Revista de nefrología, diálisis y transplante
ISSN: 0326-3428
ISSN: 2346-8548
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Asociación Regional de Diálisis y Trasplantes Renales de Capital Federal y Provincia de Buenos Aires
Argentina

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Revista de nefrología, diálisis y transplante, vol. 42, núm. 1, 2022, pp. 22-40
Asociación Regional de Diálisis y Trasplantes Renales de Capital Federal y Provincia de Buenos Aires
Buenos Aires, Argentina

Rev Nefrol Dial Traspl. 2022;42(1):22-40

Diet and fluid restriction experiences of patients on hemodialysis: a meta-synthesis study

Experiencias de pacientes en hemodiálisis con restricción de dieta y de líquidos: metasíntesis

İlknur Özkan[1], Seçil Taylan[2]

ABSTRACT

Introduction: Non-compliance with diet and fluid restriction is an important and common health behavior problem in the hemodialysis population and is associated with increased morbidity and mortality. Therefore, investigating the perceptions and experiences of patients undergoing hemodialysis regarding diet and fluid restriction is very important in terms of achieving the management of diet and fluid restriction. **Methods**: This is a meta-synthesis study. CINAHL, MEDLINE, PubMed, Web of Science, OVID, and Scopus electronic databases were utilized for the literature review. Studies were critically evaluated using the Joanna Briggs critical appraisal tool. Qualitative data were extracted, meta-summarized, and then meta-synthesized. The thematic analysis method was used in the analysis of the data. **Results**: This review consisted of 23 qualitative studies. The experiences of patients undergoing hemodialysis about diet and fluid restriction were classified into three main themes, namely, "the meaning of diet and fluid restriction for the patient", "perceived barriers", and "patient's own management strategies for diet and fluid restriction". **Conclusion**: The results of the synthesis in our study indicated that patients undergoing hemodialysis perceived diet and fluid restriction as a complex and challenging process involving a constant struggle. Some personal, social, and systemic barriers perceived by the patients made compliance with diet and fluid restriction even more difficult. More importantly, it was determined that most of the patients were not supported enough in the management of diet and fluid restriction and that they had developed strategies in their own right. In line with these results, we recommend that individual counseling services for diet-fluid restriction of patients undergoing hemodialysis should be increased, the obstacles perceived by the patient should be considered while planning patients' diet-fluid restriction, and that the planning should be realistic and feasible.

KEYWORDS: hemodialysis patients; experience; qualitative metasynthesis; renal diet; fluid restriction

RESUMEN

Introducción: El incumplimiento de la dieta y la restricción de líquidos es un problema de comportamiento común e importante en la población en hemodiálisis, con impacto en el estado de salud, y que se asocia con aumento de la morbimortalidad. Por lo tanto, investigar las percepciones y experiencias de los pacientes en hemodiálisis con respecto a la dieta y a la restricción de líquidos es muy importante para alcanzar el manejo de los mismos. **Métodos**: Este es un estudio de metasíntesis. Para la revisión de la literatura se utilizaron las bases de datos electrónicas CINAHL, MEDLINE, PubMed, Web of Science, OVID y Scopus. Los estudios se evaluaron críticamente utilizando la herramienta de evaluación crítica

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Financiamiento:
Ninguno.

Conflicto de intereses:
Ninguno

Recibido: 08-01-2021
Corregido: 15-02-2021
Aceptado: 14-03-2021

ISSN 0326-3428

de Joanna Briggs. Fueron extraídos los datos cualitativos, meta-resumidos y luego meta-sintetizados. En el análisis de los datos se utilizó el método de análisis temático. **Resultados**: Esta revisión consistió en 23 estudios cualitativos. Las experiencias de los pacientes sometidos a hemodiálisis en relación con la dieta y la restricción de líquidos se clasificaron en tres temas principales, a saber, "el significado de la dieta y la restricción de líquidos para el paciente", "barreras percibidas" y "estrategias de manejo propias del paciente para la dieta y la restricción de líquidos". **Conclusión**: Los resultados de la síntesis en nuestro estudio indicaron que los pacientes en hemodiálisis percibían la dieta y la restricción de líquidos como un proceso complejo y desafiante que implicaba una lucha constante. Algunas barreras personales, sociales y sistémicas percibidas por los pacientes dificultaron aún más el cumplimiento de las indicaciones. Más importante aún, se determinó que la mayoría de los pacientes no recibieron suficiente apoyo en el manejo de la dieta y la restricción de líquidos y que habían desarrollado estrategias por sí mismos. De acuerdo con estos resultados, recomendamos aumentar los servicios de asesoramiento individual para la restricción dietética-líquida de los pacientes en hemodiálisis, considerar los obstáculos percibidos por ellos al planificar la restricción dietética-líquida y realizar una planificación que sea realista y factible.

PALABRAS CLAVE: pacientes en hemodiálisis; experiencia; metasíntesis cualitativa; dieta renal; restricción de líquidos

INTRODUCTION

Hemodialysis, which is the most common treatment method in end-stage renal disease patients, negatively affects the quality of life of the patient due to diet and fluid restriction, obligation to go to the dialysis center, and the presence of many physical and psychological symptoms and leads to considerable changes in their daily lives.[1-2] Hemodialysis patients must take responsibility for many aspects of their treatment to successfully manage this chronic condition. These aspects include compliance with diet and fluid restriction, medication compliance, and participation in all hemodialysis sessions.[3-5]

Compliance with diet and fluid restriction is crucial for the success of treatments. However, non-compliance with diet and fluid restriction is an important and common health behavior problem in the hemodialysis population and is attributed to its complexity and highly restrictive regimen. The prevalence of non-compliance to fluid intake in patients undergoing hemodialysis varies between 22% and 77%, and the prevalence of non-compliance with diet restriction ranges from 41% to 84%.[3, 6-7]

Clinical results directly depend on the patient's compliance with the treatment regimen. HD patient's non-compliance with diet and fluid restriction predisposes them to dangerous health complications, such as cardiovascular conditions, renal osteodystrophy, interdialytic weight gain (IDWG), frequent hospitalizations, and increased mortality.[8-9] Excessive sodium intake in the diet encourages osmoreceptors to induce thirst and volume intake, increases total body water and therefore results in IDWG. Excessive IDWG requires greater volume removal during hemodialysis.[10] A serum phosphorus level of higher than 5 mg/dl is directly associated with a higher risk of death in patients undergoing hemodialysis.[11] Excessive potassium results in ventricular arrhythmias and death.[12] Therefore, it is very important to ensure the management of diet and fluid restriction in HD patients.

