Effect of Empowerment Program on Quality of Life, Adherence, Clinical Outcomes and Care Giver Burden of Patients Undergoing Hemodialysis: A Systematic Review"

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Abstract

Background: Over a million people worldwide die from chronic kidney failure each year, and the number of people with the condition is rising quickly. Patients that go through the empowerment process learn how to manage their families well, which enhances their lifestyle and quality of life. **Aim:** This systematic review's objectives were to summarise the impact of empowerment programmes on patients receiving hemodialysis's quality of life, adherence, clinical outcomes, and caregiver burden, identify the most frequently used tools, and report on the results of these programmes' effects on both patients and caregivers. **Method:** We conducted a PRISMA-compliant search for papers using the terms "empowerment programme" and "hemodialysis" or "quality of life AND adherence" or "clinical outcomes AND care giver burden" in conjunction with other terms in the PubMed, Psyc INFO, Web of Science, and CINAHL databases. **Results:** Five empirical studies were discovered to be relevant to our research. The effect of an empowerment programme on the patients quality of life, adherence, clinical results, and caregiver burden of hemodialysis patients is evaluated using a variety of methods. We discovered that there were substantial differences between the groups in terms of changes in haemoglobin and hematocrit levels, interdialytic weight gain, and changes in both systolic and diastolic blood pressure before and after the intervention. Prior to the empowerment, all caregivers had high levels of anguish; however, following the empowerment, 66% of caregivers experienced mild to moderate levels. After six weeks, the patients in the empowerment group had a higher score for quality of life. **Conclusions:** Empowering hemodialysis patients and their caregivers can improve adherence and clinical results while easing caregivers' distress, as this review emphasizes. In order to minimise the deterioration of their health issues and quality of life, it is important to consider empowering persons with renal insufficiency.

Keywords: Empowerment Program, Quality of Life, Adherence, Clinical Outcomes and Care Giver Burden.

1. Introduction

Prevalence of people with kidney failure is rising rapidly worldwide, causing one million people dying from chronic kidney failure every year. **(LeiliRabiei et al., 2020).** Empowering is a process in which patients and family members gain knowledge and skills to better manage family life, thereby improving the lifestyle and quality of life of family members. **(Amany Ibrahim Abdalla et al., 2019).** Numerous factors affect the hemodialysis patients' quality of life. Patients who are diagnosed with chronic renal failure undergo major life changes because of hemodialysis. Patients and their family are forced to live complicated, altered lifestyles due to changes in daily patterns and their constraints, which eventually lowers their quality of life. **(MohammadkarimBahadori et al., 2014).**

Adherence to the management is critical in the lives of hemodialysis patients. According to the WHO, adherence refers to how closely a person adheres in taking medication, eating a certain way, and/or changing their lifestyle. Unfortunately, poor compliance with hemodialysis is a widespread issue in healthcare with serious medical, social, and financial ramifications, especially in patients receiving hemodialysis. **(Rakshitha B. V et al., 2019)** There is a great need for all patients to receive information on medication, diseases, lifestyle and dietary changes. Patients with renal failure are put in a rigid state where significant changes in serum electrolyes, albumin, and haemoglobin levels might be harmful. **(UdayVenkatMateti et al., 2018).** Patient families are responsible for much of the care and support of hemodialysis patients and bear a significant burden in caring their loved ones which

Doi.org/10.31838/hiv22.02.775 Received: 14.07.22, Revised: 22.08.22, Accepted: 27.09.22

can be the physical, psychological and social burden associated with care giving. **(Reza Sotoudeh et al., 2019)** Patients with renal failure must adapt their lifestyles in order to manage their condition and its complications because hemodialysis is a long termprocess. **(Marwan A. Bakarman et al., 2018)**

Review Aims

This review provides and explores a conclusive summary of the efficacy of empowerment program on quality of life(QOL), adherence, clinical outcomes and care giver burden of patients undergoing hemodialysis. Thus, the major objective of this systematic review was to (1) summarize the effect of empowerment program on patients quality of life, their adherence, various clinical outcomes and care giver burden of patients undergoing hemodialysis(2) identify the tools are used to measure effect of empowerment program on patients undergoing hemodialysis and their caregivers most frequently and (3) report on the results of the empowerment program's effectiveness on quality of life, adherence, clinical outcomes and care giver burden of patients undergoing hemodialysis.

