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ORIGINAL ARTICLE

The impact of in-centre haemodialysis treatment on the everyday life of older adults with end-stage kidney disease: a qualitative study

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ABSTRACT

Background. Older adults with end-stage kidney disease experience a diminished ability to perform the activities of their daily life. For those living at home, the initiation of in-centre haemodialysis treatment (ICHD) carries a risk of cascading functional decline leading to early nursing home placement and mortality. Research on how older adults adapt to their newly impacted daily life is scarce.

Methods. Individual semi-structured interviews were conducted using a purposeful maximum variation sample of older adult (≥65 years) ICHD patients living at home. Interviews were conducted between October and December 2018. Interview coding followed an inductive and broad-based approach. Thematic analysis was used to group meaning units into common themes and subthemes.

Results. Twenty patients (12 females) were interviewed. Analysis resulted in two main themes and seven subthemes. The first main theme showed the impact of ICHD on everyday roles and functioning through four subthemes: a stepwise decline in daily activities, managing time, role changes and an incomplete retirement. The second main theme showed potential areas of remediation through three subthemes: the social environment, developing new daily activity patterns and meaningful activities and goals.

Conclusions. The older adults experienced a process of adaptation that generally progressed from a phase of initial disruption towards a period of mere survival. Being able to accept a life on dialysis was intricately connected with the ability to perform activities that were personally meaningful. Early and continued support of meaningful activities may prove valuable in breaking or delaying the cycle of functional decline.

LAY SUMMARY

For older adults (>65 years) with end-stage kidney disease (ESKD), beginning haemodialysis (HD) treatment can significantly impact their daily life and activities. For older adults living at home, this impact can lead to premature relocation to a nursing home and death. There is limited information on how older adults living at home adapt to these changes. With this study, we aimed to explore how in-centre HD affects daily activity and to identify potential areas of support. We interviewed 20 older adults (12 females) and found that they had experienced a gradual decline in activity since starting dialysis that appeared to first affect their most personally meaningful activities. To better support the physical activity levels and coping abilities of older adults with ESKD, it may be beneficial to identify and support these meaningful activities early on and consistently throughout their lives.

GRAPHICAL ABSTRACT



The impact of in-center hemodialysis treatment on the everyday life of older adults with end stage kidney disease: a qualitative study

For older adults (65+) living at home the initiation of in-center hemodialysis treatment (ICHD) carries a risk of cascading functional decline leading to early nursing home placement and mortality.

Methods



Multi-center qualitative study



Older adults living at home receiving ICHD



Semi-structured interviews. Groningen Frailty Indicator

Results

20 participants (12 female):





Impact on everyday roles and functioning:

- 1. A step-wise decline in activities
- 2. Managing time
- 3. Role changes
- 4. An incomplete retirement



Potential areas of remediation:

- 1. Social environment
- 2. Developing new daily activity patterns
- 3. Meaningful activities and goals







Conclusion: Since starting ICHD the participants experienced a process of adaptation that generally progressed from a phase of initial disruption towards a period of mere survival. Being able to accept a life on dialysis was intricately connected with the ability to perform activities which were personally meaningful.

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Keywords: activities of daily living, haemodialysis, older adults, quality of life, rehabilitation

INTRODUCTION

Older adults comprise the most rapidly growing segment of persons with kidney disease, both at earlier stages of chronic kidney disease (CKD) as well as end-stage kidney disease (ESKD) [1, 2].

For older adults, in-centre haemodialysis (ICHD) treatment is the most prevalent modality of ESKD treatment [3]. Yet ICHD carries high levels of treatment burden on top of the already extensive symptom burden typical for ESKD and that of common underlying comorbidities [4-7]. Additionally, sarcopenia and frailty are highly prevalent in this patient group with up to 81.5% of older adults on ICHD meeting the frailty phenotype criteria [8].

The survival of older persons on ICHD is grim and closely correlates with comorbidity and frailty [9, 10]. Furthermore, they typically experience a significant decline in the ability to perform and participate in the activities of their daily life, a decline that generally accelerates when initiating ICHD [7, 11-13].