Incorporating patients' living conditions, priorities, goals, and values into diet recommendations can both allow self-management and improve clinical outcomes. Therefore, examining the perceptions and experiences of patients regarding diet and fluid restriction is of significance. Qualitative studies allow a comprehensive study of a disease and its effects, thereby privileging patients' own point of view and reducing prejudice.[13] Recently, the qualitative evidence investigating the experiences of patients undergoing hemodialysis about diet and fluid restriction has increased, revealing the need for the synthesis of qualitative findings and the development of models with high-level insights.

Background

This study is based on the shifting perspective model of chronic illness. This model, developed by Paterson (2001), emphasizes that the patient's own interpretations of daily life are vital. In the model, living with a chronic illness is seen as an ongoing and ever-changing process that includes

both illness and well-being. Illness and fitness change position in the foreground or background depending on the current situation. The perceived reality, not reality itself, makes up the basis of how people with chronic illness interpret and deal with their illness. This current meta-synthesis study is based on the perspective focus of patients and is thought to help healthcare providers to better understand the profound effects of diet and fluid restriction on the patient by exploring patients' experiences with the diet and fluid restriction on a multidimensional level.[14]

2. Method

2.1 Aim

The purpose of this review is to systematically interpret and synthesize the evidence from qualitative research on the experiences of patients on hemodialysis about diet and fluid restriction.

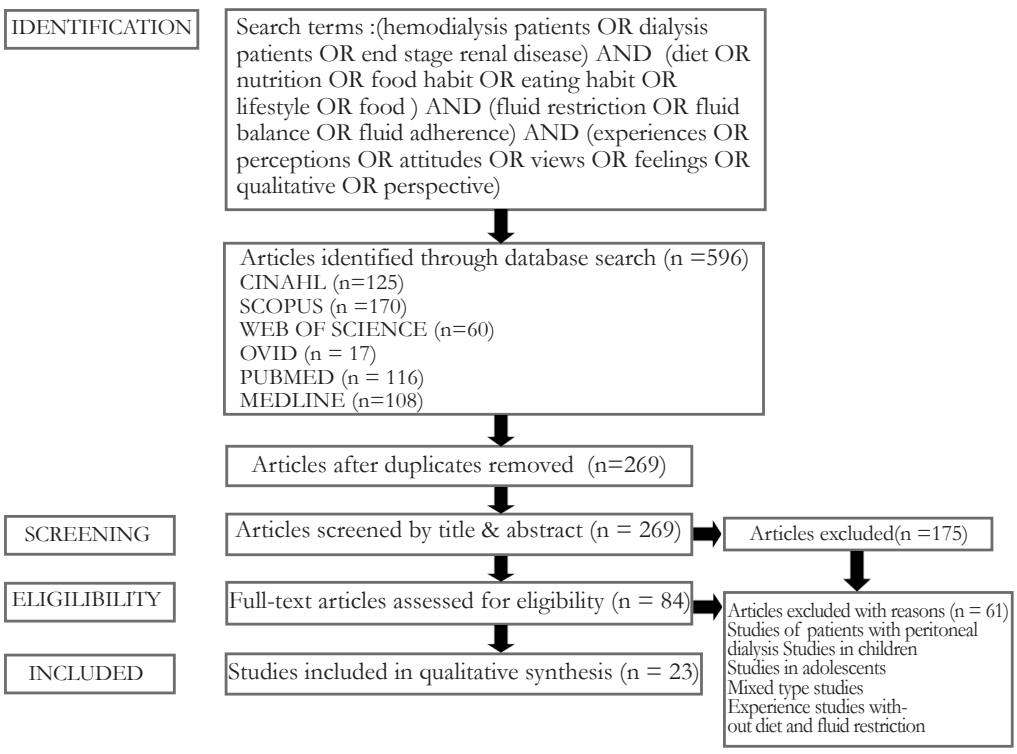
2.2 Design

This review used a meta-synthesis design and followed the approach outlined by Sandelowski and Barroso (2006).[15] Meta-synthesis is a systematic process that aims to represent an interpretative integration of the findings from qualitative studies. The literature was strategically reviewed after formulating the purpose and rationale of the study consistent with this methodology. The studies included were critically evaluated, and the findings were extracted and grouped in a way that Sandelowski and Barroso (2006) called qualitative metasummaries, and finally, the meta-synthesis was created.

2.3 Search methods

CINAHL, MEDLINE, PubMed, Web of Science, OVID, and Scopus electronic databases were used for the literature review. These databases were evaluated as the most appropriate for the literature review as they covered articles in the fields of health and social sciences. In all databases, the following keywords and options were used for the search: (hemodialysis patients OR dialysis patients OR end-stage renal disease) AND (diet OR nutrition OR food habit OR eating habit OR lifestyle OR food) AND (fluid restriction OR fluid balance OR fluid adherence) AND (experiences OR perceptions OR attitudes OR views OR feelings OR qualitative OR perspective). The search process is shown in **Figure 1**. Endnote X8 software was used for editing articles, detecting duplications, and reviewing titles and abstracts.

Figure 1. Search strategy and selection of studies



 ISSN 0326-3428

2.4 Inclusion and exclusion criteria

Studies included in the present study were subjected to some inclusion and exclusion criteria. The inclusion criteria targeted studies that were of the qualitative type, consisted of participants who were patients on hemodialysis and aged 18 or over, addressed the experiences of patients on hemodialysis about treatment or diet or fluid restriction, were written in the English language, and were published between January 2010 and November 2020. On the other hand, the exclusion criteria defined studies that consisted of participants not undergoing hemodialysis treatment, did not provide information about diet or fluid treatment in hemodialysis experience of participants, were education, congress, and thesis studies, used a mixed method, and were of quantitative type.

