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Self-determination in health is a psychological factor influencing observational survival and symptom perception among patients in hemodialysis programs. A multicenter observational study.

Franklin Mora Bravo [1], Paulina Cruz Idrovo [2], Marcia Verónica Pozo Calderón [3], Alfonso Silva Contreras [4], Marisol Pérez Herrera [5], Washington Osorio [6], Rafael Becerra Guerra [7], Nelson Rojas Campoverde [8], Guillermina Lucía Blum Carcelen [8], Gustavo Guevara Nolivos [9], Rosalina de Lourdes Lituma [10], Wilmer Stalin Sanango Reinoso [11], Santiago David Silva Tobar [12],Oscar Ron [13], Diego Adolfo Vimos Cochanga [14], Victor Hugo Ortega Coronel [15], Elizabeth González González [16], Marlon Brayan Rivilla Nieto [17], Yamilka Rodriguez Cueto [18], Juan Carlos Paz Veloz [19], Estefanía Isabel León Hernández [20], Adriana Pamela Cabrera Eugenio [20], María Cristina Chediak Terán [21], Byron Fabricio Saa Sabando [22], Karol Vacacela Guerrero [23], Gustavo Coello Becerra [7], María José Cajas Romero [20].

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1. Pafram Unidad de Hemodiafiltración, Red Complementaria de Salud de Morona Santiago, Ecuador.
2. Unidad de Diálisis Soldial, Salinas, Santa Elena, Ecuador.
3. Menydial Ibarra, Ecuador.
4. Contigo S.A. Dialicon-Quito, Ecuador.
5. Hospital del Iess La Mariscal, Quito, Ecuador.
6. Hospital de Especialidades Fuerzas Armadas N1, Quito, Ecuador.
7. SERDIDYV – Guayaquil, Ecuador.
8. Fundación Renal del Ecuador, Guayaquil, Ecuador.
9. Corporación Integral de Diálisis (CID) INSNEP Sur, Quito, Ecuador.
10. Hospital IESS-Ambato, Ecuador.
11. Hospital Universitario Católico de Azogues, Cañar, Ecuador.
12. Hospital General Docente Ambato, Ecuador.
13. Hospital General de Norte de Guayaquil Los Ceibos, Guayaquil, Ecuador.
14. Menydial-Riobamba, Ecuador.
15. Unidad Médica Vida, Riobamba, Ecuador.
16. Unidad de diálisis Contigo, El Carmen, Manabí, Ecuador.
17. Dialclinic–Quito, Ecuador.
18. Clínica Renal Centro-El Carmen, Manabí, Ecuador.
19. Hospital Militar Guayaquil, Ecuador.
20. Servicio de Nefrología, Hospital Pablo Arturo Suárez, Quito, Ecuador.
21. Servicio de Nefrología, Hospital General Docente de Calderón, Quito, Ecuador.
22. Clínica de Diálisis Renal Centro Santo Domingo de los Tsáchilas, Ecuador.
23. DIALILIFE. Centro de diálisis, Quevedo, Ecuador.

* Correspondence author
Email: Washington Osorio <dr.osoriow@yahoo.com >/Address: Nephrology Service, - Armed Forces Specialty Hospital N1, Quito, Ecuador. 170136.

Abstract

Introduction: Health self-determination (ADS), defined as a patient's inherent ability to make informed and active decisions about their health care, is a modifiable psychological factor that is correlated with motivation, proactive behavior, and improved physical health outcomes. In the context of hemodialysis (HD) therapy, ADS promotes functional autonomy and active patient engagement, even in the face of vulnerability; in contrast, its absence is associated with decision-making delegation and deterioration in health. The study hypothesizes that patients in hemodialysis programs with higher ADSs will have a lower perception of symptoms and more prolonged survival.