Previous studies have already shown the impact of ESKD and ICHD on the self-care activities of older adults (e.g. personal hygiene, dressing and eating) as well as on their more complex activities of daily living (e.g. cooking, managing medication and grocery shopping) and role functioning [14-21].

However, to our knowledge, in-depth data on how older adults adapt to their everyday life in light of these diminished activities are still scarce [6, 22]. For older adults living at home, this is a particularly important area of research, as a functional decline carries a significant risk of cascading if not sufficiently addressed from the onset, thereby increasing the risk of accelerated nursing home placement as well as early mortality compared with older adults without ESKD [12, 23].

Table 1: Inclusion and exclusion criteria.

Inclusion	Exclusion	
≥65 years of age Receiving ICHD Willingness to participate Living at home	A diagnosis of dementia Living in a residential care unit/assisted living facility Insufficient fluency in Dutch Receiving dialysis for <3 months	

With this study we aimed to increase knowledge of the impact of ICHD on the activities of daily living of older adults living at home and facilitating and inhibiting factors thereof. We hope that this improved understanding can enable clinicians and researchers to develop goal-directed interventions to improve quality of care where feasible, particularly in light of breaking or delaying the cycle of functional decline that often accelerates with the initiation of ICHD [12]. We performed a qualitative study to explore the experience, perspective and priorities of the older adults.

MATERIALS AND METHODS

Design

Semi-structured interviews were used to explore and gain a better understanding of the lived experience of older adults with ESKD receiving ICHD. Inductive thematic analysis was used according to Braun and Clarke [24]. The research team consisted of professionals and research experts with extensive expertise in their respective domains: eight occupational therapists, a gerontologist, a physical therapist, two registered nurses and two nephrologists. The study is reported according to the Consolidated Criteria for Reporting Qualitative Research (COREQ) [25] (see Supplemental File 1).

Setting, participants and sampling method

Eligible participants were recruited from four hospitals (three regional hospitals and one academic hospital) in Flanders, Belgium between October and December 2018.

Inclusion and exclusion criteria are outlined in Table 1. We used a purposeful maximum variation sampling strategy to ensure diversity in demographics and potential patient experience, sampling by sex, age, living arrangement and dialysis vintage (3 months-1 year, 1-3 years, 3-5 years and >5 years).

Eligible patients were first approached by their nephrologist and inquired regarding their interest in participating. Interested participants were then provided additional in-person information by the researcher. After obtaining informed consent interviews started. All approached patients agreed to join the

Using an iterative approach, we initially set out to include 20 participants, with the option to recruit additional participants if data saturation was not achieved. Recent guidance on qualitative research in nephrology has indicated that 20 participants can be an adequate number to reach thematic saturation on a particular topic [26]. Thematic saturation was defined as the point where subsequent data did not yield any new relevant meaning units (i.e. codes related to the impact of ICHD and facilitating or inhibiting factors), but instead yielded repeated data related to already identified groups of meaning units. Thematic saturation was reached after analysing 14 transcribed interviews; the final 6 interviews were used as a credibility check of the already identified themes.

Data collection

Data were collected during dialysis treatment in the dialysis unit. Two dialysis nurses were present in the unit but were not involved in data collection. Development of the interview guide was informed by the Brussels Integrated Activities of Daily Living Inventory, a validated assessment tool to evaluate subtle functional decline in older adults [27]. Using thematically ordered open-ended questions, we started with a general question and then probed further based on each individual's experience. The following topics were inquired about: adaptation to life with ESKD and ICHD, the emotional impact of ESKD and ICHD, the impact of ESKD and ICHD on activities of daily living, time management and coping strategies (see the Appendix for the interview guide). Additionally, the Groningen Frailty Index (GFI) was administered to identify increased frailty risk. The interviewing process was piloted with members of the research team before administration.

An independent masters-level female interviewer (S.V.D.) with previous experience in qualitative research conducted the interviews and administered the questionnaire. There was no involvement in direct patient care and there was no prior or ongoing relationship with the study participants. Interviews lasted 10-45 minutes and were tape-recorded and transcribed verbatim. Field notes of non-verbal observations were used to add additional context. Study participants were provided with the researchers' contact information and transcripts were available upon request. No repeat interviews were conducted.