2.5 Search outcomes

Systematic searches yielded 325 records from databases after duplications had been removed. First, the titles and abstracts were scanned by both authors. The full texts of potentially relevant studies (n=84) were read by the two authors (İ.Ö. and S.T.), and disagreements were discussed and resolved. A total of 23 articles were included in this review based on the inclusion and exclusion criteria. The inclusion process is shown in **Figure 1** according to the PRISMA guidelines.[16]

2.5 Quality appraisal

Qualitative studies included in the study were evaluated in terms of quality using the Joanna Briggs Institute Qualitative Assessment and Review Instrument (QARI).[17] QARI was chosen on the grounds that it is more sensitive to validity aspects than other assessment tools commonly used.[18] The QARI critical appraisal tool consists of 10 questions about eligibility, and each study is evaluated over a maximum of 10 points. The quality scores of the studies included are calculated by weighting the studies according to the "yes", "no", or "uncertain" values of the QARI assessment tool. Studies were evaluated according to each QARI question, and 1 point was given for a satisfactory "yes" response and 0 points for "no" or "uncertain" responses. The final score was obtained by summing the values assigned to each question. The cutoff point was determined as "yes" responses to a total of six out of 10 questions and it was applied by all the reviewers. The researchers evaluated the reports independently with scores ranging between 6 and 9. Accordingly, none of the qualitative studies included in the study were excluded from the study.

2.6 Data abstraction and synthesis

As suggested by Sandelowski and Barroso (2006), first, a meta-summary of qualitative research findings was made in the included studies **(Table 1)**. This meta-summary contained information about the authors, year of publication, country, study method, the purpose of the study, sample, and the main findings. Second, a qualitative meta-synthesis was carried out, which is an interpretive integration of findings of the included studies. The thematic analysis method of Braun and Clarke was used in the analysis of the data. The text extracted from the findings sections of the primary studies was read several times to become familiar with the context. The first codes were developed later, and these coded expressions were categorized, and themes were identified, reviewed, and named. To reduce the risk of possible bias in this meta-synthesis study, the processes of literature review, article selection, data extraction, and the quality assessment of the article were carried out independently by the first and second researchers. Then, these two researchers checked each stage again and reached a consensus.

"I can't find a way to avoid the drinking need; my thoughts are always fixated on the bottle, and I am always close to the fridge. When I wake up in the night, the first thing I do is to go into the kitchen, open the fridge to see what to drink, and I drink because I can't resist, like children who can't stop themselves... I am still thirsty even if I drink an entire liter of water". [25]

"There are times when I crave to eat more. But I know I shouldn't so I restrain myself." [30]

I know I should not eat it, but I still want to eat it. (P20)Especially in a hot day, you want to drink but you know you have to control your intake. [41]

results in participant feelings of guilt when families complain about needing to cook separate meals". [24]

"Yep I feel good; you know we (Aboriginal Peoples) are a part of it (traditional foods) the food and the gathering of the food with the family". [33]

Table 1. Summary of articles examined, contribution to findings, and quality appraisal

CODE	Author, year country	Study aims	Methodology and theoretical perspective
1	Lee *et al.*, 2020, Korea	Aimed to explore the barriers and facilitators affecting fluid restriction adherence among Korean HD patients	focus group interviews; contentanalysis method; ecological model
2	Hong *et al.*, 2017; Singapore.	To explore the perspectives of patients undergoing haemodialysis in Singapore on an imposed dietary and fluid restriction regime	face-to-face individual interviews; A hermeneutics phenomenological thematic analysis
3	Griva *et al.*,2013; Singapore	To explore factors that act as barriers to treatment adherence in patients on HD and identify facilitators of treatment adherence and effective self-management and to explore cultural perspectives on non-adherence	Descriptive exploratory design; semi-structured interviews;focus groups; inductive thematic approach
4	Smith *et al.,*2010; USA	To describe the perspectives and experiences of chronic hemodialysis (CHD) patients regarding self-care and adherence to fluid restrictions	semi-structured focus groups; QSR NVivo 2.0; content analysis
5	Stevenson *et al.*,2018; Australia	To describe the perspectives and experiences of patients on hemodialysis regarding their dietary management to understand both facilitators and barriers to adherence and to identify strategies to improve care	semi-structured interviews thematic analysis grounded theory
6	Brito-Ashurst *et al.*,2011; Bangladesh.	To identify barriers and facilitators of dietary change to inform the development of health promotion interventions to reduce dietary sodium intake	focus group thematic analysis
7	Tovazzi and Mazzoni 2012; Italy	To explore the perspectives of patients on hemodialysis about their experience of fluid restriction	face-to face interviews phenomenological analysis
8	Aker and Yüksel 2016; Turkey	To investigate the factors to determine treatment compliance in hemodialysis patients, the importance of these factors, and relationship of factors	phenomenological qualitative study. semi-structured interview inductive content analysis
9	Cervantes *et al.* 2017; USA	To explore the preferences of Latino patients receiving dialysis regarding symptom management and advance care planning	semistructured face-to-face interviews thematic analysis. Atlas ti version 7.5.12

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Continuación de la tabla 1

Sample	**Themes**	**QARI[a]**
27 hemodialysis patients 13 female, 14 male	(1)Intrapersonal Level (2)Interpersonal Level (3)Organizational Level	8
14 hemodialysis patients 5 female, 9 male	(1) Pessimism, (2) Existing struggles, (3) Perceived quality of support, and (4) Immensity of self-discipline.	8
37 hemodialysis patients (age:21-63) 15 female, 17 male	(1)Perceived facilitators of adherence (2) Perceived barriers to adherence	8
19 hemodialysis patients (age:18-70) 12 female,7 male	(1) Barriers (2) Facilitators	9
35 hemodialysis patients (age:20-80) 16 female, 19 male	(1)Exacerbating disruption (2) Losing control (3)Attaining health benefits (4)Achieving treatment goals (5)Succeeding with support	8
32 patients chronic kidney disease patients (age mean:60) 32 female	(1)Barriers to change (2)Facilitators of change (3)Explanatory models of health and disease (4)Beliefs and attitudes about foods (5)Dietary acculturation and traditional (6)Bangladeshi diet	8
12 hemodialysis patients (age:37-77) 4 female 8 male	(1) Fluid restriction introduces the perception of individuals to see themselves as addicts who deal with a constant inner conflict, (2) The difficulty in finding the right boundaries between common sense and scientific knowledge about fluid restriction, (3) The role of personal motivations and willingness in pursuit of compliance	8
10 hemodialysis patients (age:18-65) 1 female, 9 male	(1) Disease and health perception, effect on professional and social life, (2) Coping, (3) Fear, (4) Expectations, (5) Diet and (6) Fuid restriction, (7) Education and information	6
20 hemodialysis patients (age:30-78) 10 female, 10 male	(1)Avoiding Harms of Medication (2)Barriers and facilitators to advance care planning, faith, family, and home (3)Means to improve wellbeing (4) Challenges of illness	7

