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Coping with fatigue for people with end stage kidney disease: a qualitative study

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Abstract

Introductie: Vermoeidheid is het meest voorkomende gevolg van hemodialyse en is onlangs geïdentificeerd als de belangrijkste uitkomst die verbeterd moet worden bij mensen met een nierziekte in het eindstadium. Dit komt door de grote impact op de participatie in dagelijkse activiteiten en de kwaliteit van leven. Onderzoek naar vermoeidheid en hoe deze wordt ervaren door mensen in het eindstadium van nierziekte is de laatste jaren toegenomen, maar er is nog steeds een hiaat. Deze thesis richt zich op hoe mensen hiermee omgaan en de vermoeidheid managen.

Methode: Twintig patiënten, gemiddeld 51 jaar oud, van één academisch dialysecentrum werden geïnterviewd over de impact van vermoeidheid en hoe zij omgaan met deze vermoeidheid. De hermeneutische fenomenologische methode volgens Lindseth & Norberg werd gebruikt als uitgangspunt om de ervaringen en narratieven van de deelnemers te exploreren en analyseren.

Resultaten: De deelnemers gebruikten verschillende strategieën om met vermoeidheid om te gaan. Er werden twee hoofdthema’s en vijf subthema’s geïdentificeerd: 1) de biopsychosociale impact van vermoeidheid (met subthema’s: 1.1 fysieke aspecten; 1.2 mentale aspecten; en de 1.3 impact op rolmanagement) en 2) coping (met subthema’s: 2.1 context; en copingstrategieën). De belangrijkste copingstrategieën waren het uitvoeren van energiegevende activiteiten, het hanteren van een dagindeling en het aanpassen van dagelijkse activiteiten. Qua context speelden de steun van familie en vrienden, maar ook professionele hulp een belangrijke rol in het omgaan met vermoeidheid.

Conclusie: Dit proefschrift dient als basis voor het identificeren en ontwikkelen van effectieve interventies ter ondersteuning van mensen met een nierziekte in het eindstadium die vermoeidheid ervaren, en kan een eerste basis vormen om de toekomstige zorg voor patiënten met chronische nierinsufficiëntie te verbeteren. Verder onderzoek wordt aanbevolen…

Trefwoorden: chronische nierziekte, kwalitatieve studie, hermeneutische fenomenologische methode, vermoeidheid, coping, zelfmanagement, ergotherapie

Aantal woorden thesis: 7703

Abstract

Introduction: Fatigue is the most reported consequence of hemodialysis and recently identified as the most important outcome to improve in people with end stage kidney disease. This is due to the big impact on participation in daily activities and the quality of life. Research on fatigue and how it is experienced by persons with end stage kidney disease has been expanding in recent years but there is still a gap. This thesis focuses on how people cope and manage fatigue.

Method: Twenty patients, mean age 51 years old, from one academic dialysis centre were interviewed about the impact of fatigue and how they cope with it. The hermeneutic phenomenological method according to Lindseth & Norberg was used as a starting point to explore and analyse the participants' experiences and narratives.

Results: Participants used different strategies to cope with fatigue. Two main themes and five subthemes were identified: 1) the biopsychosocial impact of fatigue (with subthemes: 1.1 physical aspects; 1.2 mental aspects; and the 1.3 impact on role management) and 2) coping (with subthemes: 2.1 context; and coping strategies). The main coping strategies were performing energising activities, adopting a daily schedule and adapting daily activities. In terms of context, support from family and friends, as well as professional help, played an important role in coping with fatigue.

Conclusion: This thesis serves as a base to identify and develop effective interventions to support people with end-stage kidney disease who experience fatigue and can form a first basis to improve future care for patients suffering from chronic kidney disease. Further research is strongly recommended on several issues…

Keywords: chronic kidney disease, qualitative study, hermeneutic phenomenological method, fatigue, coping, self-management, occupational therapy

Amount of words in thesis: 7703

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Preface

The finalisation of this thesis marks the end of an incredible year, one that has been filled with challenges, growth and many learning experiences. With this thesis, I tried to find out which coping skills people with end stage kidney disease use to cope with the fatigue that has a major impact on their daily life. By this means, I tried to give an incentive to develop a tool that can be used among this target group.

I would like to thank prof. dr. Van de Velde and prof. dr. De Vriendt for providing their professional guidance, knowledge and expertise. Their insightful feedback have helped shape the direction and scope of this thesis. They helped shape my research and have enriched my understanding of healthcare and renal disease.

I would also like to express my sincere appreciation to my mentor, Drs. Moreels. Without his dedication, patience, expertise and feedback, this would not have been possible. His skills, attention to detail and priceless suggestions have played an important role in improving the quality and accuracy of this work. I am deeply thankful for his support and commitment to my academic growth.

I express my deep appreciation to all the participants who generously shared their perspectives and insights. Their willingness to contribute to this study has been vital, and their narratives and experiences have given the foundation for understanding the complex nature of fatigue and coping mechanisms in people with end stage renal disease.

Finally, I owe many thanks to my family and close friends, my mom, Dr. Ingenieur S. Denaeghel and Liezl de Geeter. Their support, encouragement and belief in my capacities have been a constant source of strength throughout this exacting journey. Their love, understanding and patience have been the foundation of my academic and personal development.

Kyara Boete

Ghent, 15 May 2023

1. Introduction

1.1. Chronic diseases

A major global societal trend is the presence of non-communicable diseases, also known as chronic diseases. Chronic conditions are defined as: ‘diseases which have one or more of the following characteristics: they are permanent, leave residual disability, are caused by nonreversible pathological alteration, require special training of the patient for rehabilitation, or may be expected to require a long period of supervision, observation, or care’ (Dictionary of Health Services Management, 2nd ed). According to the World Health Organization (WHO), these chronic diseases account for 41 million deaths each year, equivalent to 74% of all deaths worldwide. Seventeen million of these fatalities are in people of less than 70 years of age.

1.2. Chronic kidney disease

One highly prevalent chronic condition is chronic kidney disease (CKD). CKD is defined as kidney damage lasting for 3 months or more, regardless of cause, and is typically diagnosed by a reduced rate at which the kidneys are able to filter the blood, specified as an estimated glomerular filtration rate (eGFR) of <60 ml/min/1.73 m2. CKD is a progressive condition that affects more than 10% of the general population worldwide, equivalent to more than 800 million individuals. CKD has become one of the leading causes of death worldwide, and it is one of the few non-communicable diseases whose death rates have increased over the past two decades. It is currently projected to become the 5th highest leading cause of death by 2040. The large and increasing number of people affected, in addition to the significant negative consequences of CKD both for people and economies worldwide, call for increased efforts for better prevention and treatment (Kovesdy, 2022).

1.3. Functioning of the kidneys

The function of the kidneys is to regulate blood chemistry, blood pressure and the amount of fluid in the body. In addition, the kidneys also filter waste products and toxins from the blood and ensure that vitamins, amino acids, hormones and other vital substances are returned to the bloodstream. As noted above, when this functioning becomes impaired and the kidneys perform below their normal levels for more than three months, it is referred to as CKD. CKD is classified into five stages depending on two factors. First, the decrease in glomerular filtration rate and secondly remaining function of the kidneys. The end stage of CKD, when the kidneys can only take up 15% of their normal functions, is called end stage kidney disease (ESKD) (Wallace, 1998). Entering this stage, the kidneys cannot adequately perform their functions and one will have to undergo dialysis or kidney transplantation. There are three main options in terms of kidney function replacement therapy, namely: hemodialysis (HD), peritoneal dialysis and kidney transplantation. The focus of this thesis will be on hemodialysis, more specifically, in-center hemodialysis including daytime dialysis, nocturnal dialysis and self-care dialysis, each discussed more in depth in the next paragraph.