2. Material and Method

Study selection and data collection processes

This review was performed according to PRISMA guidelines. A comprehensive search of electronic databases including PubMed,Psyc INFO, Web of science,and CINAHL database was conducted as part of a systematic review examining outcomes of effect of empowerment program on quality of life, adherence, clinical outcomes and care giver burden of patients undergoing hemodialysis. All databases' searches were using a combination of the Following Free-Text Terms: "empowerment program" AND "hemodialysis OR "quality of life ANDadherence"OR "clinical outcomes AND care giver burden".In the initial phase, duplicates were eliminated and reference lists of relevant articles were examined to identify additional studies that met the inclusion criteria. Following this preliminary examination of the literature, reviewers looked over titles and abstracts to find those that matched the requirements for inclusion [31].

Eligibility criteria

The studies which were included in this systematic review met the following requirements: (1) effect of empowerment program on quality of life, adherence, clinical outcomes of patients undergoing hemodialysis and care giver burden (2) An intervention study focused on impact of empowerment program on quality of life, adherence, clinical outcomes and care giver burden of patients undergoing hemodialysis, (3) Used quantitative research which includes a non-experimental or pre test –post test comparison group to assess the effect of empowerment program on quality of life, adherence, clinical outcomes and care giver burden of patients undergoing hemodialysis and (4) These papers were published as original research articles in peer –reviewed journals .Paper was rejected if they were :(1) Without effect of an intervention that is empowerment program on quality of life, adherence, clinical outcomes and care giver burden of patients undergoing hemodialysis, (2) qualitative research studies, review articles, case reports or case series, theses or dissertations, and (3) the language of publication was not in English.

Data extraction

Data from included studies were systematically recorded using a data extraction tool: (1) Study characteristics, authors, research design of the sudy, year, and place of data collection, (2) Characteristics of study particiapnts undergoing hemodialysis:number of patientsand mean age of patients, (3) Tools used to measure impact of empowerment program on quality of life, adherence, clinical outcomes and care giver burden of patients undergoing hemodialysisand (4) Findings

Study quality assessment

The Critical Review Form for Quantitative Studies and the STROBE Reporting Guidelines for Observational Studies and were used to assess the study's quality. Each question could have a complete (score = 2), partial (score = 1), or imprecise (score = 0) answer. For each study, a total score was calculated. Based on the grades received, the studies were rated as poor (score<12), fair (score between 13 to 24 points), good score between 25 and 30 points), or excellent (score between 30 to 36 points). Studies were evaluated by the External experts independently.

3. Results

The search strategy produceed 405 studies (PubMed n = 175, PsycINFO n= 124,Web of Science n = 85, CINAHL n = 21). Publications which were duplicate were eliminated, leaving 252 viable articles. All selected studies' titles and abstracts were reviewed during the step of screening. As a result, 153 papers were excluded since they weren't deemed appropriate for the current review. 56 studies were ultimately chosen for the eligibility phase. 51 of them were disqualified as the selection criteria was not met. In the end, 5 empirical studies were pertinent to our research (Table 1). More information on the procedure of study selection is available in the PRISMA flow diagram (Fig. 1).

