

Article

Social support and self-management among end-stage renal disease patients undergoing hemodialysis in Indonesia

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Abstract

Background: Self-management is the latest multidisciplinary intervention that empowers end-stage renal disease (ESRD) patients to be active in maintaining their health status. The implementation of self-management among ESRD patients undergoing hemodialysis in Indonesia remains relatively low, contributing to the high prevalence of complications and morbidity. The social cognitive theory proposes that social support is one of the environmental factors affecting health behavior change. Therefore, this study aimed to investigate the association between social support and self-management among ESRD patients undergoing hemodialysis in Indonesia.

Design and Methods: A cross-sectional study was conducted among 107 ESRD patients selected by consecutive sampling. Data were collected online from four chronic kidney disease communities in Indonesia in June 2020. Medical Outcome Study Social Support Survey and Hemodialysis Self-Management Instrument were used to measure patients' functional social support and self-management levels. Statistical analysis using the Chi-square test was applied to evaluate the association between social support and self-management.

Results: More than half of the patients had high social support (51%) and good self-management (53%). There was a significant relationship between social support and self-management ($p=0.027$; $\alpha=0.05$; odds ratio 95% CI = 2.386).

Conclusions: Social support is a potential environmental factor that can be modified to enhance health behavior change among ESRD patients in Indonesia, with the specific behavior being self-management. This study recommends functional social support as an integral part of self-management intervention provided through cooperation between health workers, chronic kidney disease community, and patient companions.

Introduction

End-stage renal disease (ESRD) is the final stage of chronic

renal failure, characterized by a decrease in the glomerular filtration rate below 15 mL/min.¹ ESRD has become a serious global health problem with a prevalence of 10.5 million people and is expected to increase, with the most significant growth occurring in Asia. In Indonesia, ESRD cases have increased significantly from 15.3 thousand in 2012 to 23.8 thousand in 2017.²

ESRD patients have permanent deterioration in renal function and, therefore, require renal replacement therapy to maintain body homeostasis. Approximately 98% of ESRD patients in Indonesia choose hemodialysis therapy.² The success of hemodialysis, nevertheless, cannot be achieved by adherence to the therapy alone but also by lifestyle modifications. Health workers have long applied rule-based education as a multidisciplinary intervention to involve patients' active role in lifestyle modification. However, studies found that this intervention was less relevant because patients could not be forced to follow a lifestyle determined by others.^{3,4}

The above phenomenon has led to the development of self-management as the latest multidisciplinary intervention to empower ESRD patients in modifying their lifestyles. Self-management can be defined as patients' positive effort to supervise and participate in the care process to optimize their health status. This effort consists of four components: self-care, problem-solving, partnership with health workers, and emotional management.^{5,6} Self-management has been shown to have a significantly positive impact on ESRD patients' health status, for instance, improving clinical outcomes and quality of life and reducing the incidence of complications. Nevertheless, the implementation of self-management in Indonesia is still far from ideal, resulting in high cases of complications and mortality.⁵ Social cognitive theory (SCT) proposes that self-management, as one of the forms of health behavior, can be influenced by personal and environmental factors.⁶

The authors explored that previous studies were more likely to identify the relationship between personal factors and self-management rather than study the role of environmental factors, one of which is social support.⁷ In addition, SCT states that social support has a vital role in encouraging both personal factors and health behavior.⁸ Moreover, the majority of previous studies that

Significance for public health

The prevalence of end-stage renal disease (ESRD) has significantly increased year over year, yet more than 50% of ESRD patients still do not comply with the recommended lifestyle modifications. Self-management is a new multidisciplinary treatment that empowers ESRD patients to monitor and participate in health care and lifestyle modifications, replacing previous compliance-based treatments. However, the implementation of self-management in Indonesia is still far from ideal. This study indicates a significant relationship between social support on self-management among ESRD patients undergoing hemodialysis in Indonesia. This study can provide new insights for health workers and social networks active in the interaction and care of ESRD patients regarding functional forms of social support that can be applied to support self-management among ESRD patients undergoing hemodialysis.

investigated social support in ESRD patients were known to use a structural approach, such as familial support, compared to studying the functional forms of support perceived by the patients.