1.4. In-center hemodialysis: modalities

During hemodialysis, blood is purified outside the body by the use of an artificial kidney. Via a pumping system, blood is transported from the body to the artificial kidney and then back into the body. In the artificial kidney, harmful waste products and excess fluid are removed from the blood and useful substances can be added to the blood.

Self-care in-center dialysis involves this same process, but with the expectation that the patient performs their dialysis treatment with little or no professional assistance. Educating the staff and reinforcing the expectation that patients, who are able to do so, should be encouraged to participate as fully as possible in their care. The Medical Education Institute Building Quality of Life: A Practical Guide to Renal Rehabilitation (1997) has created a schedule to help staff know what these steps entail. For many patients, self-care dialysis has unprecedented social and emotional benefits. By being able to take control of their own health, they are empowered, more attentive and motivated (The Life Options Rehabilitation Advisory Council et al., 1997).

Nocturnal dialysis is a longer hemodialysis treatment that takes place at night. The treatment lasts approximately six to eight hours, and this is performed three or more times a week. The longer duration means that the treatment is milder and easier for the patient's body to tolerate, while a greater amount of waste and fluid is removed from the blood. One of the main benefits is that being dialyzed at night leaves more time during the day for activities of daily living (Pierratos et al., 1997).

1.5. Consequences of CKD and treatments

People living with CKD experience multiple symptoms due to both the disease and its treatment. However, these symptoms are often insufficiently acknowledged in existing trials and interventions (Kalantar-Zadeh et al., 2021). Furthermore, these symptoms have a significantly negative impact on health-related quality of life (HRQoL) and functional capacities, leading to a significantly decreased ability to participate in their meaningful activities of daily life (i.e. life participation) (Almutary et al., 2013; Bonner et al., 2010; Sharma et al., 2022).

Recently, fatigue was identified as the most important outcome to improve for people with ESKD receiving HD, particularly because of its impact on life participation (Evangelidis et al., 2017). Fatigue, described as the most commonly reported symptom, can be enervating and difficult to manage. Patients often describe fatigue as extreme exhaustion, being of a persistent nature, accompanied by weakness and a lack of energy disproportionate to the level of exertion. Physical symptoms of fatigue typically include muscle weakness or decreased endurance, while psychological symptoms include decreased cognitive endurance, coupled with an increased effort when paying attention or concentrating (Gregg et al., 2021). For people with ESKD, as for other chronic diseases, fatigue is multifactorial and may manifest itself differently from person to person. For persons with ESKD receiving HD, the three most important domains where and how fatigue manifests have been identified as: 1/ its impact on life participation, 2/ tiredness, and 3/ level of energy (Ju et al., 2020). Existing research on fatigue and how it is experienced by persons with ESKD has been expanding in recent years, with an increasingly emphasized call on identifying and developing effective interventions (Jacobson et al., 2019).

1.6. Coping and self-management

Cramer (1998) argues that, to manage and cope with symptoms accompanied by living with a chronic disease such as ESKD, it requires a conscious, problem-solving approach, that is situational and unrelated to personality or age. Lazarus, one of the foundational authors on stress theory, defined coping in 1966 as: “the constantly changing cognitive and behavioural effort to cope with specific external and/or internal demands that are perceived as burdensome or beyond the resources of the person”. In recent years, the connection between coping and self-management has been increasingly emphasized (Audulv et al., 2016).

Self-management is defined by Van De Velde et al. (2019) as "the intrinsically controlled ability of an active, responsible, informed and autonomous individual to live with the medical, role and emotional consequences of his or her chronic condition(s) in partnership with his or her social network and healthcare provider(s)". Remarkably, this definition includes the three distinct tasks identified by Corbin and Strauss (1989), which are often referenced but rarely equally explored: medical, role and emotional management. Medical management includes all tasks to address, coordinate and control the medical side of the disease. Role management includes controlling, adapting or creating new meaningful behaviours or life roles to live with the disease. Emotional management includes dealing with emotions and reconsidering life goals and identities. This is important to consider within this study as it shows that people have to cope with changes on different domains, and it inquires the question which domains they may need to manage most to continue to participate in life despite the impact of fatigue.

With this qualitative study we aim to further explore the impact of fatigue on life participation for persons with ESKD receiving HD, and assess which coping mechanisms and (self-management) strategies they use in their daily lives. This to inform the development of future interventions which aim to support the self-management of fatigue for persons on HD.

2. Method

2.1. Research design

To explore the impact of fatigue on life participation, and employed self-management strategies to manage fatigue, a qualitative approach was chosen using a hermeneutic phenomenological method. This approach is particularly useful as its strength lies in the analysis of the most complex aspects of human life, seeking to explain the nature of things, based on the essence and veracity of phenomena. The aim of phenomenology is to understand the complexity of lived experiences. This understanding aims at raising awareness and finding the meanings around the phenomenon (Howitt, 2019).

In this study, it is important to ascertain the perceptions and experience of people with ESKD regarding the impact and coping strategies to manage fatigue. The research question was formulated using “SPIDER” and can be found in **table 1**.

Table 1. Research question formulated using SPIDER

Sample	People with end stage kidney disease whom follow a renal replacement therapy
Phenomenon of interest	Impact and strategies to cope with fatigue
Study design	Hermeneutic phenomenological method
Evaluation	Lived experiences through in-depth interviews
Research type	Qualitative research

This led to the following research question: ‘What is the impact of fatigue on daily life and which coping mechanisms and strategies do people with end stage kidney disease implement to manage the fatigue they experience?’

2.2. Participants and sampling method

To best support this research topic, purposive sampling is used. Within purposive sampling, participants are invited and selected on the basis of meeting certain criteria. This means that one will have to meet predetermined criteria to be included in the study. Participants will be included if one is following in-center hemodialysis, including self-care hemodialysis and nocturnal hemodialysis. The participant must be within the age range of 18 to 65 years. Furthermore, participants should understand and speak the Dutch language, which is necessary for conducting the interview. Participants will be excluded if there are diagnosed psychiatric/cognitive problems. This because the participant must respond appropriately during the in-depth interview. In addition, no other therapies or treatments should be pursued at the same time. Participants who are bedridden will not be included within the study, participants are expected to be ambulatory. A summary of the criteria can be found in **table 2**.

Table 2. In- and exclusion criteria

Inclusion	Exclusion
• In-center hemodialysis ○ Daytime hemodialysis ○ Nocturnal hemodialysis ○ Self-care hemodialysis • Aged 18-65 • Dutch speaking	• Severe psychiatric/cognitive problems • Bedridden

2.3. Data collection

Data was collected using semi-structured in-depth interviews, conducted by two researchers. These are individual face-to-face interviews conducted by the interviewer based on an interview guide with a specifically designed topic list to explore the impact of fatigue, and how the participant copes with fatigue. The interview guide is included as an annex (appendix 1). The in-depth interviews were conducted at the Nephrology department of Ghent University Hospital either during dialysis treatment, or at a chosen time and place by the participant. Interviews were conducted after providing participants with an overview of the study objective, and after obtaining both oral and written informed consent. Interviews were recorded with the consent of the participants and transcribed verbatim. Furthermore, field notes of non-verbal observations were used to add additional context.