Data analysis

After familiarization through audible recordings and written transcripts by two authors (T.M. and S.V.D.), initial findings were discussed with the entire team. Subsequently, using a broadbased inductive approach, the two authors independently coded potentially relevant data into meaning units (i.e. data pertaining to the impact of ICHD on daily activities and potential facilitating and inhibiting factors). Meaning units were then input into Excel (Microsoft, Redmond, WA, USA) and grouped according to similarities before being condensed into preliminary themes and subthemes. Findings were again presented to the team and the entire team triangulated and adjudicated the findings (i.e. the entire team cross-checked each author's identified meaning units and ascribed them to final themes and subthemes). Study participants were provided with an overview of the derived themes but did not add further comments.

Ethics

Approval was obtained from the Ethical Committee of Ghent University Hospital (B670201837264). The study was carried out in accordance with the principles outlined in the Declaration of Helsinki. The participants received verbal and written information about the purpose and methods of the study and provided written and verbal informed consent.

RESULTS

We included 20 participants (12 females) with a mean age of 76 \pm 7.2 years (range 66–87) and with a dialysis vintage of 37 \pm 30.6 months (range 3–104). All participants identified as being primarily of Caucasian-European descent. All participants were living independently at home, nine together with a spouse. In 18 participants we measured an increased frailty risk (>4) using the GFI [28]. Table 2 provides an overview of participant de-

Table 2: Demographics of study participants (N = 20).

Characteristics	Values
Age (years), mean \pm SD	76 ± 7.2
Gender, n (%)	
Male	8 (40)
Female	12 (60)
Race/ethnicity, n (%)	
Caucasian–European	20 (100)
Employment, n (%)	
Retired	20 (100)
Living arrangement, n (%)	
Together, with a partner	9 (45)
Alone	11 (55)
Dialysis vintage (months), mean \pm SD	37 ± 30.6
Hospital setting, n (%)	
Academic hospital	7
Regional hospital	13
GFI $^{\rm a}$, mean \pm SD	6.5 ± 1.9

^aA score >4 indicates increased frailty risk.

mographics, Table 3 provides an overview of individual participant characteristics.

Thematic analysis

Analysis of the in-depth interviews resulted in two themes and seven subthemes. See table 4 for an overview. Before touching upon the immediate impact of ESKD and ICHD on their daily activities, the study participants shed light on the overall adaptation process they experienced since starting ICHD.

The initiation of treatment was generally experienced as a disruptive event. The first year was described as a difficult period filled with questions about what life would look like. Being dependent on a machine brought the inevitability of death to the forefront. For many, the initial disruption gradually transformed into either a persistent emotional struggle or into complete submissiveness towards their situation. A constant battle between

Table 4: Themes

A stepwise decline in daily activities Managing time	
Role changes An incomplete retirement	
Social environment Developing new daily activity patterns Meaningful activities and goals	

'losses' and 'gains' was mentioned: losing independence versus being able to stay alive and, for some, increased social contact because of in-centre treatment. Survival became a priority for many participants.

P11: 'I have to [keep going]. If I don't then I'll die, and then I'll be of no use to my wife'.

In general, the process of adaptation appeared to progress from an initial shock towards a focus on survival and ultimately towards the acceptance of and gratitude for dialysis, which was now seen as providing 'extended time'.

Fatigue, cognitive difficulties and decreased mobility were reported as particularly debilitating physical symptoms. Falls and especially fall-related anxiety seemed to be major factors in their decreased mobility.

Fig. 1 provides an overview of the themes and their relation to the adaptation process experienced by the study participants.

Theme 1. Impact on everyday roles and functioning

A stepwise decline in daily activities

The participants became increasingly dependent on their environment since starting ICHD. They experienced a gradual functional decline that first affected the activities most meaning-

Table 3: Participant characteristics.