Methods: This observational, case–control study was carried out in 14 hemodialysis units in Ecuador from May to June 2025. Patients aged 18 years or older who were enrolled in hemodialysis programs were included. Two groups were formed: one with patients without ADS and the other with patients with ADS. The variables studied included age, duration of hemodialysis treatment, self-determination in health, adherence to treatment, labor integration, physical dependence, acceptance of kidney disease, and scores on "The Dialysis Symptom Index". A 1:1 propensity score-matching (PSM) was performed between the groups based on age, sex, and the presence of type 2 diabetes mellitus. The means were compared using Student's t-test, while proportions were compared using chi-square tests. An observational survival analysis was also conducted to examine the length of stay in the hemodialysis unit up to the date of the survey.

Results: A total of 180 patients without ADS and 184 with ADS were analyzed. Age was similar in both groups (57.9 ± 13.7 years vs. 58.0 ± 11.8 years, P = 0.938). The proportion of men was similar in both groups (51.1% vs. 51.6%; P=0.921). The prevalence of type 2 diabetes mellitus was comparable between the groups (48.3% vs. 47.3%; P=0.841). The group without ADS had a higher rate of physical dependence (53.3%) than the group with ADS did (25.5%) (P < 0.001). Adherence was greater in the group with an ADS (51.6%) than in the group without an ADS (36.7%; P < 0.001). Work activity was more common among the group with ADS (38.0%) than among the group without ADS (12.2%; P < 0.001) (12.2%). Compared with the group without ADS, the group with ADS had a lower symptom intensity (–25.82%) (P<0.001). Increased survival was observed in the ADS group, with 29.5 months versus 36.08 months in the non-ADS group ($\chi 2$, log-rank 7.71, P <0.005).

Conclusions: Patients with ADS exhibited longer survival, significantly higher treatment adherence, and less physical dependence. Additionally, self-determination was associated with a reduction in the severity of perceived symptoms, including pain and psychological symptoms such as worry and sadness, across 18 of the 34 assessed. These findings demonstrate that ADS is not just a psychological concept but also a therapeutic goal that impacts survival. Randomized intervention studies in ADS are necessary.

Keywords:

Self-determination in Health, hemodialysis, adherence, work activity, physical dependence, symptom scale.

Self-determination in health (SHD) is defined as the fundamental right and inherent capacity of an individual to make informed and active decisions regarding their own medical care and well-being, positioning them as the primary agent in the management of their life. ADS is consistently correlated with positive effects on motivation, proactive health behavior, psychological health, and, ultimately, physical health outcomes [1].

The context of hemodialysis (HD) therapy, which involves chronic, vital, and highly dependent treatment, constitutes a particularly relevant field for the study of ADS. In this environment, ADS manifests itself as a form of functional autonomy, even in the face of physical vulnerability [2]. Illustrative examples include patients who, despite severe limitations such as diabetic retinopathy and amputations, demonstrate proactivity by ensuring their attendance at dialysis sessions—such as coordinating their transportation independently—when their usual caregiver is not available. This act reveals that self-determination can persist as an exercise of responsibility and improve patients' health [3]. In contrast, the loss of ADS is observed when the patient delegates the decision about his treatment (such as a vascular prosthesis surgery) to a third party, which implies decisional dependence that can rapidly deteriorate his health due to the lack of advice. physician. ADS is a psychological factor hypothesized to influence health. As a psychological factor, it can be modified [4]. For example, it is expected that greater self-determination leads to lower symptom intensity.

The present study hypothesizes that patients in hemodialysis programs with higher ADSs present a lower perception of symptoms and greater survival.

Materials and methods

Study design

This is an observational, case–control study. The source is prospective.

Scenario

The present study was conducted in 14 hemodialysis units within the complementary health network of Ecuador. The study period was from May 1, 2025, to June 30, 2025.

Participants

Patients older than 18 years with stage 5d chronic renal failure who were receiving renal replacement therapy were included in the study. Records without complementary laboratory data were excluded. Two groups were formed: the first, without health self-determination, and the second, with health self-determination.