2.4. Data analysis

After transcribing the interviews, data analysis was guided by the method according to Lindseth and Norberg (2004). Within this process, there are three methodological steps:
1/ The first step within this process pertains to gaining a ‘naive understanding’. Here the written interviews are read to formulate an initial understanding. By implementing this step, one tries to achieve a concise yet adequate summary of relevant answers to the research question.
2/ The second step is the ‘structural analysis’ phase. In this step themes are systematically identified and formulated. This step follows several sub-steps. First, the written interview is broken down into meaningful units. Next, these meaningful units are condensed and called condensations. After this, we proceed to give subthemes to the condensations. These subthemes will be further reduced to themes. Finally, these themes will be linked to a main theme, from which the tree structure or code tree is formed.
3/ A third and final step includes the ‘comprehensive understanding’. In this step, insights from the previous two steps are formulated, more in-depth work is done and links are made between the different main themes that emerge regarding fatigue.

2.5. Ethical approval

Ethical approval was obtained from the Ethical Committee of Ghent University Hospital (B6702022000399). 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 (appendix 2).

3. Results

Twenty participants were included, from three different in-center hemodialysis groups namely daytime hemodialysis, nocturnal hemodialysis, and self-care hemodialysis. The majority of the participants received daytime hemodialysis (n=10, 50%), compared to nocturnal hemodialysis (n=7, 35%), and self-care hemodialysis (n=3, 15%). The major part of the participants had already gone in retirement (n=3, 15%) or were placed on disability/invalidity (n=12, 60%). The mean age of the participants was 50.55 years old, ranging between 26-65 years of age. Detailed information can be found in **table 3**.

Table 3. Participant characteristics

Characteristic	**N (%)**
Mean age, years	50.55 years
Gender	
Male	12 (60%)
Female	8 (40%)
Race/ethnicity	
Caucasian-European	20 (100%)
Employment	
Employed	4 (20%)
Retired	3 (15%)
Not working due to disability	12 (60%)
Going back to work within the next year	1 (5%)
Living arrangement	
Alone	7 (35%)
With a partner	10 (50%)
At home with parents	3 (15%)
Children	
Yes	12 (60%)
No	8 (40%)
Dialysis vintage	
3 months-1 year	3 (15%)
1-3 years	4 (20%)
3-5 years	8 (40%)
≥ 5 years	5 (25%)
Modality	
Daytime hemodialysis	10 (50%)
Nocturnal hemodialysis	7 (35%)
Self-care hemodialysis	3 (15%)

3.1. Naïve understanding

Fatigue was a dominant factor among the participants, although a few participants appeared to suffer only little from it, or not at all. Fatigue was generally described as feeling languid, stagnant and experiencing a lack of energy. This caused embarrassment, frustration and stress. The participants often sought support from friends and family to cope with the effects of the disease. To cope, participants used humour and communication, and they adapted their activities and did not give up on continuing their activities.

We could distinguish two groups, one group that scheduled their days and one group that did not. One group planned their activities in advance, mainly mentally, or on paper. By doing this, they felt they could organise and expand their available energy systematically throughout the day, thereby accomplishing their daily activities. The second group did not plan their days and took everything day by day. On the one hand, this was seen in participants who suffered little or no fatigue. On the other hand, this was because the condition varied too much from day to day.

Furthermore, professional help and the social environment of the participants played a dual role in supporting the participants and how well they could manage the fatigue they experienced. On the one hand, not experiencing understanding or receiving adequate tips and tools appeared highly limiting and a cause of additional difficulties. While on the other hand, experiencing understanding, and having a good division of tasks and being well-informed, provided an incentive to the participants to cope better with the fatigue they experienced.

3.2. Structural analysis

In **figure 1** a visual representation is given surrounding the themes that were formed during the structural analysis.

3.2.1. Biopsychosocial aspects

3.2.1.1. Physical aspects of fatigue

Fatigue in the participants mostly occurred after dialysis and in the evening but is generally continually present. The fatigue often overtook them suddenly, and the need for sleep or rest could often not be postponed. People also indicated that when they went beyond their own limits, it took its toll the next day and they had to slow down.

> “It's more like the energy is out and you have to sit down. Usually you fall asleep anyway”
> -Participant 3-

> “But what I also have when I go beyond my limits, I step too far, so to speak, I have to suffer the consequences the next day.”
> -Participant 14-

Participants firstly experienced fatigue on a physical level, which caused a limitation in performing their daily activities and being able to complete them. This caused the participants to terminate or adapt certain activities to their capabilities. Participants could feel the physical impact of fatigue through languid legs, muscle pain, a backache or a headache. One participant described it as having low energy levels, having no energy left, and feeling exhausted.

“Yes so languid, so not. My legs weighing heavy, or yes”
-Participant 5-

Participants were asked how impactful fatigue was according to a scale of one to five, five being the highest impact. Participants scored an average of 3.3 out of 5. This shows that fatigue has a definite impact on participants’ daily lives. What could further be seen here was that people who scored lower usually did not take up many activities, such as work or household tasks. People who scored highly experienced so much fatigue that they were often able to take up far fewer activities than they wanted to. People who gave a ‘medium’ score experienced fatigue as impactful on their daily activities but they were still active within the household, at work, or had children living at home.

3.2.1.2. Mental aspects of fatigue

Some participants reported becoming more angry and irritable due to fatigue and noted they experienced more overall tension and stress. Negative feelings that often surfaced due to the experienced fatigue were shame and frustration. These feelings of frustration, irritation and other negative feelings also come from comparing their current situation with the past. By past is meant the period before dialysis and diagnosis of CKD. By constantly looking back at the past and the activity capital and energy they had before, one is confronted with their current situation. Participants noted experiencing many more situations of loss, having less social contact, and performing fewer activities compared to the past.

“Pff yes dealing with that, learning to live with it for sure yes. One day is fine and the next day is less so and learning to accept that is not easy and I still have a hard time with that. Even though we’re five years down the line, I still have a hard time with it. With that fatigue.”
-Participant 14-

Conversely, it can also be said that mental aspects such as stress and having to constantly deal with dialysis can also cause fatigue:

“Yes then there’s so much in my head, and that does make me tired too because you’re thinking so much.”

-Participant 8-

Participants expressed difficulty in accepting and coming to terms with their fatigue and the consequences of this. Some of the participants also indicated that they did not want to show their vulnerability and bother others with how they felt.

“On the one hand, I don’t feel one hundred percent at ease with it because I used to be able to do everything.”
-Participant 5-

3.2.1.3. Role management

Social contact

The majority of the participants experienced a loss in terms of social contact. They noted meeting up much less with friends, and sometimes contact with friends even stopped due to their mandatory termination of activities due to fatigue, or due to a lack of understanding that was experienced. However, a side note must be made. The loss in social contact was not only due to fatigue but also due to the time-intensive nature of dialysis and diet.

“And I lost some friends by not doing that [badminton] anymore but yes.”
-Participant 1-

Role Execution

In terms of role execution, two groups could be noted. One group experienced little or no limitation in terms of their role execution. The other group did report experiencing an impact on managing their roles due to fatigue. Often, certain tasks are taken up less, and taken over by family members. Furthermore, the participants perceived themselves and their relationships differently due to fatigue.

“They do have their mum but it’s in a different way.”
-Participant 15-

3.2.2. Coping with fatigue

3.2.2.1. Context

Support was often sought from family and friends, in addition to their partner, who is often a main source of support. For some of the participants, CKD was in the family, which helped in looking for support and receiving a level of understanding from family members. Though, this did cause participants to often minimise their own fatigue by seeing that family members were worse off.