Participant	Hospital	Age (years)	Sex	Dialysis vintage (months)	Living arrangement	GFI score
1	Academic	70	M	15	Together	8
2	Academic	73	F	19	Alone	9
3	Academic	71	F	15	Together	5
4	Academic	84	M	19	Together	8
5	Regional	86	M	84	Together	7
6	Regional	67	M	37	Together	6
7	Regional	87	F	35	Alone	7
8	Academic	78	F	11	Alone	9
9	Regional	71	M	42	Alone	7
10	Regional	86	M	36	Together	4
11	Regional	87	M	53	Together	5
12	Regional	76	F	104	Alone	6
13	Regional	70	M	8	Alone	8
14	Academic	75	M	48	Together	6
15	Regional	75	F	6	Alone	6
16	Regional	79	M	35	Alone	6
17	Regional	67	M	12	Alone	3
18	Regional	74	M	6	Together	3
19	Regional	82	F	42	Alone	9
20	Academic	69	F	61	Alone	8

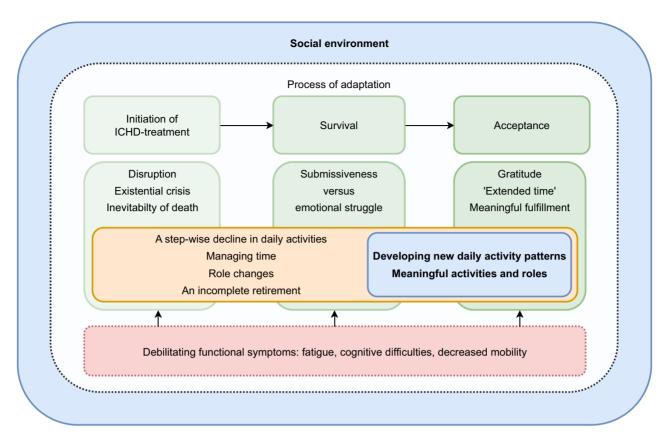


Figure 1: Overview of themes and their relation to the adaptation process. The participants experienced a general process of adaptation (green, from left to right) that started with an initial disruption upon initiating in-centre HD, progressed to a period of mere survival and ultimately led to acceptance of their condition. Across all phases (orange) they experienced a stepwise decline in their daily activities, difficulty managing their time, changes in their roles with relevant others and a feeling of an incomplete retirement. The most debilitating functional symptoms (red) included fatigue, cognitive difficulties and decreased mobility, particularly due to (the risk of) falls. Potential remediable factors (blue) associated with acceptance of their condition and through which activity may be supported included the social environment, the development of new daily activity patterns and routines and the ability to engage in meaningful activities and roles.

ful to them, as these were typically more advanced (e.g. hobby clubs). Letting go of these activities was particularly difficult and often led to a great deal of self-doubt, as they were often determinative to their identity. They looked for strategies to be able to continue to fulfil them, even if more passively. Yet this passivity felt unsatisfactory.

P1: 'To be honest, it's kind of unfulfilling. Because you still think you can do the things you like, but then it hits you it's just not possible anymore. For example, I love going to cyclo-cross events, and I used to go all the time...Now I try to follow it along on TV and it just doesn't feel the same...Then I think to myself: "Why can't I just be there in the fields...".

Subsequently, the participants experienced an impact on their household activities as well as their self-care activities. This decline often appeared less detrimental as they, unless reported as identity- or role-defining, were easier to delegate to others from a pragmatic standpoint.

Managing time

Being accommodative to treatment was an important priority, as it was synonymous with being able to continue living. Treatment had become a fixed part of their weekly schedule around which activities had to be planned. Yet the feeling of being 'contracted'

to a treatment schedule was experienced in a similar way as preretirement employment.

Juggling the 'medical obligations' with the 'obligations of daily life' often brought difficulties. Most activities had to be planned on non-dialysis days, as the time accounted for treatment in addition to the post-dialysis fatigue made it nearly impossible to plan anything on dialysis days. Some participants talked about a literal 'battle with time'.

P15: 'Before [I started treatment] my sister and her husband would come by twice a week to play cards. But now those are the days I must do all my [household] chores. So it's not as easy anymore to connect, and I can't invite anyone if my work isn't done'.

Role changes

Since starting ICHD, the participants noted having to redefine their life roles. For many, activities necessary to live independently, such as managing household chores, were seen as important and necessary parts of daily life, particularly when performed for relevant others. Although these activities appeared easier to delegate when they could no longer be performed, it still resulted in a feeling of loss when connected to an identifying role (e.g. being a partner or parent).