Study quality

The quality was "fair" for two studies. **(MarziehMoattariet al., 2012; Lee, Suk Jeong,**

2018)and "good" for the remaining three (Omebrahiem A. El-Melegy, Amaal M. Al-Zeftawy, Samia E. Khaton, 2016; Hala Mohamed MohamedBayoumy, Aml Khalil Ibrahim and Elizabeth BW,2017; HosseinShahdadi, Zahra Rahdar, Ali Mansouri, AbdolghaniAbdollahimohammad, 2018)

Study characteristics

The methodological and general characteristics of the studies reviewed are summarised. in **Table 1**.Fourstudies are experimentalstudies (Omebrahiem A. El-Melegy, Amaal M. Al-Zeftawy, Samia E. Khaton, 2016;Hala Mohamed MohamedBayoumy, Aml Khalil Ibrahim and Elizabeth BW, 2017; HosseinShahdadi, Zahra Rahdar, Ali Mansouri, AbdolghaniAbdollahimohammad, 2018;Lee, Suk Jeong, 2018). Only one study is randomized controlled trialstudy (MarziehMoattari et al., 2012). The studies were published from 2012 to 2018. Included studies had been conducted in Iran, Egypt, Saudi Arabiaand Korea.

Characteristics of patients with CKD undergoing hemodialysis

These 5 studies, the number of patients undergoing hemodialysis included were 235.

Measuring intervention used in patients undergoing hemodialysis

This review of measuring intervention used in hemodialysis patients showed **MarziehMoattari et al., 2012** used the Self-reported questionnaire, QoL questionnaire, Empowerment intervention; **Omebrahiem A. El-Melegy, Amaal M. Al-Zeftawy, Samia E. Khaton, 2016** investigated Revised scale of caregiver self-efficacy, Caregiver burden interview and Empowerment model; **Hala Mohamed MohamedBayoumy, Aml Khalil Ibrahim and Elizabeth BW, 2017** adopted dialysis symptom index(DSI), dietary and fluid compliance indices, kidney disease health related quality of life (KDQOL), Beck depression inventory and Empowerment Program; **HosseinShahdadi, Zahra Rahdar, Ali Mansouri, Abdolghani Abdollahimohammad, 2018** administered Beck Depression Inventory and Family-centered empowerment model and **Lee, Suk Jeong, 2018** administered HRQOL, self-management instrument and empowerment program.

Table1: Participant Characteristics

Author(year)	Type of study design (Nation)	Number of patients (n)	Mean age of patients (n)	Measuring intervention	Findings
MarziehMoattari et al., 2012	Randomized controlled trial study (Iran)	48	38.56 ± 11.4	Self-reportedquestionnaire, quality of life questionnaire, Empowerment intervention	The groups differed significantly in terms of both systolic/diastolic blood pressure changes, interdialytic weight gain, haemoglobin and hematocrit values.
Omebrahiem A. El-Melegy, Amaal M. Al-Zeftawy, Samia E. Khaton, 2016	Experimental study (Egypt)	50	47.18 ± 14.24		
Hala Mohamed MohamedBayoumy, Aml Khalil Ibrahim and Elizabeth BW, 2017	Experimental study (Saudi Arabia)	60	58.5 ± 17.7	Dialysis symptom index, indices of nutritional and hydration compliance, quality of life scores for patients with chronic kidney disease, Beck depression scale, and Empowerment Program	After six weeks, the patients in the empowerment group had a higher quality of life score.
HosseinShahdadi, Zahra Rahdar, Ali Mansouri, AbdolghaniAbdollah imohammad, 2018	Experimental study (Iran)	30	36 ± 5.00	Beck Depression Inventory and Family-centered empowerment model	There was a statistically significant difference between before and after the intervention in the intervention group's degree of depression and dread of dying (p = 0.001).
		47	63.1±10.6		group when compared to the control group (F=9.21, p=0.004, p=.020) and life quality