“I talk about it with friends and family, but if you’re really there. My mum had that too so she knows what it’s like, she’s actually even worse off for it if she had been on dialysis. So I can’t really complain so.”
-Participant 15-

What was noted is that the social environment can play a dual role; on the one hand, it can be supportive but, on the other hand, obstructive. Having a good division of labour, and showing understanding, appeared important in supporting the participants. Important here was being able to communicate well with their social environment, and the environment being well-informed.

“Yes because it has been less for a while but now by talking to each other once, he does understand that better.”
-Participant 8-

On the other hand, the social environment can also create pressure for completing daily activities, so when their partner or children come home they don’t have to be occupied anymore by household activities. Furthermore, not receiving understanding for their situation and the fatigue they experience could become frustrating and enervating.

“I undergo it and then the family says for the umpteenth time of yes they don’t understand, they don’t understand that. Oh you have to have a kidney out, you already had a kidney out. But I let it all pass me by these days.”
-Participant 16-

“Yes and euh that she should do as little as possible when she gets home. That is more in my head. She comes home and can sit down.”
-Participant 10-

3.2.2.2.Coping mechanisms

Day planning/week structure

Here, again two groups could be distinguished. First there was the group that did not schedule their days and secondly the group that does schedule their days. The first group that does not plan their days does this as a conscious choice. They indicated that they live from day to day and want to let their days come as they come.

“No I take it as it comes, you can never stick to it 100 per cent anyway.”

-Participant 5-

The second group does plan their days in advance. This planning often included household activities, but also social activities. This planning helped them cope with fatigue as in this way they were able to schedule moments of rest. They noted they could not always stick to their schedule or finish their activities due to unexpected things coming up, but they managed this with flexibility. This planning was done by the majority of participants. In general, it was also indicated that by following dialysis a weekly structure naturally followed and that they planned around it.

“I usually try to divide my day into activities that I feel are important. I always try to do the things per day that are most important to me, to fill my day qualitatively.”

-Participant 12-

What could be observed was that people who experienced less impact of fatigue on their daily activities were less likely to follow a schedule or structure. Often, these were also the people who were generally less active in terms of housework and work.

Professional help

Caregivers also played a dual role in learning to manage fatigue. Participants indicated that few handles or tips were provided by the dialysis centre to deal with fatigue. When they ask for advice regarding their fatigue, it is often looked at and addressed medically, such as checking blood levels. Participants miss a more personal approach towards them and their fatigue by healthcare providers. They indicate that they should be listened to more and given more advice.

“I sometimes feel that too little is done here on the ward, too little listened to. Also, it’s always others who are here, and that would be okay, but they don’t remember well. They see me here every week and yet I have to say everything myself. So I find, should I have ever done that at work... Every time I’m here, I have to say everything again. And then they tell me ‘do your best tomorrow’, but they don’t propose anything, so they don’t actually do anything. They just cannulate you and (claps hands) [they’re done].”
-Participant 17-

The participants also expressed not wanting to bother the nurses because they are generally too busy and have too much work. The participants were aware that there is a psychologist on the unit and it was often mentioned as an option for dealing with fatigue. There was one participant who had been consulting a psychologist for several years and benefited from this. The psychologist gave tools to deal with fatigue, helped with planning and how to better inform the social environment. Another participant expressed what he missed in care services, summing up what good care should stand for, for him:

“I would also definitely like to give something to the doctors: really try to look at how the person is on an individual level. For example, if it’s the ‘standard’ to push people, on an individual level it can actually have a negative effect. For example my doctor, I know he means well, but regularly he pushes me to lose weight and in a lot of moments it had the opposite effect on me. It made me lose motivation more than it helped me persevere. So really look at an individual level what the person needs and what they respond well or badly to, before you apply the same standard to everyone, because not everyone is helped by that."

-Participant 12-

Strategies

Participants used different strategies to cope with fatigue. They often mentioned taking rest on time and that listening to one's own body is equally important. Furthermore, they did activities at their own pace and started classifying or adapting activities. Strategies like using humour, putting things into perspective, persevering and not giving up were also mentioned.

Energising activities played an important role in dealing with fatigue. These were activities such as cycling and walking, activities that are active and outdoors. Furthermore, social activities also fell under this term. Because being together and meeting up with friends gives people energy to keep going. Paradoxically this was remarkable to see in the sense that these were also activities that require a lot of energy from the participants, but more on a physical level. Some also spoke of mindfulness and meditation as a way to cope with fatigue, this way one can 'shut down' and focus on oneself.

"Yes mindfulness that is yes, I need to be able to isolate myself and be in silence and that is where I can pull myself up ."

-Participant 14-

3.3. Comprehensive understanding

Participants used several mechanisms and strategies to cope with fatigue. People engaged in more energising activities, sought support from family and friends but also began to organise and adapt their activities according to their capabilities.

Coping is intrinsically related to self-management, which is the ability to learn to live actively and informed with the consequences of the condition in partnership with the social network and caregivers. There are three tasks associated with this, which overlapped with the themes and subthemes that emerged from the data.

A first task is medical management and includes all tasks to address, coordinate and control the medical side of the disease. Participants appeared well-aware of the medical aspect of dialysis and everything that comes with it such as following a diet but also keeping their blood levels right. This also helped with regulating their fatigue. The self-care in centre dialysis group appeared a bit more closely involved in their medical management as they specifically underwent training to carry out their dialysis treatment with little or no professional help. Participants reported experiencing more freedom by being able to choose their own moments and being less dependent, this could lead to a greater level of empowerment and motivation.

A second task involves role management, which pertains to controlling, adapting or creating new meaningful activities and life roles to continue to live well with the disease. Some of the participants experienced an impact of fatigue on their role management. This manifested itself mainly in changes in terms of social contact but also in terms of role management towards children or partners. Role management also includes coordination and planning when accomplishing daily activities is no longer evident due to for example fatigue. Here, two groups could be noted. On the one hand, a group that does not schedule their days and, on the other hand, a group that does schedule. The group that does not plan their days mostly indicated that they lived from day to day. In general, fatigue had a less significant impact on these participants. A second group that does schedule their days did so to balance their activities but also to schedule moments of rest to regulate their energy levels.

A third and last task is emotional management and represents the ability to deal with emotions. In addition, it deals with the inner process of revising one's life goals and identity. Indeed, the way people handle their emotions can have an effect on how they perform their role and medical management. Due to the experienced fatigue, negative feelings often surfaced among the participants. These emotions and feelings were more related to having to stop or do certain activities differently than before because of the fatigue. Participants reported finding it difficult to accept and cope with this and sought solace in their social environment, or through techniques such as mindfulness and meditation.