CODE	Author, year country	Study aims	Methodology and theoretical perspective
10	Clark-Cutaia *et al.*,2018; USA	To explore perceived barriers to adherence to dietary recommendations in a diverse hemodialysis patient population	semi-structured qualitative telephone interview Atlas.ti (v.7, scientific software)thematic analysis
11	Flythe *et al.*2018; USA	To characterize patient beliefs about and experiences with hemodialysis-related symptoms and symptom reporting	semi-structured interviews thematic analysis. Atlas.ti (v.7, scientific software)
12	Lambert *et al.* 2018; Australia	To describe the experiences of patients with CKD and their carer with respect to interpreting and implementing the renal diet	individual semistructured interviews sensemaking theory thematic analysis
13	Morris and Lycett.2020; UK	To explore patients' perspectives on the experienced impact of following low-potassium diets, to inform clinical practice and research.	NVivo 10 semistructured interviews thematic analysis
14	Oka *et al.*2019; Japan	To explore the dietary patterns of Japanese hemodialysis patients and better understand the challenges they face in adhering to dietary restrictions	A focused ethnography content analysis
15	Urquhart-Secord *et al.* 2016; Australia.	To generate a ranked set of outcomes considered important and relevant to patients and their caregivers, with a view to informing patient-centered research in hemodialysis.	Focus group/nominal group technique; thematic analysis; HyperRESEARCH (version3.7.2; ResearchWare Inc)
16	Tarakjı *et al.* 2014; Canada	To learn about their intakes of Acadian foods so we could tailor our advice for other Acadian patients receiving hemodialysis.	A group interview approach semi-structured interview guide
17	Karamanidou *et al.* 2014; UK	To explore the experience of renal patients undergoing dialysis treatment focusing on beliefs about their illness, prescribed treatment and the challenge of adherence.	semi-structured interviews interphenomeno-logical analysis
18	Fakih El Khoury *et al.* 2019;United Arab Emirates	To describe the person-centered, theory-based development of the Kidney Education for Lifestyle Application (KELA.AE app) for Arabic speaking patients.	semi-structured interviews person-driven theory-based approach MAX-QDA standard version 18.1.
19	Junhong Yu *et al.*; 2016; Singapore	To explore the experience of food cravings and thirst, and their management strategies İn patients on hemodialysis.	Semi-structured interviews NVivo 9 software Thematic analysis
20	Glyde *et al.* 2019; UK	To explore patients' perceptions of their fluid management.	semi-structured inter-views thematic analysis

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Sample	Themes	QARI[a]
30 hemodialysis patients (age: 63.2 ± 13.3) 11 female, 19 male	(1)Time and Convenience (2) Financial Constraints (3)The Experience of Routine Dietary Counseling	9
42 hemodialysis patients (age:18-77) 23 female, 19 male	(1)Symptoms engendering symptoms, (2)resignation that life is dependent on a machine, (3)experiencing the life intrusiveness of dialysis, (4)developing adaptive coping strategies, (5)creating a personal symptom narrative, (6)negotiating loss of control and (7)encountering the limits of the dialysis delivery system	7
8 hemodialysis patients (age:30-79) Female ? Male?	(1)An overwhelmıng, frustratıng and emotıonal journey (2)A complex and challengıng dıet (3)Dıetıtıan Input Is Hıghly Valued (4)Carer support ıs ımportant (5)Developıng problem solvıng strategıes (6)A desıre for addıtıonal resources and/or support	8
34 hemodialysis patients (age: 66.7 ± 10.9 years) 19 female 15 men	(1)What is left for me to eat now? (2)'I'm obviously different' (3)Food can be socially awkward (4)Money doesn't grow on trees.	7
6 hemodialysis patients (age:31-71) 1 female, 5 male	(1) Struggling with the desire to continue previous eating habits; (2) Persisting with eating traditional foods high in salt; (3) Using individualized approaches to adhere to dietary restrictions; (4) Eating as a family experience; and (5) Fearing blood test results.	8
58 hemodialysis patients (age :18-80) 19 female, 39 male	(1)Living Well (2) Ability to Control (3)Tangible and Experiential Relevance (4) Severity and Intrusiveness	8
5 hemodialysis patients (age:56-81) Female ? Male?	Definition of the Acadian diet Frequency of consuming traditional Acadian foods Generational changes Advice for others	6
7 hemodialysis patients (age:32-68) 4 female, 3 male	(1) Identity (2)Timeline (3) Consequences (4)Cure (5) Cause(6) Control (7) Non-adherence	7
6 hemodialysis patients (mean age:47) 4 males and 2 females.	(1)Experience with the diet (2) App evaluation (3) Key Findings from Healthcare Practitioner Interviews	8
32 hemodialysis patients (age:21-76) Female ? Male?	(1) Motional responses, (2)Cognitive , (3)Behavioral strategies to manage food crav-ings and thirst,(4) As well as other strategies employed to regulate diet, (5)fluid intake in general	8
12 hemodialysis patients (age:35-77) 5 female, 7 male	(1)Determınıng who has the expertıse (2) Impediments affecting patients' lifestyle (3) Additional difficulty of experiencing comorbidities (4) Perceived quality of care (5) Establishing Consistency	8

CODE	Author, year country	Study aims	Methodology and theoretical perspective
21	Nam *et al*. 2019; Hong Kong	To explore the experience of multiple concurrent symptoms over time and their impact on daily living in patients with end-stage renal disease undergoing Dialysis.	face-to-face semi-structured interviews thematic analysis approach
22	Opiyo *et al*.; 2020, Kenya	To explore the perceptions about adherence to dietary prescription among adults with CKD on hemodialysis and their family caregivers.	NVIV0-12 computer software in-depth interviews thematic analysis
23	Cubillo *et al*.; 2020, Australia	To identify the relation to traditional food from an Aboriginal perspective and the enablers and barriers to accessing traditional food post-relocation from remote regions of the Northern Territory, Australia	semi-structured interviews thematic analysis

QARI:Joanna Briggs Institute Qualitative Assessment and Review Instrument; [a] maksimum score: 10

2.7 Ethical aspects

The study was exempted from ethics committee investigation because it was a meta-synthesis study, and no human research participants were included in the study.