This study aimed to identify the association between social support and self-management in ESRD patients undergoing hemodialysis. In contrast to previous studies, this study observed social support through its functional approach, regardless of the availability of specific sources of support. This approach measured the level of social support based on its five functional forms, namely, emotional, instrumental, informational, appraisal, and social integrity.^{9,10}

Design and Methods

Design, setting, and population

This study was an analytic observational study using a cross-sectional study design. Data collection was carried out online in June 2020 from four chronic kidney disease communities in Indonesia: Indonesia Kidney Care Club, *Hidup Ginjal Muda*, *Komunitas Pasien Gagal Ginjal*, and *Komunitas Pasien Cuci Darah Indonesia*. The sample size was 107, calculated at 95% confidence interval (CI), 50% anticipated population proportion, and 10% relative precision. The sample was then selected by consecutive sampling based on the following inclusion criteria: (1) ESRD patients aged ≥ 18 years; (2) undergoing routine hemodialysis; (3) able to read and understand Bahasa Indonesia; and (4) willing to participate by signing informed consent. This study has met the ethical considerations and was approved by the Ethics Committee of the Faculty of Nursing, Universitas Indonesia (Permit ID: SK-221/UN2.F12.D12.1/ETIK2020).

Variables and data collection

The independent variable in this study was functional social support, which was measured using the Medical Outcome Study Social Support Survey (MOS-SSS). The dependent variable was self-management, measured using the Hemodialysis Self-Management Instrument (HDSMI). The characteristics of the respondents measured consisted of age, sex, education level, monthly income, interdialytic weight gain (IDWG), and the total number of comorbidities. Both questionnaires had been used and translated to Bahasa Indonesia in the previous research.⁷ The results of the validity test for the two questionnaires were higher than the r table 0.279. The r count for MOS-SSS and HDSMI was 0.361-0.780 and 0.295-0.576, respectively. The reliability test results with Cronbach alpha showed a value of 0.815 for MOS-SSS and 0.620 for HDSMI. These values indicated that both questionnaires used were valid and reliable.

Statistical analysis

Data were analyzed using statistical software Univariate analysis in the form of proportional distribution was carried out on all variables. Bivariate analysis was performed to determine the association between social support and self-management using the Chi-square test.

Results

Respondents in this study came from 18 provinces in Indonesia, predominantly Jawa Barat, DKI Jakarta, and Jawa Tengah. Most of the respondents were middle-aged adults (35–64 years) (59%), male (60%), had high education level (51%), had high monthly income (69%), had IDWG $>2-5\%$ (48%), and had one comorbidity (66%). The most prevalent comorbidities were hypertension and diabetes mellitus.

Univariate analysis indicated that 51% of the respondents had high social support, while 49% had low social support. The form of social support with the highest percentage received by respondents was informational support, while the lowest was appraisal support (Figure 1).

Approximately 53% of the respondents in this study had good self-management. The component of self-management with the highest good proportion was emotional management, while the lowest was a partnership with health workers (Figure 2).

More than half (63.6%) of respondents who received high social support were known to have good self-management (Table 1). According to the analysis result, the p -value was <0.05 , suggesting an association between social support and self-management. The odds ratio (OR) indicated that respondents with high social support were 2.38 times more likely to have good self-management at 95% CI than those with low social support.

Discussion

Social support

This study indicated that more than half of the respondents had high social support. This finding was consistent with previous studies conducted on ESRD patients in Taiwan and Indonesia.¹¹⁻¹³ Those results might be influenced by the respondents' characteristics, particularly their level of education and income, which were known to be the predictors of the respondents' social network size and social support level. The higher the level of education and income, the higher the respondents' tendency to join and actively participate in social networks, such as the chronic kidney disease community.¹⁴

Table 1. Association between social support and self-management (N=107).