Variables

The variables included demographic data, age, observation time in hemodialysis treatment, self-determination in health, adherence to treatment, work integration, physical dependence, acceptance of kidney disease, and symptom scale "The Dialysis Symptom Index" [5].

Data sources/measurements

The source was direct. The data were collected through a survey. Self-determination in health was assessed by each nephrologist using the following scale: 0, no self-determination; 1, partial self-determination; and 2, total self-determination. Virtual training via Zoom was conducted for nephrologists on the use of the form. Patients with grade 0 and 1 ADS formed Group 1; patients with total self-determination, Group 2. The consulting physician assessed treatment adherence during the outpatient consultation, which involved reviewing the patient and determining the degree of adherence to medical indications. The source was direct. The information was collected directly through surveys.

The questionnaire "The Dialysis Symptom Index," with 34 questions, asks about the intensity of symptoms over the previous 2 weeks and scores them from 0 to 4 points.

Bias

Observation and selection bias were avoided by applying participant selection criteria. The principal investigator always kept the data using a guide and records approved in the research protocol to avoid possible biases of the interviewer, information, and recall. In cases of doubt about the data's standard deviation, corrections were made through in situ reviews of the anomalous data. Two researchers independently analyzed each record in duplicate, and the variables were entered into the database after verifying their agreement.

Study size

The sample was probabilistic. The sample calculation was probabilistic. Ecuador has 19,000 patients on hemodialysis. With a confidence level of 95%, an expected frequency of 50%, and a confidence limit of 5%, the optimal sample size was 377 cases.

Quantitative variables

The results of the ordinal variables are presented as frequencies and percentages. The results of the scale variables are presented as averages. Scale variables were not converted into quantitative variables.

Pairing of groups by propensity scores

To adjust for potential confounding factors, propensity score matching (PSM) was used to balance the groups. Three variables were chosen for matching: age, sex, and the presence of type 2 diabetes mellitus. The risk of death is strongly associated with age, sex, and diabetes; thus, these factors were included in the PSM. The paired cohorts were 1:1 and created using the nearest-neighbor method with a calibration of 0.01. The balance of the baseline variables was evaluated using the standardized mean difference (SMD) before and after the MPS. Variables whose SMD was less than 0.10 after pairing were considered well-balanced.

Statistical analysis

The averages are compared using Student's t-test. The proportions are compared with chi-square tests. An observational survival analysis is presented, based on patients' historical time of stay in the hemodialysis unit up to the survey date. A P value < 0.05 was considered to indicate statistical significance. The analyses were performed with the statistical package SPSS v 31.0. (IBM Inc., Chicago, IL, USA).

Results

Participants

A total of 516 surveys were collected. After they were paired, 180 patients from the group without health self-determination and 184 from the group with health self-determination were analyzed.

Description of the sample

The Table 1 presents the characteristics of the patients analyzed; the groups were similar in terms of age, sex, and the prevalence of type 2 diabetes mellitus (pairing variables). Additionally, the proportion of patients on hemodiafiltration was similar in both groups.

Table 1. Description of the study groups.

	Without self-determination in Health N=180	With self-determination in Health N=184	X^2	*P*
Age (Years)	57.9 ± 13.7	58.0 ± 11.8	T=-0.00	0.938
Male	92 (51.1%)	95 (51.6%)	0.01	0.921
DMT2	87 (48.3%)	87 (47.3%)	0.04	0.841
HDF	19 (10.6%)	10 (5.4%)	3.25	0.071

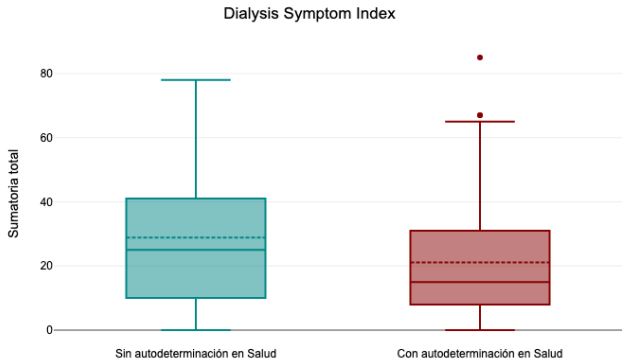
Self-determination and psychological variables

The group without self-determination in health had greater physical dependence (Delta + 27.8%), lower adherence (Delta - 22.57%), and lower work activity (Delta - 25.82%) than the group with ADS did. There was no difference in disease acceptance between the study groups (Table 2).