3. Findings

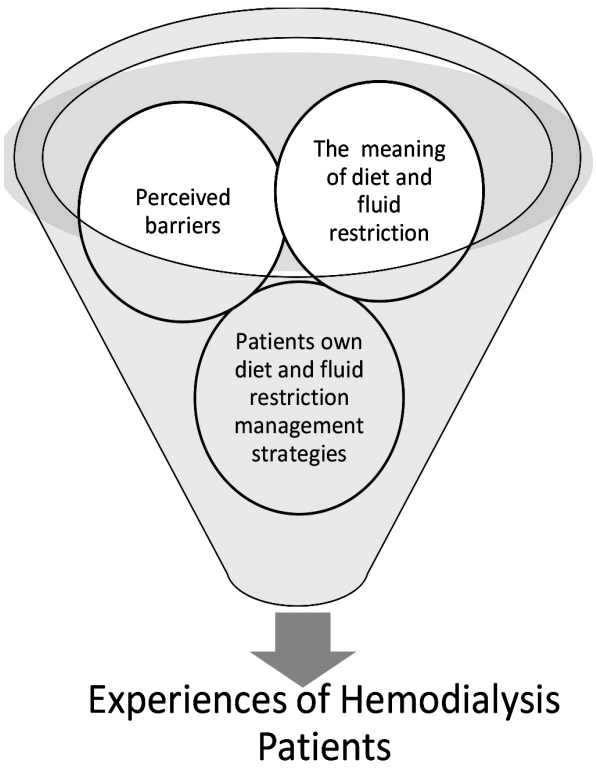
The synthesis involved findings from 23 qualitative studies and was summarized in Table 1. Of these 23 qualitative studies, four were carried out in the USA, one in Korea, three in Singapore, one in Bangladesh, one in Hong Kong, four in Australia, one in Japan, one in Canada, three in the UK, one in the United Arab Emirates, one in Turkey, one in Italy, and one in Kenya. Also, it was determined that the total number of patients on hemodialysis in the study was 538 and that the age range varied between 18 and 81 years.

As a result of the synthesis of qualitative study findings, the experiences of patients on hemodialysis regarding diet and fluid restriction were classified into three main and eight sub-themes. The main themes were determined as "the meaning of diet and fluid restriction", "perceived barriers", and "patients own diet and fluid restriction management strategies.[5, 19-40]

Main theme 1: the meaning of diet and fluid restriction

Most of the participants questioned the place of diet and fluid restriction in their lives and treatments and tried to make sense of it. This main theme consisted of three sub-themes: "a complex and demanding process", "a constant internal conflict - struggle with yourself", and "cultural identity and loss of self". **(Figure 2)**

Figure 2. Diet and fluid restriction experiences of patients on hemodialysis



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Sample	Themes	QARI[a]
28 hemodialysis patients (age:37-68) 14 female, 14 male	(1)Complex symptom experience (2) Decreased physical functioning, (3)Changes in social functioning (4)Diet and fluid restrictions.	8
52 hemodialysis patients (age: 18 and older) female ? male?	(1)Perceived health benefits (2) Ease in implementing prescribed diets (3)Cost of prescribed renal diets (4)Nutrition information and messages; (5)Transition to new diets (6) Fear of complications/severity of disease	8
12 hemodialysis patients (age: ?) 8 female, 4male	(1)The meaning of traditional food (2)Social and emotional impact of traditional food for patients (3) Enablers to accessing traditional food (4) Barriers to accessing traditional food	8

A complex and demanding process

Participants qualified diet and fluid restriction as the most demanding part of treatment. Although most patients acknowledged the necessity of restrictions, they emphasized that learning the renal diet was complex and difficult and that it was frustrating and emotionally exhausting. Some participants stated they were shocked and stunned by the complexity and difficulty of the renal diet. They were now prohibited to consume many foods they knew as healthy. They were constantly warned by their healthcare providers to avoid the intake of foods containing potassium and phosphorus and to consume less liquid. This made the situation even more complicated for them. Participants on diet specifically for different chronic diseases were more confused and more concerned.

"My fluid intake is restricted to 800 ml per day and I can only consume certain food. This makes me very frustrated sometimes"[21]

'Which one (diet) do you stick to more... the one for his diabetes... or his kidney disease, his heart... Plus he is on warfarin... I have never been so confused in my life!"[28]

"At the beginning, I was very lost, then I started asking here and there (to understand the diet better...)"[37]

"I am a prisoner; you are no longer free to do as you wish, like a person condemned to death. Because you have everything in front of your eyes and you know that you cannot do it, you cannot drink. According to me, one is a prisoner, and I would not know how to express it in any other way"[25]

A constant internal conflict - struggle with yourself

Participants talked about how they struggled with themselves to abandon their previous eating habits. Participants reported that they understood the recommended diet restrictions but experienced a constant internal conflict as they constantly had to restrain themselves. Some participants stated that when they were extremely thirsty, it was impossible to refuse it and that their struggle with fluid intake turned into daily combat.

"I can't find a way to avoid the drinking need; my thoughts are always fixated on the bottle, and I am always close to the fridge. When I wake up in the night, the first thing I do is to go into the kitchen, open the fridge to see what to drink, and I drink because I can't resist, like children who can't stop themselves... I am still thirsty even if I drink an entire liter of water".[25]

"There are times when I crave to eat more. But I know I shouldn't so I restrain myself."[30]

I know I should not eat it, but I still want to eat it. (P20)Especially in a hot day, you want to drink but you know you have to control your intake.[41]

Cultural identity and loss of self

Some of the participants saw diet restriction as a loss of cultural identity because they perceived it as culturally isolating. It was understood that when they had to eat meals different from those of their family or friends, they felt lonely, different from others and guilty thinking that they were a burden on others. This was because eating was an indispensable and important part of life for them.