Social support	Self-management				P value	Odds ratio (95% confidence interval)
	Good		Poor			
	n	%	n	%		
High	35	63.6	20	36.4	0.027	2.386 (1.097-5.193)
Low	22	42.3	30	57.5		

The respondents' active involvement in the chronic kidney disease community could also affect the level of social support they received. Of the five functional forms of social support, most respondents received a high level of informational and emotional support. This indicated that most respondents had great access to knowledge, suggestions, and feedback, as well as satisfaction with love and affection. This access could be provided by the chronic kidney disease community, which acted as a forum for the respondents to obtain information or to discuss with health experts, as well as a place to share stories, enthusiasm, and motivation with the other ESRD patients. In other words, respondents who were members of the community had a higher chance of obtaining informational and emotional support than those who were not included in the community.

On the other hand, 49% of the other respondents were shown to have a low level of social support. This phenomenon might be caused by the respondents' low level of instrumental, appraisal, and social integrity support. Each form of support had a unique functional role; hence, an inadequate level of certain forms could affect the respondents' perceptions of the availability of social support as a whole. In addition, the low level of social support among some respondents could be caused by internal and external factors.⁹ Internal factors included unsociable traits, low assertiveness to ask for help, and the fear of being a burden to others. Meanwhile, external factors included the difficulties and lack of resources from support providers to provide help or insensitivity trait to the need of others.

The phenomenon that almost half of the respondents received low social support was deplorable because high social support had the potential to improve self-care, the partnership between patients and health workers, and the ability to manage stress.¹⁵ Those potentials were significant components of self-management, which could improve clinical outcomes and reduce morbidity and mortality among ESRD patients in the long term.

Self-management

In line with previous studies conducted among ESRD patients in Indonesia and Ethiopia, this study found that more than half of the respondents had good self-management.^{7,16} This result might also be influenced by the respondents' characteristics, which were the predictor of self-management. For example, the high levels of education and monthly income could improve problem-solving and self-care skills, as well as opportunities to access ideal nutri-

tion, therapy, and information.^{5,17} In addition, most respondents were middle-aged adults who could influence better problem-solving skills than elderly respondents.⁶

Based on the four components of self-management, emotional management had the highest percentage, indicating that most respondents had good skills in overcoming emotional turmoil that might arise during the implementation of self-management. This skill was desirable, given the fact that ESRD patients undergoing hemodialysis were prone to have depression.^{1,18} The existence of good emotional management skills, moreover, could reduce patients' negative perceptions of the disease, develop adaptive coping, and prevent the emergence of various psychological problems in the future.^{7,18}

Following emotional management, self-care was the second component that had a reasonably high percentage, indicating that most respondents had the skill in controlling the disease to prevent complications. Based on the questionnaire used, this particular skill was actualized through the implementation of nutritional management, fluid restriction, consumption of medications as recommended, monitoring body weight regularly, and following hemodialysis on schedule. On the other hand, this study also found that almost half of the respondents still had IDWG above 2%, which illustrated that most respondents were still unable to maintain their dry body weight through self-management activities. This could be attributed to the fact that self-care skill alone was not a measure of one's self-management level but must be balanced by the other three skills or components as one unit to achieve the optimal results.

Contrary to the above, partnership with health workers was the lowest component the respondents had. This condition was unfortunate, considering that health workers should be one of the most significant sources to help ESRD patients develop and determine the best self-management strategy.¹⁹ This could be attributed to the cultural factors in the Asian community that tended to be more compliant with instructions from professions that were considered to have authority or expertise. Thus, the possibility of expressing opinions or feelings tended to be smaller.^{5,6} This culture is different from that in America or Europe, where people are more proactive in expressing their opinions or feelings.

The lack of some components above could also affect the respondents' ability to achieve optimal self-management skills, which explained why 47% of the respondents still had low self-management. In addition, previous studies found that individual

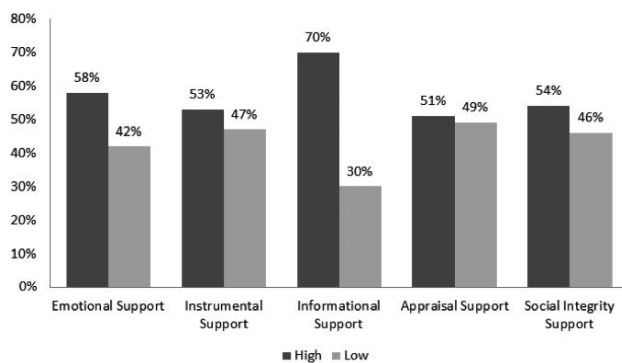


Figure 1. Respondents' level of 5 functional forms of social support (N=107).