Self-determination and pain perception

The group with self-determination showed a lower symptom intensity (-25.82%) than the group without ADS (Figure 1). Specifically, 18 of the 34 symptoms were less intense in the self-determination group (Table 3 and Figure 2).

Figure 1. Intensity of symptoms in the study groups.



Self-determination and survival

Survival (delta: +6.55 months) was greater in the group with self-determination in health (29.5 months) than in the group without self-determination (36.08 months) (log-rank chi-square 7.71, *P* <0.005) (Figure 3).

Table 2. Self-determination and psychological variables in patients on hemodialysis programs.

	Without self-determination in Health N=180	With self-determination in Health N=184	X^2	P
Physical dependence	96 (53.3%)	47 (25.5%)	29.5	<0.001
Adherence	66 (36.7%)	95 (51.6%)	0.01	<0.001
Part-time or full-time work activity	22 (12.2%)	70 (38.0%)	40.4	<0.001
Acceptance of the disease	153 (85.0%)	168 (91.3%)	3.5	0.062

Figure 2. Symptom intensity in study groups.

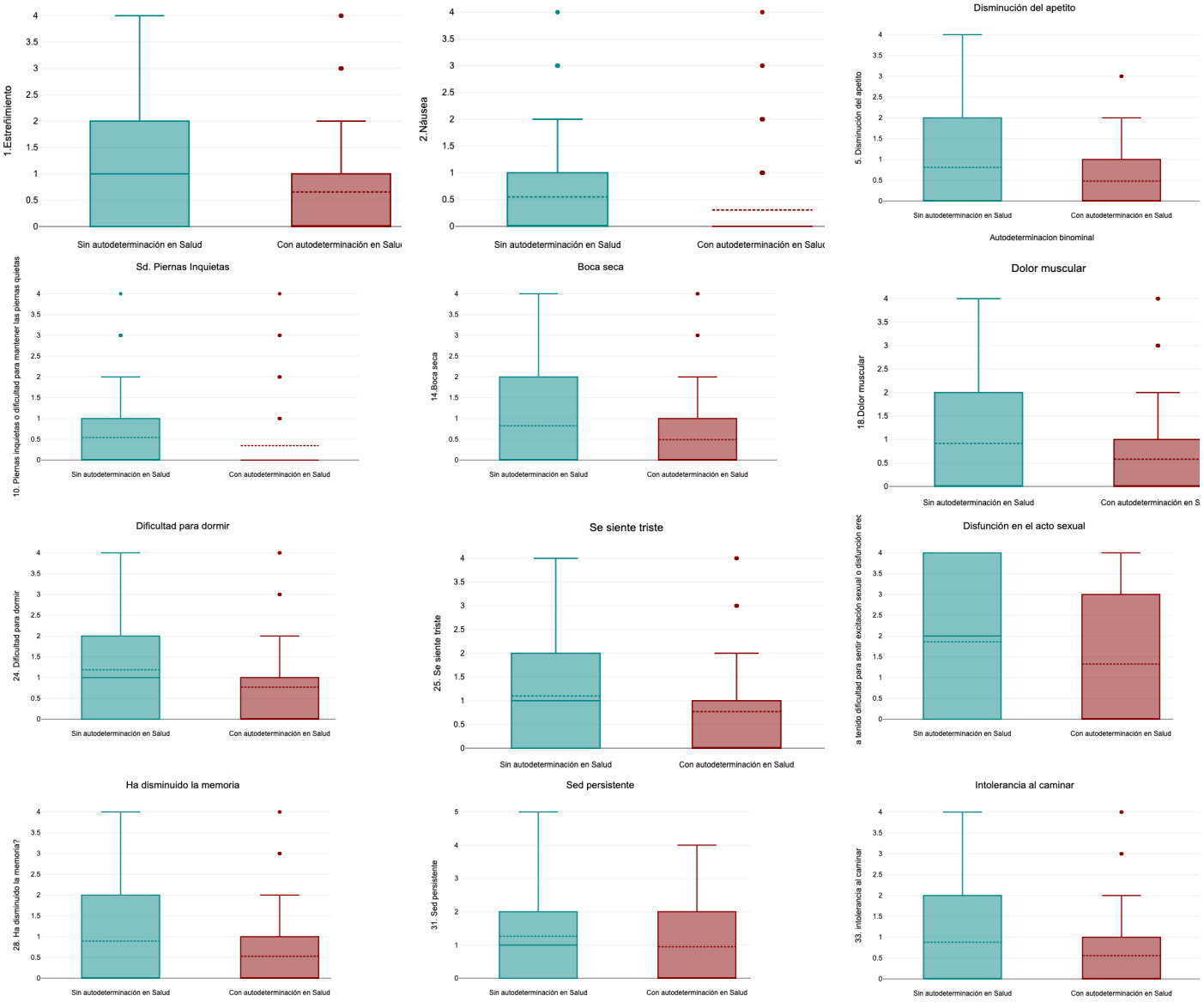
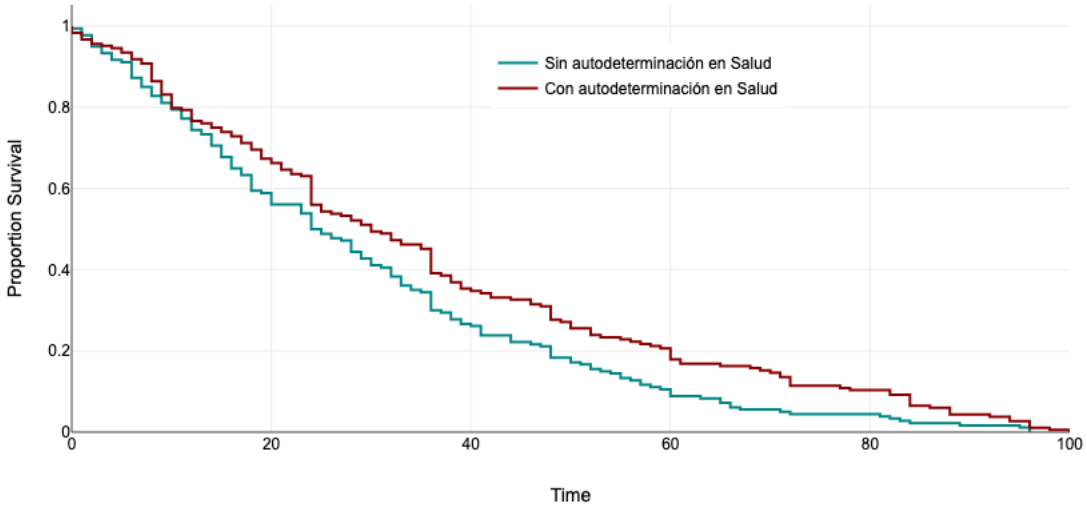


Tabla 3. Síntomas en los grupos de estudio.

