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Vision-related quality of life among patients with end-stage renal disease; a qualitative study

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Abstract

Introduction: End-stage renal disease (ESRD) is frequently treated with emphasis on systemic stability, but difficulties related to vision, continued to be disregarded even though they play an important role in daily functioning and independence. Visual impairments are an additional psychosocial and physical burden that comes along for ESRD, yet they are often not provided for in nephrology care.

Objectives: This study explores the hidden burden of visual impairment among ESRD patients in Jordan and identifies gaps in current clinical support systems.

Patients and Methods: A qualitative study design was adopted through semi structured interviews with ESRD patients in private ophthalmology clinics in Amman. Purposeful sampling assured variation on age, gender and health backgrounds. Participants gave free accounts of their visual experiences. Interviews were audio recorded with informed consent and transcribed verbatim, using inductive analysis. A local institutional review board had been obtained in respect of its ethical approval.

Results: Patients described persistent challenges with blurry vision, light sensitivity, and unreliable sight, particularly in low-light conditions. While eyeglasses and assistive tools such as audiobooks or screen readers provided partial support, they rarely restored full independence. Barriers to routine eye care included dialysis fatigue and logistical constraints. Family support often filled functional gaps but simultaneously reinforced dependency. A consistent theme was the absence of coordination between nephrology and ophthalmology; vision concerns were seldom raised during renal care visits, and patients perceived little professional interest in their visual health.

Conclusion: The quality of life of ESRD patients significantly affects visual impairment in that this activity affects independence, mobility and psychosocial changes. Improved and interdisciplinary collaboration between nephrology and ophthalmology is needed to guarantee a holistic and patient-centered care.

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Introduction

End-stage renal disease (ESRD) is the terminal, irreversible stage of chronic kidney disease (CKD) and is that point in the disease at which the kidney filtration capacity is reduced to the point at which the extracorporeal support is required (1). This is the stage where dialysis or transplantation is usually established. At the same time, patients with ESRD also suffer from a series of disabling clinical symptoms, including muscle cramps, fatigue and fluid overload, cardiovascular diseases and so on, which in combination make their physical and emotional health weak (2). The overall effect of these conditions is to infringe on the quality of life on a daily basis.

Electrolyte imbalances and systemic functioning can be successfully addressed but ocular health is an under researched area of modern ESRD management (3). Light sensitivity, difficulty focusing and loss of peripheral vision are among the common complaints of patients and these findings are commonly associated with comorbidities, which are also quite prevalent in ESRD, which are hypertension and diabetes, as predisposing factors for pathology such as diabetic retinopathy and cataracts (3,4). In addition, the vascular and retinal damage may be further improved by the uremic toxins produced by the malfunctioning renal filtration and therefore aggravate the visual impairment.

Visual loss significantly affects the daily performance. Simple tasks, such as safe navigation, reading printed text, or recognizing known persons, become more difficult. This creates the need to be dependent on others which in many cases causes frustration, emotional distress and the loss of autonomy (3,5). Although some

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Key point

- Health Policy: Incorporate vision screening in national ESRD effective management strategies to make sure that early visual impairments are correctly managed.
- Clinical practice: Stimulate structured collaboration across specialization(s) between renal specialists, including nephrologists, and experts in visual function (e.g. ophthalmologists) to address the neglected sensory requirements of ESRD patients.
- Research: Encourage additional research into the prevalence, causes and outcomes of visual difficulties from ESRD populations to direct evidence-based interventions.
- Medical education: Add training about sensory health and interdisciplinary care models to learning curricula and nephrology training, and care for patients with renal failure training, to integrate full-patient care.

partial remediation is possible using corrective glasses and magnifiers, confidence concerning vision is disjointed. These subjective but important complaints are not often given priority in clinical encounters, which are usually dominated by laboratory review and scheduling of the next dialysis treatment.