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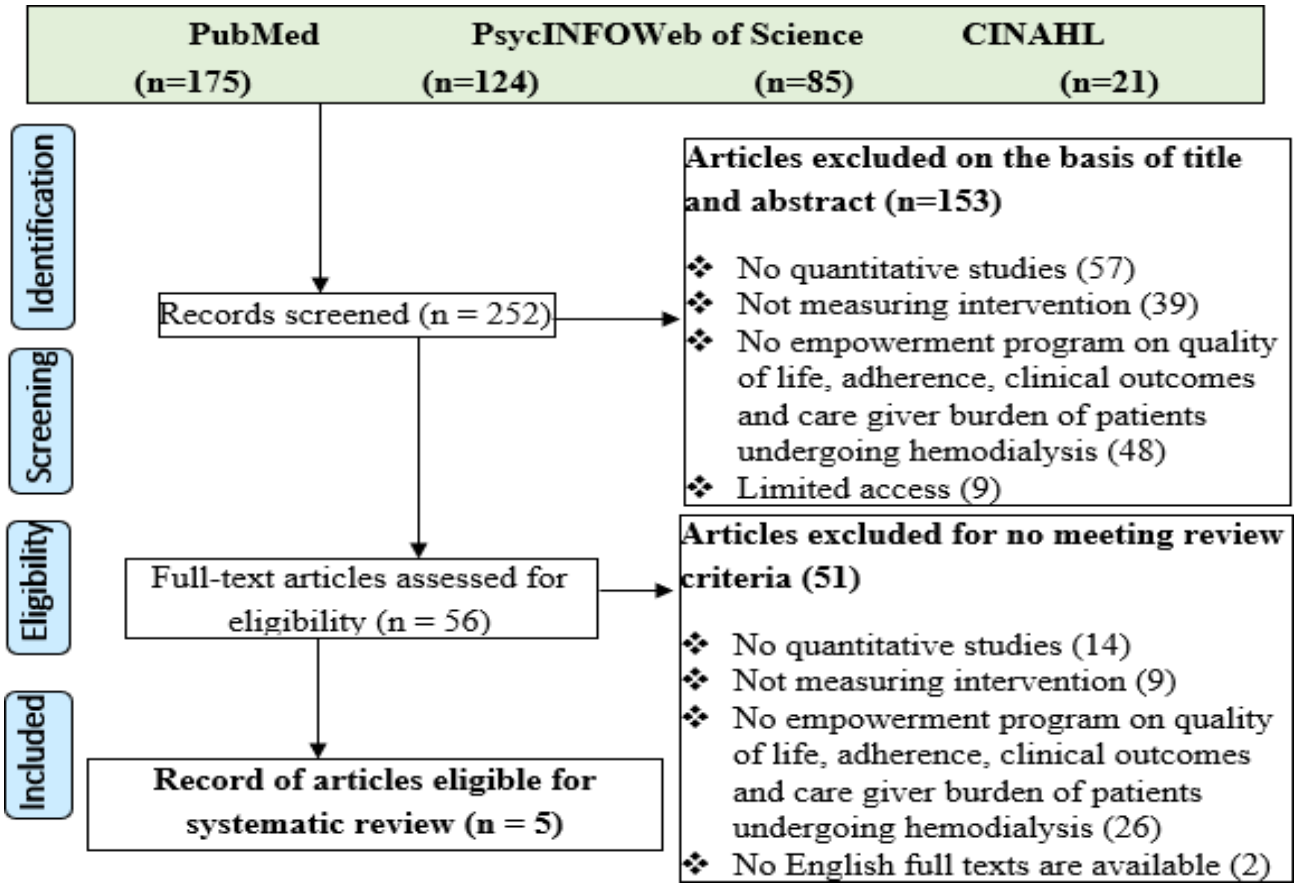

Fig. 1 PRISMA flow diagram

Outcomes of impact of empowerment program on quality of life (QOL), adherence, clinical outcomes and care giver burden of patients undergoing hemodialysis

Among selected studies reported that effect of empowerment program on patients quality of life, adherence, clinical outcomes and care giver burden of patients undergoing hemodialysis.**MarziehMoattari et al., 2012** found that the groups differed significantly in both systolic/diastolic blood pressure changes, interdialytic weight gain, haemoglobin and hematocrit levels. In Experimental study, **Omebrahiem A. El-Melegy, Amaal M. Al-Zeftawy, Samia E. Khaton, 2016** showed that all caregivers reached a severe level of distress before the empowerment, while after the empowerment 66% fall to a mild to moderate level. Significant relationship between nurses' distress level and their level of patient relationship, educational level, and duration of responsibility for patient care and companionship following empowerment was found. ($P < 0.05$).**Hala Mohamed MohamedBayoumy, Aml Khalil Ibrahim and Elizabeth BW, 2017**reported that after six weeks, Patients in the empowerment group scored higher on QOL.