P19: 'I used to take care of our personal finances; my husband wouldn't have to worry about that. I did all the accounting...But I just can't seem to process it anymore. Now our son does all of it...It's not what we would have wished for but what can we do...'

With this functional loss, for many participants their predominant role appeared to transition from being a partner who actively contributes to real physical duties to a more existential role as emotional supporter.

An incomplete retirement

The feeling of having an 'incomplete retirement' seemed universal. Retirement was originally seen as a time of freedom, of being able to undertake new meaningful activities and take up new roles (e.g. taking care of grandchildren and being a grandparent) after having lived a life of 'obligatory' employment. Yet this was suddenly disrupted.

P11: 'It's now over 30 years since I've retired if we include my pre-retirement. But to be honest I never imagined it would be like this. Initially I assumed I would eventually get used to it, and to some degree I guess I have. But before [ICHD] I was taking small trips all the time, I was part of a hobby-club...It felt liberating. Yet suddenly it was all over, I had to now tend to dialysis. I haven't been able to do any of these things anymore since then'.

The participants also noted experiencing an accelerated ageing process when comparing themselves to their non-ESKD peers. Not knowing whether this was due to the natural process of getting older, the impact of their ESKD or ICHD or a consequence of other comorbidities often led to uncertainty.

Theme 2. Potential areas of remediation

Social environment

The participants noted that their relevant others were an important factor in adapting to a life on dialysis. They noted experiencing a great deal of support from relevant others (including pets), although a certain lack of understanding could also bring difficulties, e.g. when turning down drinks or food while playing cards with their friends because of symptoms related to their condition.

P2: 'You travel back and forth to the dialysis centre [three times a week]...but if you still have your partner you have a lot to come home to. I think if my husband was still alive it would have been easier to accept'.

For many, relevant others provided a reason to continue living.

P19: 'For myself, I wouldn't care if it [my life] ended today. But yesterday my son came to visit and it made me realize why I'm doing all of this again. He gives me courage to keep going'.

Developing new daily activity patterns

The participants noted that to adapt to life on dialysis they had to develop new daily activity patterns, which was challenging.

Spontaneous activities had become a thing of the past. Everything had to be planned in advance while preserving the option of cancelling plans at any time. The manner in which they were able to adapt their activity patterns to this 'new life' was closely related to acceptance of their condition.

P19: 'I can't really tell my friend he can come by tomorrow, or promise him we'll be able to do something then or there. You really have to adjust [your daily life]. You have less time to do things, also in-between dialysis days. But I guess when you have a full-time job [you'd have this as well], it's not that different. You're not really free then either'.

Meaningful activities and roles

Being able to fulfil some meaningful activities and goals, even if now to a smaller degree, was noted as making the difficulties dialysis can bring all worth it. For some participants, this meant still being able to perform such activities as taking a short walk through the town centre, while for others it was the 'extended time' dialysis provided, which they could still spend with relevant others.

P9: 'Today I feel good. Though every day is different... But just the fact I can have days where I feel good and am able to cook a meal for my daughter, it really makes it all worth it'.

For some participants this gradually transformed the initial feeling of loss into gratitude for dialysis.

P11: 'On the one hand it really makes you question life and your life's purpose. But on the other hand, you're still alive, you're taken care of. And I can still make my wife happy, that's my mission, that's why I want to keep going'.

Individual differences between participant demographics

Older adults living alone reported a greater focus on (obligatory) household chores, whereas those living together with a partner generally participated in a more diverse range of extrahousehold activities (e.g. painting, drawing, attending the theatre). They noted their partner took on a significant amount of the household work, leaving more time for them to explore other activities. For the participants living alone, all but one participant reported having regular contact with their children or close relatives, who assisted them with household work. For these participants, this extra household help did not translate into an increase in extra-household activities. Their occurring meaningful activities were mostly related to being a (grand)parent (e.g. cooking their daughter's favourite meal, visiting their son's finished artwork). There were no particular differences between male and female participants.

DISCUSSION

This study sheds light on some potentially modifiable factors driving the impact of ICHD on the everyday lives of older adults with ESKD living at home.