The sidelining of visual issues in nephrology practice is a structural failure. Although ocular symptoms are not as noticeable as systemic complications, they have a devastating impact on the quality of life. The scope of ESRD care is not complete without systematic consideration of visual status. Here, the concept of vision-related quality of life (VRQoL) is relevant, which includes functional and psychosocial consequences of visual impairment; however, this aspect is poorly investigated in ESRD (3). The biomarkers of creatinine and potassium remain in the spotlight of regular clinical surveillance, whereas the lifestyle and psychological impact of the loss of vision is frequently unrecognized, and the comprehensive care planning is lacking (5).

Besides exacerbating the physical and psychological stresses, visual impairment increases the difficulty of living with ESRD. When visual acuity is impaired, fatigue management, spatial orientation, and daily routine become more burdensome, thus further expanding the disease load beyond metabolic or circulatory dysfunction and further deteriorating overall well-being (3,6). However, the existing literature is unbalanced in terms of the emphasis on systemic pathology, and little attention is paid to ophthalmic outcomes. Few studies have examined the impact of visual impairment on the independence, psychosocial status, and lived experience of ESRD patients, and fewer still have included the subjective views of patients on visual loss and its effects on quality of life (3,7).

The current research thus attempts to correct this imbalance by clarifying patient accounts related to ESRD and associated visual impairment. The emphasis on lived experience emphasizes the need to incorporate vision into ESRD management as a whole. The results support the systematic incorporation of ocular screening into renal practice and promote the increased cooperation between nephrologists and ophthalmologists. This way may improve patient functionality, autonomy, and emotional resilience.

Objectives

In this exploratory study, the researcher examines how visual deficiencies influence the lived experience of patients with ESRD. The research took a qualitative design to solicit the opinion of the patients, especially the common challenges, how they affected their normal operations, and the coping mechanisms that they used. The results support the importance of visual impairment to patient autonomy and the necessity of clinicians to incorporate thorough ophthalmic evaluation and corrective action into regular ESRD management.

Patients and Methods

Setting

The study was conducted in a privately owned ophthalmology clinic in Amman, Jordan. This clinical context was a good and favorable one to elicit detailed narratives and rich information about the experiences of patients with VRQoL (8).

Study design

An interpretative phenomenological approach (IPA) as a qualitative research design was used. The choice of this design was to know the lived experiences of the patients with ESRD about their vision related issues. The IPA was particularly suited to the purposes of the study as it gives attention to the subjective, descriptive accounts of people and allows for the liberation of meaning through the reflective and interpretive functioning of the individual (9).

Sample size

The sample size was purposive consisting of nine adult patients with ESRD suffering from vision-related problems including blurriness, sensitivity to light or focusing problems. All of the participants had consulted ophthalmology. Inclusion criteria included participants in the study being able to consent informed and participate in Arabic interviews. Exclusion criteria was implemented to filter out those who had not reported concerns associated with vision, had not visited an ophthalmologist or reduced cognition that can affect participating. This sampling methodology ensured that the participants could offer valuable information on the intersection between ESRD and VRQoL and is consistent with the qualitative design (10).

Instrument

The data were collected using a semi-structured interview guide that included open-ended questions that could be responded to in detail. A number of dimensions were

covered within the guide including visual symptoms, problems with daily functioning, independence, mobility, coping strategies, professional implications and healthcare support views (3-7,11-14). The main questions were:

- Are you able to explain any problems you have with your vision, including blurred vision, difficulty focusing, or light sensitivity?
- What impact do these vision problems have on your performance of daily tasks such as reading, identifying individuals, or adapting to light changes?
- How do your vision-related problems affect your independence? Are you the person who is usually in need of assistance?
- What effect have your vision problems had on your work or other professional activities?
- Are you experiencing any particular difficulties with mobility, including moving around your home or in the public areas?
- How do you cope with your vision-related difficulties (e.g., glasses or other visual aids)?
- To what extent do you feel the support of family or friends is helpful in helping you to cope with your day-to-day activities?
- Do you do anything to modify activities to suit your vision problems, e.g. use audiobooks or other substitutes?
- Have you had your vision-related problems addressed in the course of your ESRD treatment? Otherwise, why do you suppose they are neglected?
- Do you go to an ophthalmologist? What have you found useful about this in terms of managing your vision-related issues?
- Do you think your nephrologist and ophthalmologist communicate or collaborate adequately to meet your overall health needs?
- How could the healthcare services be improved to enable you to better cope with your vision-related difficulties?
- Is there anything that you would like to add about the effects of your vision on your quality of life as an ESRD patient? (3-7, 11-14).