Dialysis Symptom Index	Without self-determination in Health N=180	With self-determination in Health N=184	*P*
1.Constipation	1.01	0.66	0.04
2.Náusea	0.56	0.3	0.003
3.Vómito	0.32	0.18	0.041
4. Diarrhea	0.37	0.27	0.202
5. Decreased appetite	0.82	0.48	0.001
6. Cramps	0.81	0.76	0.971
7. Swelling of legs	0.75	0.63	0.247
8. Shortness of breath (especially at night)	0.53	0.36	0.073
9. Mareo	0.67	0.44	0.021
10. Restless legs or difficulty keeping the legs still	0.55	0.35	0.026
11. Numbness or tingling in the feet	0.82	0.7	0.263
12. Feeling tired or lacking energy after dialysis.	1.23	1.04	0.189
13.Persistent or chronic cough	0.31	0.29	0.807
14.Boca seca	0.84	0.49	0.002
15.Bone or joint pain	1.01	0.79	0.092
16.Chest pain	0.41	0.3	0.208
17.Headache	0.91	0.65	0.19
18.Muscle pain	0.93	0.58	0.003
19.Difficulty concentrating	0.65	0.46	0.084
20. Dry skin	1.31	1.02	0.04
21. Comezón	1.05	0.94	0.409
22.Concern	1.36	0.97	0.003
23. Feeling nervous or anxious	0.82	0.68	0.199
24. Difficulty sleeping	1.19	0.77	0.002
25. Feels sad	1.11	0.77	0.01
26. Interest in sex has decreased	1.72	1.32	0.013
27. Has had difficulty feeling sexual arousal or erectile dysfunction	1.86	1.33	0.001
28. Has your memory decreased?	0.9	0.53	0.001
29. Has your hearing decreased?	0.59	0.38	0.028
30. Has your visual acuity decreased?	1.23	0.82	0.002
31. Persistent thirst	1.27	0.95	0.019
32. Pain and redness of the vascular access site	0.42	0.29	0.113
33. intolerance when walking	0.88	0.56	0.007
34. Have you had black stools (like Coca-Cola)?	0.1	0.07	0.453

Figure 3 . Kaplan–Meier of survival in the study groups.



	Mean	Median	Lower limit CI 95% Median	Upper limit CI 95% Median
Without self-determination in Health	29.53	24	20	29
With self-determination in Health	36.08	30	24	35

Discussion

Main findings of the study

This study compared patients in hemodialysis programs with and without self-determination in health (SDH) and found significant differences in psychological variables, perceptions of pain and symptoms, and survival. The groups (with an SDH, N = 184; without an SDH, N = 180) were comparable in terms of age, sex, and baseline prevalence of type 2 diabetes mellitus (T2DM). No statistically significant differences were found in these variables. The group with SDH presented a significantly more favorable psychological and lifestyle profile, with less physical dependence, with a marked difference: 53.3% of physical dependence in the group without SDH, compared to only 25.5% in the group with SDH ($P < 0.001$). Greater Adherence: The group with an SDH had greater adherence (51.6%) than the group without an SDH did (36.7%) (P<0.001). Regarding work activity, much greater participation was observed in the SDH group (38.0%) than in the non-SDH group (12.2%) ($P < 0.001$). Survival was greater in the group with SDH.

Importance of the findings

Patients on hemodialysis who are not physically dependent on family members, maintain mobility and autonomy, and retain the ability to perform daily activities in general have better overall health and a lower risk of complications.

Self-determination in health, or the ability to make informed decisions about one's own health, was associated with more prolonged survival. This is because when patients actively participate in their treatment, they can be more committed, adhere better to treatment plans, and achieve better results. Self-determination in health is not only a psychological construct but also a factor associated with tangible and superior clinical results and quality of life in patients undergoing hemodialysis.

The most significant finding was the greater survival observed in the SDH group (36.08 months on average) than in the non- SDH group (29.53 months on average; $P < 0.005$); this finding has clinical relevance and suggests that SDH may be a prognostic factor and a therapeutic target. A drastic reduction in physical dependence (from 53.3% to 25.5% in the SDH group) directly translates into greater autonomy, and these events are strongly related. An increase in work activity (38.0% vs. 12.2%) is an indicator of better social reintegration and quality of life, allowing patients to maintain a productive role.