The results show that, although both degree and ways to adapt varied substantially, this process appeared to follow a general pattern. An initial disruption often accompanied by an existential crisis at the start of ICHD was followed by a period in which mere survival was at play. Then, whether or not patients reached a new state of equilibrium hallmarked by acceptance appeared to largely depend on their social environment, the ability to adapt to new activity patterns and the ability to take up (new) meaningful activities or roles.

The most common debilitating functional factors were fatigue, cognitive difficulties and a risk of falls. Fatigue has been identified as the most important outcome to improve for pa-

tients on ICHD, exactly because of its impact on life participation [29]. Next to fatigue, cognitive difficulties and a risk of falls significantly correlate with impeded mobility and diminishing activities of daily living capabilities in the older adult population [12, 30, 31]. Our data show that there is also a non-negligible aspect of fall-related anxiety involved. Thus interventions should not only focus on physical rehabilitation, but also on measures to increase the confidence of patients, to ensure devices are used (e.g. rollators) and to implement a safe and mobility-friendly environment at the patient's home, e.g. by involving an occupational therapist. Additionally, providing easy-to-understand information about the impact on everyday life to patients and their relevant others could prove valuable in aiding their adaptation

Starting with the initiation of ICHD, activities tended to decline following a stepwise pattern from their most advanced activities (e.g. hobby clubs) to instrumental (e.g. household chores) and eventually basic activities of daily living (e.g. self-care) [27]. The study participants noted however that they felt most affected by a decline in their ability to perform those activities that were most meaningful to them and which were often seen as identity defining. A loss of these activities has been suggested as a reason for the high prevalence of depression and anxiety in this population [6].

This pattern of decline has been identified in previous studies and the initiation of ICHD is typically seen as a major contributing factor [12, 14, 33]. A focus on supporting meaningful activities and helping patients delegate other tasks to (external) assistants could prove a valuable area to support physical activity. For older adults, performing social and productive activities, even if they involve little or no physical exertion, have been shown to lower the risk of all-cause mortality as much as physical exercise does [34]. For the participants in this study, not being able to identify whether a certain symptom was due to their advancing age or a side effect of their condition was often challenging. They would compare themselves to their 'healthy' peers and felt as if they were dealt an 'incomplete retirement'. Here the literature does show an accelerated aging process for older adults with ESKD receiving ICHD [13, 19, 35], though to a certain degree symptoms related to natural ageing could also frequently be incorrectly ascribed to dialysis treatment. Providing age-adequate and easyto-understand information on the dynamic interaction between ageing and ICHD may provide clarity for older adults contemplating the nature of their symptoms.

The social environment was seen as facilitating as well as inhibitive, depending on the level of understanding the participants experienced. A previous study showed that needs regarding social support may differ by frailty status [36]. For frail older adults, being alive meant surviving from day to day, leading to a preference of practical social support. For older adults with a non-frail status, being alive meant enjoying new life experiences within which socialization was seen as 'enriching' rather than practical [36]. In this study, despite an indication of frailty in 18 of the 20 participants, perspectives appeared to polarize towards the latter delineation. Further research exploring the connection between frailty, social needs and the ability to engage in meaningful activities could be beneficial. Additionally, as the social environment can be an important area to support activity, research involving dyadic interviews with both patients and their relevant others, particularly in light of developing targeted interventions, could add valuable

The tendency in dialysis care to polarize towards medicaltechnical aspects can invoke the danger of overlooking what is most important to patients [37-39]. In this study we noticed that acceptance of their condition was intricately connected with the ability to perform activities that were personally meaningful to the older adults. Hence we hypothesize that supporting meaningful activities (with or without physical exertion) may prove valuable in breaking or delaying the cycle of functional decline.

