransson, Urstad, et al., showed that being active in managing their health and engaging with health care providers was associated with higher adherence to lifestyle recommendations in hemodialysis patients. It has been suggested that nurses should provide education, consultancy, and motivation for patients with CKD.[23] Some patients are confused about their role as patients, whether they are expected to ask questions or simply wait for a health care provider to tell them.[10] They state that the health aspect interests them and they want to learn more.[10] In addition, a study exploring health literacy among Norwegian patients with CKD found that the patients have different lengths to balance the amount of information they accessed and suggest that they needed.[24]

A study found that a higher health literacy clusters reported better quality of life in 4 of the 5 Kidney Disease Quality of Life–36 domains, fewer depressive and anxiety symptoms, and higher serum albumin (average difference = 2.06 g/L,p =.04) than lower health literacy clusters.[16] These results showed that people receiving dialysis felt more supported and informed about their health than other health consumers but were less active in managing it.[16] Higher health literacy is associated with better mental health and quality of life.[16] Identifying health literacy characteristics can help direct specific interventions to improve patient education and support.[16] The study results are inversely proportional from Green et al., that the average patient undergoing hemodialysis has limited health literacy and all of it has nothing to do with age, gender, serological value, adequacy of dialysis, quality of life or level of depression.[25]

The review have several limitation. First, all the literature sources obtained in this study are English articles. Second, the review only included studies that clearly mentioned the study was conducted in settings that included hospitals and clinics. Third, most studies are quantitative studies that can hinder the exploration of patient's expectation and experiences in health literacy.

CONCLUSION

The review found that most studies found a lower level of health literacy among patients undergoing hemodialysis. Several factors influence patient's health literacy that include psychological factors. Therefore, nurses and healthcare professionals must improve patient health literacy and provide comprehensive care. In addition, further studies could explore the experience and expectation of patient's health literacy to enable a deeper understanding of the topic.

CONFLICT OF INTEREST

The author declares that there is no conflict of interest in the writing of this article.

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There is no relevant financial or material interest in the research describe in this article.

ETHICS APPROVAL

Not applicable.

AUTHOR CONTRIBUTION

Conception and design of the manuscript: Berlian Ayu Rahmawati (BAR) and Erna Rochmawati (ER). Literature search, data analysis and interpretation, supervision : Berlian Ayu Rahmawati and Erna Rochmawati. Study screening and data extraction: Berlian Ayu Rahmawati and Erna Rochmawati. Writing original draf and editing or revising it critically for important intellectual content, read and approved the final manuscipt for submission: Berlian Ayu Rahmawati and Erna Rochmawati.

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