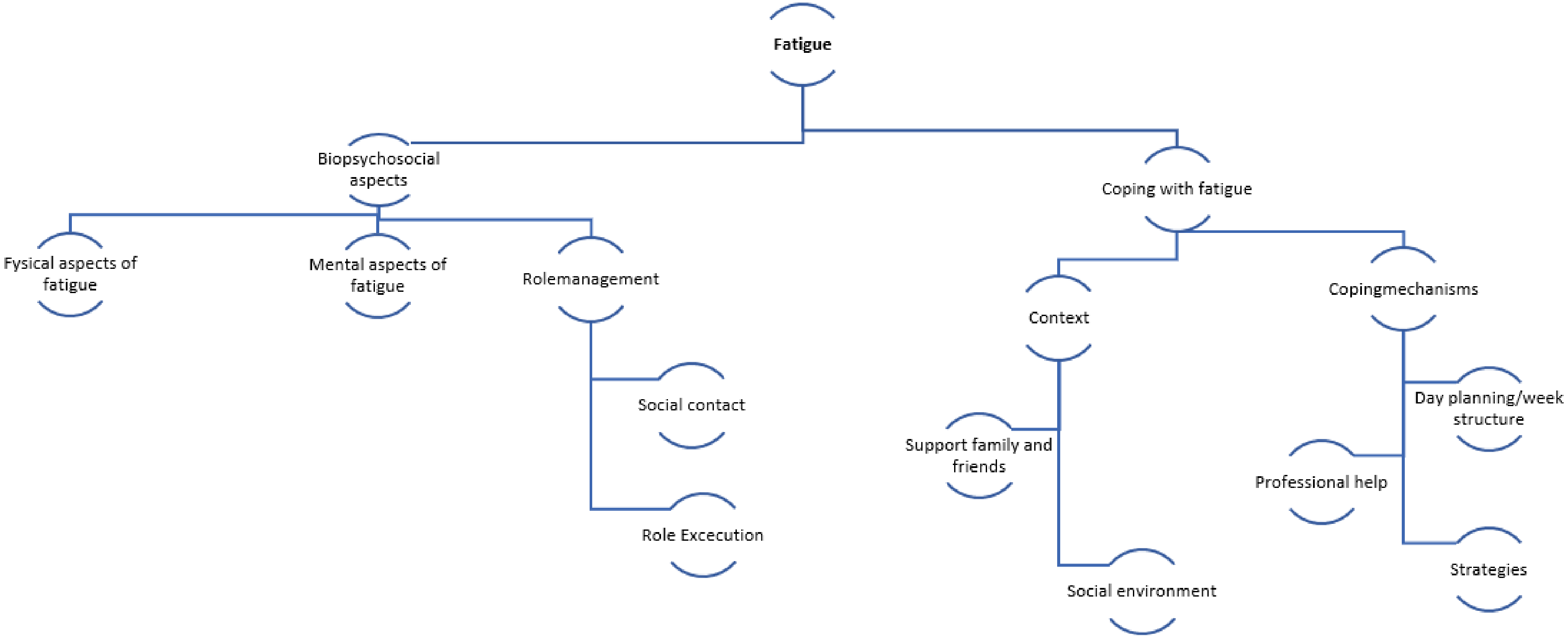

Figure 1. Themes and subthemes

4. Discussion

4.1. Link with literature

The aim of this thesis was to explore the nature and impact of fatigue on the life participation of adults (18-65) receiving in-center hemodialysis. Three groups were included: daytime dialysis, nocturnal dialysis, and self-care dialysis. Overall participants used several mechanisms and strategies to cope with fatigue. The main coping mechanisms were performing energising activities, handling a daily schedule and adapting their daily activities. The support from family and friends but also professional help played an important role for managing and coping with fatigue and could be found to be both obstructive and supportive.

Cramer (1998) states that coping is a conscious process and has a problem-solving function. In light of the results of this study, it can be said that adapting activities, performing energising activities and so on are conscious problem-solving solutions to cope with experienced fatigue.

To go more in depth on self-management and more specific emotional management (Strauss 1989), one model that could add value, in light of self-management and specifically emotional management (Strauss 1989), is the model of the conceptualizations of transformations (Dubouloz et al., 2010). This framework was initially developed for chronically ill people in primary care, but could be useful within the target group in this thesis. This model, as seen in **figure 2**, depicts the complex processes that occur in someone living with a chronic illness. Transformation in chronic illness is represented as a process of learning about oneself and the chronic illness in an iterative and continuous evolving manner.

The model characterises the transformation process as an initial reaction period leading to two other phases: “embracing the challenge” and “integrating new ways of being”. People with chronic illness begin the transformation process in the initial response phase and this can last up to five years (Dubouloz et al. 2010). This will eventually lead to a catalytic experience and constitutes the transition to the next phase “embracing the challenge”. In “embracing the challenge”, people make a decision to recognise the challenges that the disease presents to them and think critically about what is needed to meet the challenges. These are things like acknowledging the disease, exploring, etc. This triggers people to critically reflect and will lead to change and adjustments in certain areas of their life. The last stage of the transformation process is “integration of new ways of being”. In this phase, a person experiences the results of their transformation process, such as understanding and acceptance of self. The model is surrounded by the person's social and personal context. This includes health professionals, social support, the healthcare system and the person's readiness, willingness and capability.

[1]

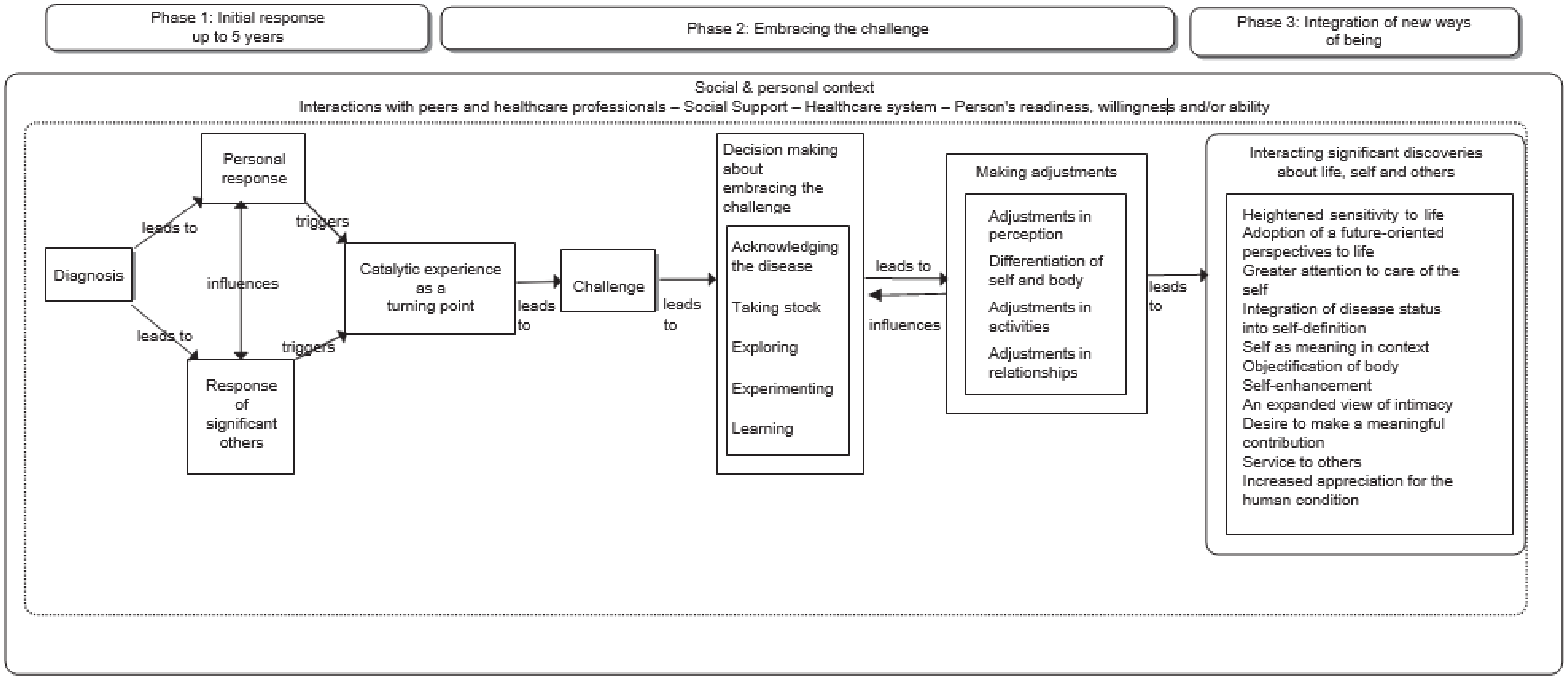

Figure 2. The model of the conceptualizations of transformations (Dubouloz et al., 2010)

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[1] Dubouloz, C., King, J. A., Paterson, B., Ashe, B., Chevrier, J., & Moldoveanu, M. (2010). A model of the process of transformation in primary care for people living with chronic illnesses. Chronic Illness, 6(4), 282–293. https://doi.org/10.1177/1742395310383340

What could be seen among the participants was that people on dialysis for shorter amounts of time had often taken less peace with fatigue and the accompanying loss in activities. They frequently still found it difficult to accept their illness and its consequences. These are people who are in the initial phase and have yet to come to embrace their disease and its consequences. Participants who had been on dialysis for already quite some time had embraced the challenges and made adjustments to cope with the disease and its consequences.