Data collection

The sample was selected by purposive sampling method when participants visited the ophthalmology clinic on regular basis. Patients who met the eligibility criteria were approached and informed about the study and given written consent forms. After getting the consent, interviews would be conducted at convenient times in the clinic. The interviews took around 30-45 minutes and were carried out by a trained researcher in a separate and quiet room. Interviews were audio-recorded with the consent of the participants to make them accurate. All tapes were transcribed verbatim and participants were provided with the opportunity to check transcripts to ensure accuracy or to clarify.

Credibility and integrity

In order to achieve methodological rigour, a number of strategies were conducted according to the standards of qualitative research.

Credibility was also achieved by spending a lot of time with the participants in the in-depth interviews where rich and detailed accounts were obtained. Member checking was performed by asking participants to check their transcripts to ensure that they were accurate and to explain any misinterpretations. Triangulation was conducted by comparing the emerging themes in various participants to make them consistent.

The issue of transferability was also addressed by specifying the study setting, sampling criteria, and demographics of the participants in as much detail as possible so that the readers could determine whether the findings could be applied to other settings. The potential generalisability of insights in similar ESRD populations is also supported by thick description of lived experiences of participants.

The reliability was secured with the transparent audit trail of the research process, i.e, documenting the methodological decisions, interview procedures and coding strategies. This made the process of analysis systematic and reproducible.

Reflexivity promoted confirmability. In order to detect and reduce personal biases, the researcher kept reflective notes as part of the data collection and analysis. Moreover, peer debriefing with a qualitative research expert was used to discuss coding and theme development, and make sure that the findings were well-grounded in the accounts of participants as opposed to researcher preconceptions.

All these measures helped to make the results of the study credible and thoroughly formulated and close to the real life experiences of ESRD patients in the context of dealing with vision related issues

Data analysis

The data was interpreted through thematic analysis, and special interest was paid to translation and cultural nuance. The researcher started to immerse in the dataset through repeated listening to audio recordings and reading transcripts. Arabic interviews were transcribed verbatim, and then translated to English. Translations were reviewed by a bilingual expert to maintain meaning and accuracy. The line-by-line coding was conducted to determine meaningful phrases and frequent patterns concerning VRQoL. These codes were categorized into more general themes and were clustered into emergent themes that were representative of common experiences among participants. To achieve validity, themes were checked against Arabic transcripts and English translations. Redundancies were removed and every theme was described and illustrated with quotations of participants. The last step entailed the development of a narrative synthesis that merged the

thematic results, and it provided the genuine voices of the patients without being culturally insensitive.

Results

Demographic characteristics

This study enrolled 9 patients with ESRD and formed a diverse group characterized by age, gender, disease duration, and etiology. The age of the participants was between 39 and 72 years, and the gender was approximately balanced. Durations of the diseases were 2-10 years and etiologies included diabetes mellitus, hypertension, glomerulonephritis, and polycystic kidney disease (Table 1). All the subjects were receiving renal replacement therapy, either hemodialysis or peritoneal dialysis, with most of them using hemodialysis. The consultations with ophthalmologists were noted as regular, but with varying frequencies (e.g., once a year or once every three months), which reflects the differences in the severity of the vision-related symptoms of the participants.