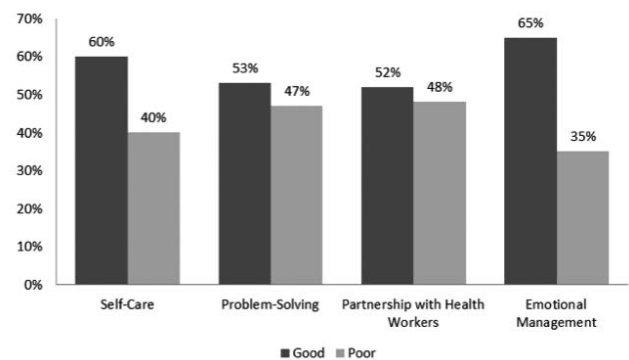


Figure 2. Respondents' level of 4 components of self-management (N=107).

characteristics could influence low self-management. Male sex was known to have lower self-care skills than female, while the presence of comorbidities could increase the burden of patient care, which then resulted in a lower problem-solving skill.^{6,20}

Association between social support and self-management

The findings of our study indicated an association between social support and self-management, and this finding is in line with the previous studies conducted in Indonesia, Brazil, and Taiwan.^{6,7,21} This consistency proved SCT's proposal that health behavior, in this case, self-management, could be influenced by environmental factors, such as social support.

ESRD and hemodialysis had a significant impact on the various aspects of the patients' life. Hence, social support played a vital role in helping them carry out the responsibility of optimizing their health.⁶ This role was actualized through the ability of social support to influence each component of self-management.^{6,7,13,21}

In the self-care component, social support had a positive impact on limiting fluid intake, as well as increasing adherence to nutritional therapy, medication, and hemodialysis.^{13,21} Social support also affected the problem-solving component of ESRD patients, which in the long term could help them to adapt to the disease and the challenges associated with the therapy.²² In the partnership with health workers component, social support was known to increase active communication regarding the self-management process, for example, checking dialyzer's parameters or determining dialysis time with the nurses.⁶ Whereas in the emotional management component, social support could help the formation of positive perceptions related to illness and health conditions, which was the base of adaptive coping.^{6,7,21}

Future directions

Future research is recommended to explore the factors that influence social support and self-management among ESRD patients undergoing hemodialysis. Due to many differences in the questionnaires used in previous studies regarding social support and self-management, this study recommends the development of a standardized social support and self-management questionnaire representing a broader population of ESRD patients undergoing hemodialysis. In addition, introducing the concept of functional social support and its association with self-management among ESRD patients in the curriculum and additional training of current healthcare professionals is recommended to increase awareness among healthcare professionals and indirectly among patients and the general public.

Conclusions

This study indicated that social support was one of the environmental factors that had the potential to promote self-management among ESRD patients undergoing hemodialysis, specifically in Indonesia. Furthermore, it recommends the fulfillment of functional social support as an integral part of self-management intervention provided through the cooperation of health workers, chronic kidney disease communities, and patient companions. Future studies are recommended to explore the factors influencing social support and self-management in ESRD patients undergoing hemodialysis.

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Key words: End-stage renal disease, Hemodialysis, Self-management, Social support.

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Institutions where the research was carried out: This study was carried out in several communities of kidney failure patients, including: Indonesia Kidney Care Club, Hidup Ginjal Muda, Komunitas Penderita Gagal Ginjal, and Komunitas Pasien Cuci Darah Indonesia

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Patient consent for publication: Prior to the study, all patients had signed an informed consent, which explained that the results of this study could be used in the form of reports, presentations, and publications, but the researcher would not identify the patient's personal data.

Informed consent: Online informed consent was obtained from each subject after they were provided with complete descriptions of the aims and procedures of the study, were made aware of data protection, and were ensured they could terminate the study at any time.

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