For the participants, being on dialysis caused a lack of time to do the things they enjoyed, and this often brought a lack of peace with the fatigue and the accompanying loss in activities. They often found it difficult to accept their illness and its consequences. When linked to the model, this refers to people who are in the initial phase and have yet to come to embrace their disease and its consequences. Participants who were on dialysis for some time had embraced the challenges and made adjustments to cope with the disease and its consequences. Importantly, none of this can be separated from the participant's social environment and how well they can interact with their social environment. Here there is also a role for the healthcare professional to support and guide the participants during this transformation process. This can be done by providing personalized information, tools and tips to cope with fatigue.

It can be argued that currently too few handles and tools are given to dialysis patients to deal with fatigue. Advice that is given is often described as too medical. Literature mainly shows a focus on medical aspects of the condition. Medical outcomes are often rated more important by medical professionals than for patients and their environment (Urquhart-Secord et al 2016). Patients and those close to them attach much more importance to outcomes such as their daily lives and well-being. The focus of healthcare providers should be much more directed towards patient-reported outcomes and how one can incorporate fatigue within their daily lives to maintain or improve their well-being and quality of life (QoL).

This gives rise to the importance of providing holistic care. Within this vision, people are seen as a whole, physically, mentally and socially. It also pays attention to circumstances and environment, because people have to adapt to these. The extent to which a person can adapt, will affect functioning and QoL. Fatigue and the patient must be addressed holistically, this is where occupational therapy can play a valuable role, particularly as participants reported mostly performing energising activities to cope with their fatigue. Often these were activities that were physically demanding, but mentally and psychologically energising. It can be said that these energising activities were also meaningful activities for the participants. Meaningful activities are activities that enable the person to achieve better health or QoL.

People in the social environment of the participants were often under- or misinformed, making them less understanding and supportive. There is a need to better inform the social environment as this currently appears sometimes lacking within the dialysis centre. The importance of informing the people near to the patients is because they are often the informal carer or closest person to the person with CKD and their symptoms and are therefore the ideal party to be able to act on this accurately and to support a patient closely. Healthcare providers, informal caregivers and the social environment all play an integral role in the support of someone living with CKD. But the potential impact of caring for people with end stage kidney failure treated by dialysis on the QoL of informal caregivers is less frequently addressed. However, the impact and care of CKD can also place a burden on the environment. Within the participant group, the partner was often the sole breadwinner. Furthermore, things like career goals and other occupational and leisure aspects can also be affected. This can affect the dynamics within the relationship and even lead to burn-out (Kalantar-Zadeh et al., 2021). Therefore, according to Gilbertson et al (2019), there should be interventions to help caregivers within the care and relationship to improve their QoL. And by doing so enable them to sustain their role and support the dialysis patient in the long term. The focus should be shifted from mere disease and individualised care to a holistic one, towards empowering the patient as well as the partner and social environment. This is also confirmed in the theme of World Kidney Health by Kalantar-Zadeh et al (2021), in which they called for a shift to a strength-based approach to care. This means that individuals with CKD and their surrounding are empowered to achieve certain health outcomes and life goals that are meaningful and important to them. Empowerment is about gaining control over decisions or actions that affect their health, understanding roles, having knowledge to engage in shared decision-making, having skills and support for self-management.

However, people do not appear to get enough support and information from the service and healthcare professionals to deal with aspects beyond the medical. As also noted by Ania-González et al (2022), patients and families experience a lack of information and continuity of care by healthcare providers. Support from healthcare professionals should focus on knowledge, psychological, social and spiritual needs of the social environment.

4.2. Recommendations to the field

Based on these results, recommendations include the implementation of a more holistic care approach, with a continued focus not solely on the medical side and physical aspects, but also on people’s mental and social aspects. Not only the person with ESKD following HD should by informed but also the social environment. This to create a safe space where chances are increased for people with ESKD to receive support to accurately cope and manage their fatigue. Performing energising activities, handling a daily schedule and adapting daily activities should be stimulated by

healthcare professionals to help patients cope with fatigue. For this the right tools and tips should be given by healthcare professionals.
Although the literature is scarce, there are some existing interventions that may offer a possible solution in regards of managing fatigue and its impact on life participation.

A first one is the ‘Personal Energy Planning’ (PEP) programme developed by Farragher et al. (2020), which offers individualised training in energy management. The programme consists of six to eight weekly sessions and is split into two parts. The first part consists of two short educational web modules that introduce participants to basic energy management concepts such as prioritising, simplifying tasks, organising the home and/or work environment. Each participant is instructed on the computer modules and the programme workbook during an introductory meeting. The two computer modules are then completed one per week, during dialysis sessions or at home. The second part includes four to six face-to-face sessions with a therapist or clinician. During these 20- to 30-minute sessions, patients choose three goals for life participation and are taught to use a modified version of an established problem-solving framework to identify energy management strategies that will help them achieve their goals. From a pilot study, it could be seen that medium intervention effects were observed on the Canadian Occupational Performance Measure Performance Scale (COPM), the Global Life Participation Scale and the Global Life Participation Satisfaction Scale after 1-week follow-up. At 12-week follow-up, large and very large intervention effects were observed respectively on the COPM Performance Scale and the COPM Satisfaction Scale (Farragher et al., 2022). Admittedly, this survey is small-scale (n=22) and larger quantitative surveys are necessary

A second intervention is the Cognitive Behavioral Therapy for Fatigue in Hemodialysis (BReF) intervention (Picariello et al., 2021), which is a cognitive behavioural therapy (CBT)-based self-management intervention. BReF addresses individuals’ fatigue thoughts, emotions and behaviours by creating consistent activity and rest routines, gradually increasing daily activity, and identifying and managing unhelpful thoughts related to fatigue. A self-management manual was provided, accompanied by three to five sessions with the primary investigator having an academic background in Health Psychology, basic CBT training and experience in working with fatigued patient groups (FP) or a registered health psychologist working in the renal setting. The effects of the intervention seem acceptable and beneficial for HD patients, but the sample size is too small to say conclusive things about this intervention.

4.3. Future research

Further research is strongly recommended on several issues. On the one hand, which interventions can be implemented for people with CKD experiencing fatigue. On the other hand, research into how healthcare professionals could better support the patient and the environment within self-management and empowerment to deal with fatigue. It is important to look more in depth at the needs and desires of the persons and the involvement of the social environment as well. The environment should also be assessed to see what is missed in care delivery and what can be done for them. By doing so, it is possible to better address what is needed for the patient and their environment and improve the provided support and given information.