Except for URR, Kt/V was significantly lower in the control group only at baseline (p=0.02), and albumin was significantly higher in the eintervention group both at baseline and 6 weeks after the programme (p=0.001), the most of the parameters measured were not significantly different between the two groups before or after the programme. **HosseinShahdadi, Zahra Rahdar, Ali Mansouri, AbdolghaniAbdollahimohammad, 2018**found that the level of depression and fear of death in the intervention group was significantly improved after the intervention(p = 0.001). **Lee, Suk Jeong, 2018** showed that the pre- and post-intervention increase in overall self-management in the intervention group (F=9.21, p=0.004), efficacy (F=5.81, p=0.020), and quality of life all showed a substantial improvement when compared to the control group..

4. Discussion

This systematic review was aimed at exploring the effect of empowerment program on patients quality of life, adherence, clinical outcomes and care giver burden of patients with CKD undergoing hemodialysis. The quality evaluation of the articles under examination revealed that they satisfied the majority of the necessary criteria, including the relevancy of the topic, methodological quality, analysis, and acceptable impact. The articles under evaluation demonstrated the impact of empowerment programmes on patients undergoing hemodialysis's quality of life, adherence, clinical results, and caregiver burden. Both

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Systolic/diastolic blood pressure fluctuations, interdialytic weight gain, haemoglobin levels, and hematocrit levels were substantially different between the groups before and after the intervention.Except for urea reduction ratio (URR), dialysis adequacy (Kt/V), and albumin, most compliance metrics were not differed substantially between groups before or follow-up after 6 weeks. The empowerment group had successfully curbed their interdialytic weight increase and systolic blood pressure when the the follow-up was carried out. In comparison to the control group, they also showed significantly lower prevalence and severity of DSI symptoms six weeks after the programme ($p < 0.001$). After six weeks, patients in the empowerment group had a higher QOL score. With the exception of URR and Kt/V, which were considerably lower for the control group only at baseline ($p=0.02$, $p=0.01$), the bulk of parameters assessed between the two groups before the programme or 6 weeks after the programme were not significantly different and albumin (significantly higher for the empowerment group both at baseline and after the program) ($p=0.001$, $p=0.02$).**MarziehMoattari et al., 2012; Hala Mohamed MohamedBayoumy, Aml Khalil Ibrahim and Elizabeth BW, 2017.**Supportively,the post-total mean scores for participants' adherence are considerably increased during the periods of the follow-up evaluation compared to the pre-program assessment ($X2=34.587$, $P=0.001$). Prior to the intervention, there was no significant difference found between the two groups in adherence to the medication regimen or diet programme ($P=0.600$, mean difference 1.96, mean difference 0.2000). ($P = 0.700$ mean difference 1.33) and physical activity. At two weeks, the family-centered education (intervention) group showed considerably better adherence to the medication ($p=0.001$, mean difference 2.72), diet programme ($p=0.001$, mean difference 43.1), and physical activity ($p=0.035$, mean difference 2.41). Compared to the group receiving patient-centered education, both the overall adherence score ($P=0.030$) and 0.89 were higher.Only adherence to the medication regimen distinguished the groups significantly ($P <0.001$) after 4 weeks. a notable difference ($P< 0.001$) existed between the two groups in the rate of change in the mean adherence ratings across all the three levels of measurement. Daily pill intake was independently correlated with both medication adherence and attendance for HD sessions ($P=0.020$, $P=0.026$). Both the total adherence score and the score of medication adherence were independently correlated with the vascular access site ($P<0.001$).**GaneshSritheranPaneerselvam et al., 2022;Hala I. Abo Deif et al., 2015;ParvanehAsgari et al., 2015;Reza Masoudi, MasoodLotfizade et al., 2020; Victoria Alikari et al., 2018;HosseinHabibzadeh et al., 2020 and Asmaa M. Hassana et al., 2019.