So far, some existing interventions have shown promise in supporting the meaningful activities of older adults, while simultaneously improving their ability to cope with their condition. A recent pilot study demonstrated that a self-management program focusing on supporting daily life goals (e.g. cooking, gardening) through education and guidance on energymanagement strategies (e.g. simplifying tasks, pacing, organizing the home environment) may enhance life participation in both the short and medium term [40]. Another recent pilot study that evaluated a home-based program with home visits by an occupational therapist, nurse and handyman demonstrated potential effectiveness in improving activity and life participation outcomes for older adults living at home [41]. Other promising studies have included interventions employing personal goalsetting or problem-solving therapy (e.g. goals related to being able to do some household tasks again, being able to garden and fish again, being able to take care of grandchildren again) [42, 43]. Additionally, studies evaluating cognitive behavioural therapy or acceptance and commitment therapy have demonstrated potential in increasing activity levels by aiding patients' acceptance of their condition, supporting the rediscovery of personal values and shifting thinking towards engaging in enjoyable activities and committing to (new) meaningful goals [44-46]. Irrespective of the intervention employed, a person-centred approach is essential to ensure that patients' values and goals are guiding their care [47]. By engaging with patients, being willing to listen, going beyond our job description, making time and discussing care and treatment options that align with their unique life goals, circumstances and priorities, and recognizing and addressing our own potential biases and practice styles, we may ultimately better support those outcomes that are most important to our patients [47, 48].

Limitations

With a first-year mortality rate of 30% in patients ≥65 years of age [49], it must be noted that the participants in this study should not be seen as representative of the entire population of older adults with ESKD receiving ICHD. As we only included patients living independently at home (with 9 of 20 living with a spouse), it should be assumed the study participants had increased functional abilities and social support systems when compared with older patients living in assisted care units [12, 36, 50].

SUPPLEMENTARY DATA

Supplementary data is available at ckj online.

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AUTHORS' CONTRIBUTIONS

T.M. led the writing of the manuscript. D.V.D.V., T.L., W.V.B. and P.D.V. conceived and designed the study. T.M. and S.V.D. analysed and interpreted the data. All authors reviewed, triangulated and adjudicated the identified meaning units, themes and subthemes. All authors revised and approved the final version of the manuscript.

DATA AVAILABILITY STATEMENT

Data are available upon reasonable request.

CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest.

APPENDIX 1: INTERVIEW GUIDE

Demographic information

Questions

What is your age?

What is your living situation? Are you living alone or with a partner?

Since when have you been receiving in-centre haemodialysis treatment?

Topic 1: Adaptation to life with ESKD and ICHD

Questions

Can you tell me how your experience since starting haemodialysis has been?

How would you say it has affected your life?

What have been the most notable changes you've experienced compared with before?

Which, if any, physical/functional challenges have you experienced?

Topic 2: Emotional impact of ESKD and ICHD

Questions

How have you been emotionally affected since starting dialysis treatment?

How has it affected how you feel/think about yourself? Topic 3: The impact of ESKD and ICHD on activities of daily

living

Can you describe a typical day from when you wake up until you go to bed, and what activities you engage in throughout the day?

What self-care activities do you engage in?

Have you noticed any differences in the number of self-care activities you perform, the way they are carried out, or any other changes since you started undergoing dialysis?

Can you describe any specific changes or challenges you have experienced with regards to your self-care routine? How do you feel when you are unable to perform certain self-care activities due to your dialysis treatment?

What household activities do you engage in?

Have you noticed any differences in the number of household activities you perform, the way they are carried out, or any other changes since you started undergoing dialysis?

Can you describe any specific changes or challenges you have experienced with regards to your household routine? How do you feel when you are unable to perform certain household activities due to your dialysis treatment?

What other activities do you engage in that haven't been mentioned yet, such as recreational activities, complex cooking tasks, gardening, hobbies, use of digital media, going on vacation, or caring for others?

Have you noticed any differences in the number of these activities, the way they are carried out, or any other changes since you started undergoing dialysis? How do you feel when you are unable to perform these

activities due to your dialysis treatment? Have you experienced any potential changes in family dynamics since starting dialysis?

Can you describe any specific changes or challenges you have faced in this regard?

Topic 4: Time management

Questions

How do you experience the impact of dialysis on your time and daily activities?

In what ways do you plan the activities that are important to you around your dialysis sessions?

Topic 5: Coping strategies

Questions

How have you been able to cope with the changes you've experienced since starting dialysis?

What would you say has been the most pivotal in being able to cope?

What advice would you give to new patients on how to best cope with the changes in their lives due to dialysis?

Additional questions

Questions

Is there anything else that you would like to share?

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