4.4. Strengths and weaknesses

Lastly the quality criteria established by Lincoln et al. (1985) will be covered, starting with credibility. This concerns confidence in the "truth" of the findings. Research triangulation was done by using two researchers to start identifying selective perception and blind spots. This was done in both data collection and data analysis, both researchers conducted interviews and analysed them. The process of data analysis was iterative, after five interviews the researchers sat together to go over the results. This was to explore different perspectives of the researchers and not think too narrowly within the results. The obtained results confirmed existing results on fatigue and its major impact. There was no member checking and peer debriefing which can be a pitfall towards the credibility of this research.

Following is transferability, which is defined as showing that the findings can be applied in other contexts. In qualitative research, the aim is by no means to generalise the results. However, based on these results, conclusions can be transferred to a comparable population. An attempt has been made to represent with inclusion and exclusion criteria for which population the results might apply. Data was collected until saturation was reached. It can be stated with relative certainty that the results will apply to a large proportion of the population and little to no information was missed.

An attempt was made to provide enough info using a thick description for people to determine whether these results are applicable within their own context. The participant group (n=20) consists only of people following in-center HD and consists of a 'younger' population from one dialysis centre. This was a deliberate choice as these people are generally more active in daily life. This ensures that the results obtained are not necessarily transferable to other dialysis centres, cultures, home dialysis or age groups.

Dependability is defined as the consistency and repeatability of the results. The interview guide was constructed from existing literature and queried via topics. Structured interviews were chosen because they were conducted by two researchers. In an open-ended interview, this would cause the results to have a higher variation and differences in collection. This would add more complexity to the processing and analysis of the results. Furthermore, a focus group was also not opted for. Because it involves personal experiences, there is less control and the interviews were conducted during dialysis. Participants could not be expected to make time after dialysis to conduct a focus group. The coding process was iterative and open-ended, with the code tree attached to the structural analysis.

Finally, there is confirmability. As mentioned above, the data collection and data analysis involved two researchers and the process was iterative. This attempts to increase the objectivity and neutrality. All knowledge is gained through this study and the participants, the results are in no way influenced by intuition, assumptions or perspectives of the researchers. No audit was conducted by an investigator not involved within the process. This means that findings and conclusions have not been checked to see if it is supported by the data.

5. Conclusion

In this thesis, an attempt was made to form a better understanding regarding fatigue in CKD, especially focused on how one tries to deal with it. The main coping mechanisms were performing energising activities, handling a daily schedule and adapting daily activities. Participants generally experienced some shortcomings within their care, it was often felt to be too medically focused and participants opted for more holistic care. They were also often unable to access care professionals. These should be an active partner to achieve self-management and empowerment of the person with CKD and their environment. The environment also plays an active role in this, having to be informed and supportive towards the person. Therefore, within the treatment for CKD, attention should also be given to interventions to support the environment in the overall process.

To conclude, it can be said that there is still a long way to go. This research serves as a first basis to inform the development or expansion of interventions to support people with end-stage kidney disease who experience fatigue and can form a base to improve future care for patients suffering from CKD.

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Appendix

Appendix 1. Interview guide

1. Introductie:

Wat is uw geboortedatum? Hoe oud bent u?

Bent u alleenwonend of samenwonend?

Heeft u kinderen?

Werkt u nog?

Heeft u hobby's?

2. Diepgaande vragen:

Algemeen:

Hoelang volgt u al hemodialyse?

Wanneer zijn uw dialysedagen en hoeveel tijd nemen deze ongeveer in beslag (inclusie vervoer…)

Kan u een typische dag op een dialysedag beschrijven?

Hoe vult u uw tijd in tijdens de hemodialyse in het ziekenhuis?

Kan u een typische dag beschrijven op niet-dialysedag?

Vermoeidheid:

Ervaart u vaak vermoeidheid? Zo ja, hoe zou u deze omschrijven? Kan u enkele voorbeelden geven van situaties waar u vermoeidheid ervaart? En van situaties waar u energie van opdoet, of die u geen energie kosten?

Hoe kan u aan uw lichaam voelen dat deze vermoeidheid opkomt/zich voordoet?

Hoe kan u aan uw gevoel en uw emoties voelen dat u vermoeid wordt?

Hoe zou u omgeving/partner zeggen dat hij/zij kan zien aan uw gedrag dat u vermoeid bent/wordt?

Op een schaal van 1 tot 5 (1niet impactvol – 5 heel impactvol), hoe impactvol is de vermoeidheid op uw leven? Kan u ook aangeven waarom u dat zo erg (als score>3) of niet erg (als score<3) vindt?

Kan u enkele voorbeelden geven van activiteiten die u meer zou doen moest u meer energie hebben?

Op welke manier en bij wie zoekt u steun om de invloed van die vermoeidheid aan te kunnen, of in te passen in uw leven??

Wat zou u kunnen helpen om minder vermoeid te zijn of beter met de vermoeidheid om te gaan? Vanuit uw partner/omgeving- vanuit de zorgverleners rond u?

Dagelijkse activiteiten:

Welke activiteiten geven u het meeste energie?

Welke activiteiten eisen veel energie van u?

Welke activiteiten krijgen voorrang?

- Waarom krijgen deze voorrang?

Welke activiteiten zou u meer of minder doen als u geen dialyse had?

Strategieën:

Hoe pakt u dat aan als u weet dat u op een bepaalde dag activiteiten wil doen/zou willen doen die belangrijk zijn voor u of uw omgeving? En in het dagelijkse leven, hoe doet u dat dan om alles wat u wil doen rond te krijgen? ?

Hebt u een vaste structuur in uw dagen, bijvoorbeeld een weekplanning? Hoe gaat dat dan/hoe doet u dat dan juist?

Rolmanagement:

Hoe beïnvloedt deze vermoeidheid uw sociaal leven en het opnemen van bepaalde rollen, zoals… (aangepaste voorbeelden geven voor deze patiënt)?

3. Afsluitende vragen:

Kan u enkele voorbeelden geven van hoe u nu al advies of bepaalde handvaten mee krijgt om reeds om te gaan met die vermoeidheid vanuit de dienst hemodialyse?

Wat zou u als raad geven aan andere hemodialysepatiënten omtrent het omgaan met vermoeidheid?

Wilt u nog iets toevoegen?

Appendix 2. Informed consent and information letter

INFORMATIE- EN TOESTEMMINGSFORMULIER

Doelpubliek: volwassenen vrijwilligers die nierfunctie vervangende therapie volgen
Anonieme dataverzameling: er worden geen persoonsgegevens verzameld
Taal: Nederlands

LUIK 1 – Informatiebrief voor deelnemers aan onderzoek

Titel van de studie: Vermoeidheid bij personen die nierfunctie vervangende therapie volgen

Dit is een onderzoek dat wordt uitgevoerd door de Universiteit Gent in samenwerking met UZ Gent Nefrologie. De verantwoordelijke onderzoekers zijn:

Timothy Moreels Onderzoeksgroep Ergotherapie, vakgroep revalidatiewetenschappen	Prof. Dr. Dominique Van de Velde Onderzoeksgroep Ergotherapie, vakgroep revalidatiewetenschappen
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A. Informatie over de studie

Beste,

U wordt uitgenodigd om deel te nemen aan een klinische studie. Neem, voor u beslist om deel te nemen aan deze studie, voldoende tijd om deze informatiebrief aandachtig te lezen en dit te bespreken met de arts-onderzoeker of zijn/haar vertegenwoordiger, of met andere personen van uw keuze. Neem ook de tijd om vragen te stellen indien er onduidelijkheden zijn of indien u bijkomende informatie wenst. Dit proces wordt 'informed consent' of 'geïnformeerde toestemming' voor deelname aan een experiment genoemd. Eens u beslist heeft om deel te nemen aan de studie zal men u vragen om het toestemmingsformulier achteraan deze bundel te ondertekenen.