"It is hard when I go out with friends and everyone is drinking around me, and I like a beer but I can't have it. I just feel like I am isolated sometimes".[24]

"I find it difficult. Social situations are hard. Eating out or having friends out or going to friends where you are not in control of what is put on the table and what you eat. Alternatively, you are at their house, it is very rude to sit there, and say, "I can't eat that. I'm not supposed to eat that much potassium," you sound like a right idiot".[29]

"Not being able to eat traditional foods causes distress due to both loss of cultural identity and a decreased ability to socialize with loved ones. In addition, families do not understand or forget about restricted foods and serve them anyway, which results in participant feelings of guilt when families complain about needing to cook separate meals".[24]

"Yep I feel good; you know we (Aboriginal Peoples) are a part of it (traditional foods) the food and the gathering of the food with the family".[33]

Main theme 2: Perceived barriers

While the participants were sharing their experiences with diet and fluid restriction, they frequently mentioned the existence of barriers that affected their compliance. These barriers consisted of three sub-themes: personal barriers, social barriers, and systemic barriers.

Personal barriers

Most of the participants reported that they experienced a lot of difficulty in complying with fluid restriction and diet due to symptoms, such as thirst, dry mouth, nausea, vomiting, loss of appetite, and fatigue, especially in hot weather. They admitted that they felt inadequate about diet and fluid management and that they did not know enough about it. Participants with a low socioeconomic level stated that the renal diet had a considerable cost and therefore they could not adapt to their diet. In general, participants mentioned the lack of motivation in diet and fluid management. According to them, dialysis treatment took a long time, and they felt tired when they returned home. Especially single and male participants with no social support experienced a lack of motivation more. Single male participants stated that it was harder for them to comply with the diet because they did not know how to cook and did not have a spouse cooking for them. What made compliance with fluid intake restrictions difficult for some participants was their beliefs and their own convictions. They stated that water and the air we breathe are indispensable elements of life and that they did not believe in the necessity of fluid restriction. Some participants, on the other hand, noted that the lack of fluid intake would cause other complications, particularly dehydration. Some others believed that dialysis would compensate for this even if they violated diet and fluid restrictions. Moreover, some participants' belief in fatalism or supernatural powers was another obstacle in the management of diet and fluid restriction.

"I don't think that the doctor is aware but there is a lot of black magic going on around here in England. This does make you sick and takes your will for living".[36]

"I do believe that everything happens for a reason. I have no choice. This is it. This is as good as it gets".[19]

"Our body is made of 70% water, so how can a person not drink? How can a person not drink? Water is life".[25]

"it's like a pregnant lady, your body's asking for a particular food. It really wants that thing".[24]

"And then people [on] low sodium [diet], like for us, you could get a big thing of seasoning salt for about $7.00 and Mrs. Dash will cost you $9.00 and it's a little shaker. If you get two or three different types it could be mighty expensive, like $30, for something you can get for $7.00".[26]

Social barriers

Culture and stigma were identified as two major social barriers to compliance with diet and fluid restriction. Some participants stated that it was very difficult to give up the habits of their culture and therefore they had problems in adapting to the diet. Particularly refugee participants thought that dieticians did not know about foods and diet patterns specific to certain cultures and that they were not supported enough in this regard. Some felt they had to restrict traditional food and found this isolating, especially in social contexts, as they

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had to avoid eating what their family and friends enjoyed.

"High salt diets are part of the Japanese culture, which was established early in our childhoods, and that having salty condiments easily accessible on the dining table is a common practice".[30]

"Indeed, Indian food are mostly oily, with chilli and spices. That's why I've to take care".[21]

"This will take time. We grew up accustomed to put salt in our food. I like the taste of salt. It will not be easy".[36]

"They told me that I could reduce fluid intake by eating lemon dipped in sugar, but Korean people hardly eat lemons. If you teach us things that do not go well with the Korean diet, it does not have any real effect".[22]

Anxiety about stigma was also an important barrier to compliance with diet and fluid restriction for the participants. Some participants reported that they consumed fluids like a healthy person and hid their illnesses in order not to disturb their friends and colleagues and not to feel excluded in social environments. While some participants stated that comfort and wealth in their society were associated with abundant food and traditional spices, they worried that reducing dietary salt could be seen as a sign of poverty.

"If people know that I am sick and receiving dialysis, who would want to make a deal with me? They will think that I am going to die soon. Thus, for 5 days a week, I drink alcohol like everyone else. That's the public's perception of kidney disease in this country".[22]

"People will think we are very poor and can't afford salt. They will think we are starving and have no money".[36]

Systemic barriers

While participants were discussing their experiences about diet and fluid restriction, they explained the systemic barriers to compliance with diet and fluid restriction. These obstacles were generally identified as hemodialysis center regulations, deficiencies in diet and fluid counseling, communication problems with healthcare providers, and deficiencies in public health policy.

Participants also stated that the duration of dialysis was long and that when the transportation time for those coming from far places was added to the total time, it took even longer. For this reason, some participants stated that they were hungry for a long time and that they ate whatever they could find after leaving the center and could not comply with their diet. Furthermore, they reported that the dialysis center did not have an application for the nutrition of the participants.

"On dialysis days, I don't have a chance to eat lunch. [It] makes me hungrier when I get home. If you don't eat before you get up and get out, and then you're hungry when you get out, and there really isn't a place where you can get some regular food. You might go to McDonald's and all that fast food really isn't good for you". [26]

A significant portion of the participants found the support they received for diet and fluid restriction inadequate. They stated that they were generally told clichés, such as "don't consume too much fluid", "don't consume salt", or "stay away from foods containing potassium and phosphorus" and that they did not receive detailed training for diet and fluid restriction. Some of the participants said that although the doctor emphasized the importance of potassium and phosphorus, they were unfamiliar with these concepts and that they were confused about which foods to choose and how to cook meals. Some stated that dietary counseling should be arranged individually and continuously customized to their learning style. According to them, a superficial explanation was made, ignoring their accompanying chronic diseases and cultural eating habits.