The prevalence of comorbidities was very high; the most commonly documented were diabetes mellitus and hypertension. Ocular complications that were frequently linked to these systemic diseases are diabetic retinopathy, hypertensive retinopathy, cataracts, and glaucoma. The overall agreement between these systemic and ocular disorders highlighted the complexity of the relationship between ESRD and ocular wellbeing. The inclusion of participants that had a wide range of demographic characteristics, medical history, and visual experience allowed the study to capture a wide range of perspectives which in turn enhanced the understanding of the impact of ESRD on vision-related quality of life.

Thematic analysis results

Thematic analysis of participant narratives revealed four broad themes, namely, Visual Difficulties, Effects on Daily Activities, Coping Mechanisms, and Healthcare System Responses. Blurred vision, light sensitivity, and focusing difficulties, particularly between near and distant objects, were reported consistently by participants, and they affected activities like reading instructions, safe navigation, and face recognition and forced participants to rely more on family members. The coping strategies were different. Other participants used corrective lenses but they were not equally effective. Other people were more dependent on family support, but this contact could also increase the sense of dependency. A small number used adaptive strategies, e.g. listening to audiobooks rather than reading print, which are stopgap measures not solutions. Healthcare-related experiences became one of the critical themes. The majority of the participants noted that vision-related issues were rarely discussed at the nephrology visits. They viewed kidney care and eye care as separate entities, and there was little integration between nephrology and ophthalmology services. This disintegrated care enhanced the feeling that visual health was neglected and emphasized the necessity of improved cooperation between specialists to facilitate holistic, patient-centered care (Table 2).

Vision-related challenges

The most common visual disturbance was blurriness especially when performing activities that required accuracy- like reading or complex manual activities. This symptom was found to be particularly frustrating by four participants. One of the participants reported that she could not identify people at a distance every day, and another participant mentioned that it was physically demanding to switch between near and distant objects. Photophobia was also prevalent and two of the participants reported feeling uncomfortable moving between dark and bright places.

Regardless of the heterogeneous experience, vision-related symptoms were always a disturbance in daily life. Sensitivity to light was explained by patients in various forms: some of them complained of constant squinting, others complained of temporary loss of clarity in bright areas. These visual issues were an added burden to those already coping with the needs of ESRD

Effect on everyday life

Routine activities were limited by functional limitations. Five participants stated that they needed help with activities like reading medication labels or going up and down the stairs. Although physical mobility was not affected, visual impairments created a feeling of insecurity, even in short walks. Some of the participants reported a loss of confidence in crossing the roads and some reported

Table 1. Participant characteristics

Participant	Age (years)	Gender	Duration of ESRD (years)	Dialysis type	Primary cause	Comorbidities
P1	39	Male	2	Hemodialysis	Diabetes	Diabetic retinopathy, hypertension
P2	45	Female	3	Hemodialysis	Hypertension	Hypertension, cataract
P3	52	Male	5	Peritoneal	Glomerulonephritis	Glaucoma, hypertension
P4	60	Female	7	Hemodialysis	Polycystic kidney disease	Cataract
P5	67	Male	10	Hemodialysis	Diabetes	Diabetes, hypertensive retinopathy
P6	72	Female	4	Peritoneal	Hypertension	Glaucoma
P7	48	Male	6	Hemodialysis	Glomerulonephritis	Hypertension
P8	55	Female	8	Hemodialysis	Diabetes	Diabetes, cataract
P9	63	Male	9	Hemodialysis	Hypertension	Hypertension, glaucoma

Table 2. Exemplary quotes from interviews organized by themes and subthemes (n=15)