Greater adherence (51.6% vs. 36.7%) is essential, since compliance with the dialysis and medication regimen is intrinsically linked to the control of complications and long-term prognosis. The lower overall intensity of symptoms, including 18 specific symptoms (such as pain, gastrointestinal symptoms, and psychological difficulties such as worry and sadness), implies that SDH provides patients with better coping and self-care strategies, resulting in substantial relief of suffering associated with hemodialysis. The results suggest that hemodialysis psychological care programs should focus on promoting SDH through specific interventions that empower patients to make active decisions about their treatment and improve their self-care and disease management skills. They could use SDH as a measurable therapeutic target to improve clinical outcomes and quality of life.

Studies with related findings

Previous studies have shown that hemodialysis patients, especially men, experience decreases in physical and psychological quality of life, and emotional support, information, and marital status improve outcomes for hemodialysis patients. [6]. Physical activity in daily life is more closely associated with patients' quality of life; thus, routine physical activity programs should be implemented in hemodialysis units [7]. Specifically, regarding psychosocial factors, it has been reported that depressive symptoms are significant predictors of mortality from all causes in hemodialysis patients, with a relationship independent of nutritional or inflammatory status [8]. The effects of self-determination on treatment compliance and self-care level among hemodialysis patients were reported in 1 study with a small sample (N = 45) and controls without self-determination (N = 45). For patients on hemodialysis, compliance with fistula self-care, diet, and fluid intake was supported. After the intervention, the total scores of problem solving, association, emotional processing, self-care activities, the physical domain, the psychological domain, the domain of social relationships and the total scores of quality of life in the intervention group were higher than those in the conventional group ($P < 0.05$); thus, the management of self-determination theory is effective in improving knowledge related to hemodialysis, treatment compliance, level of self-care and quality of life in patients with hemodialysis [9]. It has also been shown that health education based on self-determination theory can improve knowledge of hemodialysis and self-management capacity among maintenance hemodialysis patients, and reduce interdialytic weight gain, anxiety levels, and depression [10].

Alternative explanations

A patient without physical dependence is likely to have greater muscle mass and better overall nutritional health. Protein-energy malnutrition is common in dialysis patients and is closely linked to frailty, weakness, and muscle loss. A patient capable of performing daily activities (such as walking and grooming) probably consumes enough calories and protein, which helps maintain muscle mass and strength. Good nutrition and muscle mass directly support a better treatment response and reduce inflammation, both of which help prolong survival. Physical independence is strongly associated with age—younger patients tend to have fewer comorbidities and less age-related weakness. Consequently, they are more often physically independent, which partly explains their more prolonged survival. Symptoms like fatigue, nausea, and loss of appetite are prevalent in CKD patients and indicate poorer overall health. A patient with mild symptoms is likely to have better nutritional status and less muscle loss. Maintaining good nutrition prevents extreme fatigue and weakness, reducing symptoms and enhancing quality of life, ultimately contributing to more prolonged survival. The sense of self-determination and acceptance is not directly caused by nutrition, muscle mass, age, or kidney function, but is inherently connected to these factors. A patient who accepts their illness and is self-determined is more likely to adhere to an open diet plan (including more protein and fluid restrictions) and engage in exercise to preserve muscle mass. A psychological commitment to treatment leads to better nutrition and prevents muscle loss, which are associated with improved physical health and increased survival.

Clinical relevance of the findings

Management of CKD should not focus solely on laboratory values and dialysis dose. Physical rehabilitation programs, physiotherapy, and education on symptom management (such as fatigue, nausea, and pain) should be established as clinical interventions. Regularly evaluating patients' functional capacity and symptomatic status, and proactively intervening, can have a direct and significant effect on their longevity. With respect to self-determination in health and acceptance of the diagnosis, these findings are the most relevant from a holistic care perspective, with impacts of +9 and +26 months, respectively. The 26-month difference in survival among patients who accepted their diagnosis is a finding with direct implications: mental health, as a pillar of treatment—psychological support, cognitive-behavioral therapy, and counseling—is as important as the treatment doctor. Similarly, promoting self-determination involves educating patients to understand their disease, treatment options, and the importance of diet and exercise, and training them to make informed decisions. Treatment adherence, which improves self-determination, is the leading cause of failure in clinical outcomes. By empowering patients, they not only improve their quality of life but also directly impact their survival.