'Pictures and colours I remember.. .and the potassium pyramid...was helpful for me.. .because I am a visual person'.[28]

"They told me that I could reduce fluid intake by eating lemon dipped in sugar, but Korean people hardly eat lemons. If you teach us things that do not go well with the Korean diet, it does not have any real effect".[22]

"Everybody is different. Our needs are different. You have to respond to the people who have the means and the ones that [don't] have the means. You know what I mean? Yeah, you wouldn't recommend my diet to someone else because they might not be able to afford it, ok [laughs]? You have to be aware of that".[26]

"At the beginning, I also gained 5 kg. They told me that I needed to reduce fluids, but they didn't tell me how. I learned how to reduce them on my own".[25]

Participants reported that the environment was hectic, healthcare providers avoided communicating and did not listen to them in

the busy dialysis environment, and therefore they hesitated to ask questions. Some participants also stated that there was inconsistency among the statements made by the team members, so they experienced confidence problems and confusion. Communication problems occurred between the ethnically incompetent patients and staff due to language problems.

"...Sometimes I feel that it's very difficult to speak to the nurses....too busy too many patients.. .I want to ask questions but feel bad to take their time there are more old and needy patients here... "[20]

"The nutritionist advised me before and I left everything. I left all fruits! So the nurse asked me "what is wrong with you? Nowadays your blood levels are just low! You are so white what is wrong?" and I told her "I have stopped eating fruits because I was told that fruits are bad, they will harm me." The nurse told me "no! go ahead and eat the fruits that you were eating".[5]

Some participants stated that most food products contained a significant amount of sodium, there were no administrative regulations on the subject, and that fluid restriction was difficult for them for this reason. Another important problem was that food labels did not usually show potassium and phosphorus content. Besides, some mentioned the lack of programs for dialysis patients despite many training programs on chronic diseases such as diabetes which are organized within the scope of public health programs.

"Almost all processed food contains a lot of salt, and so it is very difficult to choose food low in salt. Restaurants must reduce their use of salt not only for dialysis patients but also for the entire population's health as well".[22]

"Potassium is not on food labels...I have a chart with the (foods) to avoid...but the list is far from complete".[3]

"They told me to visit the diabetes education program at the public health center and I received a lot of help. But the government does not provide any service for kidney patients. That is exactly what we need".[22]

Main theme 3: Strategies developed for diet and fluid management

All the participants considered coping with diet and thirst as a daily challenge for patients on hemodialysis, and some developed their own strategies to manage the situation. These strategies were discussed under two sub-themes, namely, cognitive, and behavioral strategies.

Cognitive strategies

Participants explained the cognitive strategies they used consciously or unconsciously while trying to achieve diet and fluid management. Some of the participants stated that they accepted their disease, they now considered the renal diet prescribed to them as their normal diet, and that they believed that the management of the disease could only be successful with their own self-discipline, and thus adapted more easily. Some said that they often reminded themselves of their sources of motivation, considering the benefits of diet and fluid restriction in their treatment, remembering how valuable the support they received from their family and friends made them feel. In addition to this, some participants stated that they remembered their negative experiences and possible complications and increased their motivation for diet and fluid compliance by frightening themselves.

"Renal diet is just my normal diet".[24]

"I oftentimes just think about me and what I need to do for me. Who is going to stop you from doing for you? Nobody. Help yourself".[23]

"And my siblings, husband, children. They understand that I get very tired after dialysis and they help out with the housework. They don't want me to worry too much. Then for my part, you feel that family help you so much and you feel more motivated to work through and take care of yourself because you don't want to disappoint them. Then you look forward to everyday and the next day".[20]

"I will think of the spasms I will suffer later and then tell myself not to drink too much".[41]

"About 2.3... because I know if I take anymore I get cramp".[38]

Behavioral strategies

Participants talked more about the behavioral strategies they discovered in diet and fluid management. Few of them mentioned healthcare providers' intervention when developing behavioral strategies. The behavioral strategies used consisted of seeking information, avoidance behavior, discovering new behaviors for symptom management, receiving social support, and using facilitators. All the participants stated that they sought information on diet and fluid management and that their sources of information were

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healthcare providers, the Internet, and other patients on dialysis. Most participants said that family support was primarily direct assistance for applying the medication and preparing meals and a direct facilitator for following treatment recommendations by providing direct assistance, advice, or reminders for controlling fluid and dietary intake. A significant portion of the participants stated that to comply with diet and fluid restriction, they exhibited some avoidance behaviors, such as avoiding social circles, environments where prohibited foods were found or making close friends. Participants stated that they sometimes discovered new behaviors to manage their symptoms. Some of them said that they kept a diary to monitor their fluid intake, took their scale with them even on vacation to monitor their weight, thus making it easier to monitor their liquid intake, and used applications on their mobile devices to learn about the ingredients while choosing foods. A significant portion of the participants stated that they received support from their families, friends, and other patients on hemodialysis in fluid and diet management so that they could manage this process more easily.

Discussion

In this meta-synthesis study, 23 qualitative studies investigating the experiences of patients undergoing hemodialysis about diet and fluid restriction were examined. As a result of the analysis, the experiences of patients on hemodialysis about diet and fluid restriction were classified into three main themes: "the meaning of diet and fluid restriction for the patient", "perceived barriers", and "patient's own management strategies for diet and fluid restriction". The findings of this study, which was based on the shifting perspective model of chronic illness, are thought to guide healthcare providers in supporting the diet and fluid management of patients on hemodialysis. The findings of the study were discussed in line with the main themes.

The meaning of diet and fluid restriction

In the study, although diet and fluid restriction were deemed necessary by most of the participants, it had different implications for the patients. Participants perceived diet and fluid restriction as a complex and demanding process and a constant internal conflict - self-struggle and loss of cultural identity. Some quantitative studies have shown that perceptions of patients on hemodialysis about diet and fluid restrictions differ and affect their compliance.[42-45] For example, in a multicenter cross-sectional study, it was determined that patients on hemodialysis who perceived more difficulty in monitoring diet and fluid intake had worse clinical parameters.[45] The shifting perspective model of chronic illness suggests that the health perspective of living with chronic illness has specific functions in one's world and that it is an ongoing and ever-changing process.[14] For this reason, it is very important for healthcare providers to know the patient's perception of diet and fluid and to change the patient's negative perception by applying cognitive and behavioral strategies when necessary.