Theme	Subtheme	Exemplary quote
Vision-related challenges	Blurred vision	*"I struggle to read small print now; it's frustrating because I used to enjoy reading books."* (Participant 4, Female, 60)
	Difficulty focusing	*"It's hard to focus on objects at a distance. Even recognizing people has become difficult."* (Participant 7, Male, 55)
	Sensitivity to light	*"Bright lights make my eyes water, and it feels like I can't see properly for minutes after."* (Participant 8, Female, 44)
Impact on daily life	Dependence on others	*"I need my family to help with simple things like navigating stairs or reading medication labels."* (Participant 6, Female, 72)
	Difficulty with work activities	*"I had to stop working because I couldn't see clearly enough to use the computer or review documents."* (Participant 1, Male, 65)
	Reduced mobility	*"Crossing the street is terrifying because I can't see cars until they are too close."* (Participant 5, Male, 39)
Coping mechanisms	Use of visual aids	*"I rely heavily on my glasses now, even for things I didn't need them for before."* (Participant 9, Male, 61)
	Support from family	*"My family helps me with everything—reading letters, helping with appointments. I couldn't manage without them."* (Participant 4, Female, 60)
	Adaptation to limitations	*"I've learned to adjust my activities. For example, I listen to audiobooks instead of reading."* (Participant 2, Female, 48)
Healthcare experiences	Limited vision care in ESRD	*"My nephrologist focuses on my kidneys, but no one asks about my vision unless I bring it up myself."* (Participant 7, Male, 55)
	Importance of regular checkups	*"Visiting the ophthalmologist regularly has helped me manage some of the problems before they get worse."* (Participant 3, Male, 53)
	Gaps in coordinated care	*"I feel like the doctors don't talk to each other. My kidney and eye issues feel like separate problems to them."* (Participant 8, Female, 44)

a loss of occupational capacity. In the case of those whose occupation required screens or a lot of paperwork, visual problems had a devastating impact on performance, and some had given up work altogether. Loss of independence was a trend that ran through accounts. Support of family was appreciated, but was associated with gradual loss of independence. Participants described this dependence as a creeping process, which was not apparent at first but became more apparent, as vision became worse.

Coping mechanisms

The participants had various adaptive measures taken to deal with the vision-related problems. The most common aid was corrective glasses that is reported by five individuals but not all of them worked. One respondent said glasses were not too helpful and others had blurred vision or unreliable vision even with glasses. Another important coping strategy was family support volumetric support, as four of them reported using relatives to make appointments, read document or give advise in new places. In addition, three of participants mentioned individual adjustments which helped to preserve autonomy. These included the substitution of reading material with audiobooks, and reorganisation of home set-ups to prevent accidents. Though often these approaches were quite humble in scope, they were creative and evidence of a will to be independent without official medical aid.

Healthcare experiences

One of the underpinning themes was that vision was not being addressed in nephrology care. Five participants said that their nephrologists rarely talked about problems in their eyes unless the patient mentioned them. This negligence was frustrating and, further, supported the feeling that visual health was not felt to be a part of ESRD management. One of the participants said that despite the frequent visits of the ophthalmology department, there appeared to be little or no communication between the ophthalmologist and nephrologist.

But there are other participants who also admitted to the utility of periodic ophthalmologic examination. Three of them were attributed the prevention of further deterioration with such examinations. However, two others raised the issue of fragmented care, presenting a system whereby nephrology and ophthalmology were existing in the vacuum. They did not blame such fragmentation on the indifference of individual clinicians, but it was due to the compartmentalized nature of healthcare, they did not have any idea who was in charge of their overall wellbeing.

Discussion

TThe current results outline that eye disorders such as blurred vision, photophobia, and reduced focus are common and severely disruptive phenomena in persons with ESRD. The study supports the studies that have linked co-morbidities like diabetes and hypertension with retinal pathologies (15,16).

In addition, optic neuropathy has been associated with long-term dialysis. Despite the fact that blurry vision is a common complication of diabetes, ESRD participants were more likely to have more severe symptoms due to concomitant systemic needs. Participants reported poor

daily functioning: most needed help to navigate and to read, as reported in the literature on older adults with vision loss (3,13). Others gave up paid work or became immobile, which is in line with previous research on visual disability and labor market integration (8,9), and some resisted these limitations. Eyewear was of little help, and family participation became a crucial resource. Dependence on the extended family was strong in the Jordanian context where kinship caregiving is normative.