Limitations of the study

It is possible that patients who already had better mental health, a better social support system, or a more resilient personality (factors

not measured) were more likely to accept the diagnosis and stay longer in the ADS group. It isn't easy to control all the variables that can influence survival. Unmeasured factors, such as nutritional status, muscle mass, adherence to dialysis, quality of medical care received, or residual renal function, may affect the results. "Psychosocial variables, such as 'self-determination' and 'acceptance,' can be subjective, and the precision of the measurement can vary." The study does not explain how these factors (independence, acceptance, etc.) change over time or how these changes could affect survival. On the other hand, observational survival is defined as the time at which patients remain in the hemodialysis program until the date of the survey. Since the group of patients not included in the study consists of the deceased, the outcome of death is missing, and follow-up is censored for all patients because the event is not observed.

Future research

Intervention studies to improve survival in patients with self-determination in health. Lines of research: To evaluate whether interventions aimed at increasing self-determination in health (such as psychology programs and focus groups) can improve the survival of patients with chronic kidney disease (CKD). Another line of research would examine the impact of self-determination and acceptance of the diagnosis on understanding the mechanisms by which self-determination in health and acceptance of the CKD diagnosis affect survival. It could be investigated whether these factors lead to better adherence to treatment, greater commitment to self-care, or better mental health, which, in turn, impacts clinical outcomes.

Conclusion

In the present study, self-determination in health (SHD) was associated with better clinical and psychosocial outcomes. Specifically, patients with ADS had greater survival, significantly greater treatment adherence, and less physical dependence. Additionally, self-determination was associated with a reduction in the intensity of perceived symptoms, covering 18 of the 34 evaluated, including pain and psychological symptoms such as worry and sadness. These findings demonstrate that ADS is not only a psychological construct but also a therapeutic goal that impacts survival. Randomized intervention studies in ADS are needed.

Abbreviations

ADS: Self-Determination in Health.
CKD: Chronic kidney disease.

Supplementary information

The supplementary materials have not been provided.

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Not applicable.

Authors' contributions

Franklin Mora Bravo: Conceptualization, methodology, formal analysis, project management, software, validation, visualization, writing - review and editing.
Paulina Cruz Idrovo, Marcia Verónica Pozo Calderón, Alfonso Silva Contreras, Marisol Pérez Herrera, Washington Osorio, Rafael Becerra Guerra, Nelson Rojas Campoverde, Guillermina Lucía Blum Carcelen, Gustavo Guevara Nolivos, Rosalina de Lourdes Lituma, Estefan Stalin Sanango Reinoso, Santiago David Silva Tobar, Oscar Ron, Diego Adolfo Vimos Cochanga Victor Hugo Ortega Coronel, Elizabeth González González González, Marlon Brayan Rivilla Nieto, Yamilka Rodriguez Cueto, Juan Carlos Paz Veloz, Estefanía Isabel León Hernández, Adriana Pamela Cabrera Eugenio, María Cristina Chediak Terán, Byron Fabricio Saa Sabando, Karol Vacacela Guerrero, Gustavo Coello Becerra, María José Cajas Romero: Conceptualization, data curation, research, visualization, writing-original draft, resources, software, supervision,
All the authors read and approved the final version of the manuscript.

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Availability of data or materials

Not applicable.

Statements

Approval of the ethics committee and consent to participate

The study has a letter of exemption issued by the Ethics Committee of the Ecuadorian Society of Nephrology, Dialysis, and Transplantation. The authors have the institutional permits of the participating centers.

Consent for publication

Does not apply when specific images, radiographs, or photographs of patients are not published.

Conflicts of interest

The authors declare that they have no conflicts of interest.

Author information

Not declared.

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