**In addition, experimental designstudy, **Omebrahiem A. El-Melegy, Amaal M. Al-Zeftawyand Samia E. Khaton, 2016**showedthat the majority of carers are not very empowered. Following the empowerment, nearly a third and more of them drop to medium and high levels, respectively. Before the empowerment, all caregivers reached severe distress levels; after the empowerment, 66% of caregivers decreased to mild to moderate levels. Hemodialysis patients who feel empowered are better able to manage their health issues, have higher levels of self-efficacy, and experience lower caregiver burden..Similarly, **Dalia I. Abd El-Azem et al., 2018; GolnarGhane et al., 2017; NasrollahGhahramani et al., 2022; VincenciusSurani et al., 2021; Bent Al HodaTaheri and AlirezaSalar, 2021; Zahra Royani et al., 2013** described asthe group of online peer mentors, the ZBI (Zarit Burden Interview) score significantly decreased ($p=0.002$ vs. baseline). Online peer mentoring helped caregivers of CKD patients feel less stressed out. Hemodialysis patients can promote and maintain their self-care by using the family-centered empowerment approach, which is implemented through enhancing the patient's and their families' capacity for care..Our review study,**HosseinShahdadi, Zahra Rahdar, Ali Mansouri, AbdolghaniAbdollahimohammad, 2018 and Lee, Suk Jeong 2018**reported that the intervention group, significant difference was found in the degree of dread of dying between before and after the intervention ($p = 0.001$). No statistically significant difference was identified ($P = 0.21$) in the control group. The fear of death variable significantly differed between the intervention group and the control group before the intervention ($p=0.014$). This difference was significant ($P = 0.001$) following the intervention. The level of depression in the intervention group after intervention differed significantly ($P = 0.001$). In terms of improvements in overall self-management and self-efficacy before and after the intervention, there was a significant improvement in the experimental group than the control ($F=9.21$, $p=0.004$). $p=0.020$) and life quality Supportively. **Bindoo S Jadhav et al 2014;EileanRathinasamy Lazarus 2019; SeyedehAzamSajadi et al., 2021; MasoudRayyani et al., 2014; Victoria Alikariet al., 2015** showed thatthe In the intervention group (mean 66.5), mean scores for the subscales of renal illness and overall quality of life were higher and statistically significant ($p<0.01$) than in the control group (mean 55.25), Suburban dwellers, the unemployed care givers spouses, those with lower educational and economic levels, caregivers who cannot leave their patients alone in home, those who are living in the same house as their patients, and those caring for male patients had much lower quality of life than other groups. ($P< 0.05$) in comparison to other participants. Patients' overall quality of life, overall physical, and mental health were all measured using the SF36 (mean = 45.82, SD = 19.06, and 45.52, SD = 19.26 in low.

Finally, our study reveals the scarcity of published studies on the effect of empowerment program on quality of life, adherence, clinical outcomes and care giver burden of patients undergoing hemodialysis.In order to ascertain whether initiatives to improve the impact of empowerment programmes on quality of life, adherence, clinical results, and caregiver burden of patients receiving hemodialysis are effective, more study in this area would be helpful. Data on follow-up evaluations, transfer and generalisation outcomes of the effectiveness of a comprehensive nursing interventional package, and the impact of an empowerment programme on patients undergoing hemodialysis patients' quality of life, adherence, clinical outcomes, and caregiver burden are also lacking. Despite their major contributions to the literature in this field, we excluded qualitative research explicitly because its findings cannot be generalised to broad populations of people with the similar level of reliability as quantitative analysis.

5. Conclusion

Our review shows that Empowering hemodialysis patients and their caregivers can ease caregivers' workloads while also assisting patients in managing adherence and clinical outcomes. It is crucial to pay more attention and importance to be given to the role that families play in empowering the individuals if we are to enhance levels of mental health and, by extension, quality of life. In order to minimize the deterioration of their health issues and quality of life, it is essential to consider empowering persons with renal insufficiency.

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