Comparatively, western healthcare settings are more inclined to formal providers or institutional services. Adaptive practices were also observed among the participants, including the use of audiobooks, which are similar to those, observed in other visually impaired communities (4). It is noteworthy that vision issues were not routinely addressed during nephrology consultations unless specifically stated, an oversight that has been reported in the study of chronic illnesses, where the need to maintain life-sustaining interventions may take precedence over quality-of-life considerations (2,14).

In high-income countries, where integrated care models are popular, often also the ophthalmological screening is an integral component in the management of chronic diseases; this type of coordination is not well-developed in Jordan. Routine eye testing had mixed results; barriers were encountered including cost and dialysis priority. Such barriers are not limited only to Jordan and are greatly influenced by socioeconomic factors: High-accessibility healthcare systems routinely include vision screening in chronic disease management guidelines (5,11).

On an emotional level, the participants described the loss of vision as frustrating and lonely, which is in line with high rates of anxiety and depression that are commonly observed in visually impaired populations. These effects were multiplied by stressors particular to ESRD and integrated mental health services were needed, but rarely addressed. Caregivers also reported very high strain which underscores the need for supportive mechanisms to be in place to also support the needs of the patient and family (4,16).

The respondents rated disjointed care: the nephrology and the ophthalmology services were operating in parallel without much interdisciplinary interaction. Siloed organizational structure compromises comprehensive supervision and follows previous literature on chronic illness documenting less than excellent outcomes when care is offered in silos.6 In comparison, the experience of interdisciplinary models in high-income settings shows better results and patient satisfaction which Jordanian health policy must take into account particularly in complex ESRD cases (7,14).

Overall, the research provides an indication of the need to have a holistic therapeutic model that includes vision screening as part of the basic management of ESRD. Models of care based on patient-oriented views of quality of life have the potential to improve clinical indicators and psychosocial well-being.

Conclusion

The visual impairments in patients with ESRD are not limited to low acuity. They affect locomotion, work performance, social life, and subjective well-being. Family support and personal coping strategies help to reduce this burden but not eliminate it. The inability of modern chronic-disease management to integrate vision care as a natural element of it compounds the issue. To provide better care, healthcare systems should consider sensory health as a necessity, not an option.

Limitations of the study

There are a few limitations to the current study. Its generalizability is limited by the small sample size and the fact that it was recruited in one private clinic. The information is based on self-report, which questions the accuracy of recall or bias of the participants. Additionally, the quantitative values were not acquired, thereby ruling out an objective evaluation of visual severity. In addition, gender, income, and educational status, which are likely to have an impact on the coping process to access to care were not systematically investigated.

Recommendations

Standard ESRD protocols should involve regular ophthalmic exams. The early identification of visual deficits would reduce the negative effects of these deficits and improve daily functioning. The cooperation of ophthalmologists and nephrologists is a necessary multidisciplinary approach. At the same time it is suggested to increase patient education and access to ophthalmic services. Finally, the holistic approach, by not focusing on the disease itself, is essential in getting the most from ESRD.

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Conflicts of interest

The authors declare no conflicts of interest related to this study.

Ethical issues

The research conducted in this study adhered to the principles outlined in the Declaration of Helsinki and was approved by the Ethics Committee of the Hashemite University (Ethics Committee reference number: 19/3/2024/2025). Prior to any intervention, all participants provided written informed consent. The Institutional Review Board (IRB) at Hashemite University was consulted and gave consent to collect data. Participant confidentiality was guaranteed by anonymizing all the identifying information and securely storing transcripts and recordings. It was voluntary and people were told that they could withdraw at any point without any penalty. Informed consent was obtained in written form after the participants were provided with all the information regarding the purpose of the study, its procedures, and risks. The interviews were carried out with respect and sensitivity and the participants were allowed to skip questions or halt interviews when they felt uncomfortable. These precautions guaranteed that ethical standards of research were met and that the well-being of the participants was not compromised during the research. Accordingly, ethical issues (including plagiarism, data fabrication, double publication) have been completely observed by the authors.

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