Perceived barriers

In the study, most of the participants mentioned the existence of perceived personal, social, and systemic barriers to compliance with diet and fluid restriction. Personal barriers consisted of physiological symptoms experienced, self-inadequacy, lack of knowledge, low socioeconomic level, being male and single, lack of motivation, and beliefs and fatalism. In an integrative review research that examined 44 studies evaluating the dietary compliance of end-stage renal disease patients, barriers to dietary compliance, similar to this study, were categorized according to the World Health Multidimensional Adherence Model as (i) socioeconomic factors, (ii) factors related to the condition, (iii) treatment-related factors, (iv) healthcare team and system factors, and (v) patient-related factors.[3] Similarly, in another study investigating dietary compliance in patients on hemodialysis based on the health belief model, perceived barriers, such as self-efficacy, gender, marital status, and socio-economic level, were determined as predictors of diet compliance.[46] It is thought that healthcare providers should consider the personal barriers of their patients when they are planning fluid and diet management because this will enhance adherence.

In this study, the social barriers experienced by the participants were determined as culture and stigma. The patients had difficulty in giving up the food habits of the culture they had, even if it was completely against the renal dietary principles, and they saw this as a loss of cultural

identity. In their study examining compliance with dietary management, Oquendo et al. found that the cultural structure of the country had a direct effect on healthy food intake.[47] Similarly, some other quantitative studies found that culture was an important barrier to compliance with renal diet.[48-49] The present study, which evaluated the renal dietary compliance of patients on hemodialysis living in different countries, revealed that the culture of patients was important to them and could create a barrier to diet and fluid restriction. While making diet and fluid planning of patients, considering their cultural characteristics, making realistic and practical diets for them, and their follow-up by the nurse and dietician are very important aspects.

In the present study, stigma was another social barrier that participants suffered in managing diet and fluid restriction. It was understood that participants did not obey diet and fluid restrictions so that they could show themselves as normal in social circles due to the anxiety of stigma. In the thematic synthesis study of Palmer et al., which investigated the diet and fluid restriction of 816 chronic kidney patients living in high and middle-income countries, it was determined that patients had difficulty in adapting to diet and fluid restriction due to the fear of social stigma.[50] Stigma is a condition that affects adherence to treatment also in many chronic diseases just as it is in chronic kidney disease.[51-53] Therefore, healthcare providers should take stigma into account. They must be aware of whether the stigma is internal or external, and they should plan their initiatives accordingly.

In the study, it was determined that participants perceived some barriers, such as the regulations of the hemodialysis center, deficiencies in diet and fluid counseling, communication problems with healthcare providers, and lack of a public health policy. Some studies have shown that the quality of the relationship between the patient and the healthcare provider is important in compliance with diet, end-stage renal disease patients who receive intensive training from healthcare professionals have better compliance with diet compared to patients who do not receive support at all, and that those who receive inadequate expert support, on the other hand, are adversely affected especially in terms of dietary compliance.[3, 47, 54-56] Similarly, studies have also revealed that patients on hemodialysis have difficulties in understanding information about appropriate diet and fluids, experience communication problems with healthcare providers, and perceive education programs for dialysis patients and policies regarding social health as inadequate.[3, 47, 57] One study showed that policy changes such as producing low-sodium food products or reducing sodium levels in processed foods are very important for HD patients, as 75% of their daily sodium intake comes from processed foods.[58] In this sense, it is important to make legal regulations and organize training programs to protect public health.

Patients own management strategies for diet and fluid management

All the participants in the study saw coping with diet and thirst as a daily struggle. Some of the participants developed some cognitive and behavioral strategies to cope with the situation, and, remarkably, most of these participants did not mention any interventions of healthcare providers when developing strategies. Indeed, some studies have shown that educational and self-management interventions have a beneficial effect on fluid intake and compliance with diet.[59-61]

In the study, to achieve diet and fluid management, participants used cognitive strategies, such as accepting the disease and seeing diet and fluid restriction as a normal part of their life, believing that management alone can provide self-discipline, and remembering negative and positive motivation sources. It was reported that an individual's perception of illness would affect the coping strategies they use to manage their illness and was a predictor of their desire to engage in self-management behaviors.[47, 62, 63] Since disease perception can be changed through intervention, early planning of interventions based on disease perception is extremely important in terms of diet and fluid compliance. Another cognitive factor used by the participants in the study was to consider sources of motivation. Similarly, studies have determined that motivation increases compliance with diet and fluid restriction in patients on hemodialysis, and lack of motivation is seen as a barrier to compliance with diet and fluid therapy.[4, 47, 61] Besides, in some studies, it has been observed that motivational interviews conducted by nurses increase adherence to the fluid and diet management of patients on hemodialysis.[61, 64-65] For this reason, it is important that health care

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providers, especially nurses, who are in close contact with patients on hemodialysis, know motivational interview techniques and can intervene when necessary.

For most of the participants, family support was found to be a direct help in the preparation of meals and a direct facilitator in their behavioral strategies by providing help, advice, and reminders to monitor fluid and dietary intake. In other studies, supporting the finding of this study, it was determined that the presence of social support increased dietary compliance and the lack of social support was perceived as a barrier to compliance with diet.[3, 47, 66]

This study has some limitations. The possibility of missing some keywords is a risk in meta-synthesis research and is one of the limitations of this study. Another limitation is that only studies published in the English language were included in the study. On the other hand, the analysis of 23 qualitative studies in this meta-synthesis study, which allowed an in-depth analysis of the experiences of patients on hemodialysis about diet and fluid restriction, constituted the strength of the present study.

CONCLUSION

As a result of the synthesis carried out in the present study, it was understood that diet and fluid restriction for patients undergoing hemodialysis was a complex and demanding process in which a constant struggle was given. In this challenging and complex process, some personal, social, and systemic barriers perceived by patients on hemodialysis made compliance with diet and fluid restriction even more difficult. More importantly, it was determined that most patients thought that they were not sufficiently supported by healthcare providers in the management of diet and fluid restriction and that they developed some correct or incorrect cognitive and behavioral strategies. In line with these results, we recommend that healthcare providers should evaluate the patient's perception of the disease and diet and fluid restriction at the initial stage of diet and fluid restriction management and carry out interventions for negative perceptions. As stated in the shifting perspective model of chronic illness, patients' perceptions can be changed. Moreover, we recommend that individual counseling services for diet and fluid restriction of patients on hemodialysis should be increased, patients' barriers should be considered while planning diet and fluid restriction, and that the plan should be realistic and feasible.

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 ISSN 0326-3428