Wat is het doel van het onderzoek?

Wij nodigen u uit om deel te nemen aan een klinische studie met als doel het in kaart brengen van de ervaring van vermoeidheid bij personen die nierfunctievervangende therapie volgen.

Tijdens deze studie zullen er diepte-interviews afgenomen worden. De diepte-interviews zullen ofwel afgenomen worden op de dienst van het UZ Gent ofwel in de thuissituatie van de participant. Binnen deze thesis zullen vragen zich richten op hoe de vermoeidheid zich manifesteert. Hoe de vermoeidheid een rol speelt op vlak van zelfmanagement en de impact op ADL en kwaliteit van leven. Er zal dieper ingegaan worden op bepaalde substraten van vermoeidheid, zoals energieniveau, duur, intensiteit enzovoort.

De opdrachtgever van deze studie is Dominique Van De Velde. Studente, Kyara Boete van de vakgroep Master in de ergotherapeutische wetenschap zal deel uitmaken van het onderzoeksteam.

Ethische goedkeuring

Deze studie werd op 19/09/2022 goedgekeurd door de Ethische Commissie van de Faculteit UZ Gent van de Universiteit Gent. In geen geval dient u de goedkeuring door de Ethische Commissie te beschouwen als een aanzet tot deelname aan deze studie. De studie wordt uitgevoerd volgens de richtlijnen uit het Algemeen Ethisch Protocol van de Faculteit UZ Gent. De onderzoekers voeren dit onderzoek uit in overeenstemming met de geaccepteerde maatstaven voor wetenschappelijk en ethisch gedrag. Hierbij houden zij zich aan de principes van onderzoeksintegriteit zoals beschreven in “The European Code of Conduct for Research Integrity” (2017, revised edition, ALLEA)[2] en hanteren ze goede onderzoekspraktijken.

Informatie over Privacy en Persoonsgegevens

In deze studie worden geen persoonsgegevens verzameld. Alle gegevens die worden verzameld zijn van bij aanvang anoniem. Dit betekent dat wij noch andere personen je identiteit kunnen afleiden uit de verzamelde gegevens of deze gegevens kunnen koppelen aan uw identiteit.

B. Informatie over deelname aan het onderzoek

Wat houdt deelnemen aan dit onderzoek in?

De verwachte totale duur van de studie voor u is 1 interview dat ongeveer twee uur kan duren.

Uw deelname aan de studie omvat geen extra bezoeken in vergelijking met een behandeling zonder deelname aan de studie. Voor het welslagen van de studie, is het uitermate belangrijk dat u volledig meewerkt met de arts-onderzoeker en dat u zijn/haar instructies nauwlettend opvolgt.

De procedure van dit onderzoek bestaat uit het afnemen van diepte-interviews. Dit zijn individuele interviews die aan de hand van een interviewleidraad met een specifieke topiclijst omtrent vermoeidheid door de interviewer wordt afgenomen.

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[2] https://allea.org/code-of-conduct/

Het studieverloop zal als volgt plaatsvinden: eerst zal er een screeningsfase plaatsvinden, dit houdt in dat er wordt gekeken naar potentiële participanten en dat mensen zich kunnen opgeven om deel te nemen aan het onderzoek. In een tweede fase, de selectiefase, zal er gekeken worden naar de pool van mogelijke participanten. Hiervoor worden de in-en exclusiecriteria voor gebruikt. Van zodra de participanten officieel geselecteerd worden en toestemming geven voor deelname, start de laatste fase. Dit is de onderzoeksfase, hier zal er actief aan de slag gegaan worden. Participanten zullen diepte-interviews afleggen met de onderzoekers, omtrent hun persoonlijke ervaring van vermoeidheid bij de nierfunctie vervangende therapie.

De deelname aan deze studie is volledig vrijwillig, er kan op geen enkele manier sprake zijn van dwang. U kunt weigeren om deel te nemen aan de studie en u kunt zich op elk ogenblik terugtrekken uit de studie zonder dat u hiervoor een reden moet opgeven en zonder dat dit op enige wijze een invloed zal hebben op uw behandeling of de verdere relatie met de onderzoeker of de behandelende arts. Dit zal ook geen negatieve invloed hebben op de kwaliteit van de zorgen en uw verdere opvolging.

Uw deelname aan deze studie zal beëindigd worden als de arts meent dat dit in uw belang is. U kan ook voortijdig uit de studie teruggetrokken worden door de onderzoeker als u de in deze informatiebrief beschreven procedures niet goed opvolgt of u de beschreven items niet respecteert.

Indien u uit de studie gehaald wordt, zullen de reeds verzamelde gepseudonimiseerde gegevens in de databank blijven voor analyse, maar er zal geen nieuwe data toegevoegd worden.

Wat zijn de risico’s en voordelen bij deelname aan dit onderzoek?

Deelname aan deze studie brengt voor u waarschijnlijk geen onmiddellijk therapeutisch voordeel. Uw deelname in de studie kan wel helpen om in de toekomst patiënten beter te kunnen helpen.

De waarschijnlijkheid dat u door deelname aan deze studie enige schade ondervindt, is extreem laag.

U hebt het recht om op elk ogenblik vragen te stellen over de mogelijke en/of gekende risico’s van deze studie. Als er in het verloop van de studie gegevens aan het licht komen die een invloed zouden kunnen hebben op uw bereidheid om te blijven deelnemen aan deze studie, zult u daarvan op de hoogte worden gebracht. Mocht u door uw deelname aan de studie toch enig nadeel ondervinden, zal u een gepaste behandeling krijgen.

Is er een vergoeding of beloning voorzien bij deelname aan dit onderzoek?

U zult geen financiële compensatie of vergoeding van reiskosten ontvangen voor uw deelname aan deze klinische studie.

Verder brengt deelname aan deze studie geen extra kosten mee voor u.

Hergebruik van gegevens

De hier verzamelde onderzoeksgegevens kunnen ook nog nuttig zijn bij het beantwoorden van andere onderzoeksvragen. Daarom bestaat de mogelijkheid dat de anonieme onderzoeksgegevens worden hergebruikt op een later tijdstip voor ander onderzoek. Het hergebruiken van de anonieme onderzoeksdata kan zowel gebeuren binnen het eigen onderzoeksteam, als door externe onderzoekers binnen en buiten de Europese Unie via een speciaal daarvoor bedoeld deelplatform voor onderzoeksdata.

LUIK 2 – Toestemmingsformulier

A. Toestemming m.b.t. deelname aan de studie

Gelieve het juiste vakje aan te kruisen	**ja**	**nee**
Ik neem vrijwillig deel aan deze wetenschappelijke studie en geef toestemming aan de onderzoekers om mijn gegevens te verwerken, ze te bewaren, te analyseren en er over te rapporteren.	o	o
Ik weet dat ik me op elk ogenblik uit de studie mag terugtrekken zonder een reden voor deze beslissing op te geven en zonder dat dit op enige wijze een invloed zal hebben op mijn verdere relatie met de onderzoeker. Ik begrijp dat het stopzetten van mijn deelname geen negatieve invloed heeft op mijn behandeling of ondersteuning.	o	o
Ik heb het informatieformulier gelezen en heb voldoende uitleg gekregen over de aard, het doel, de duur, en de voorziene effecten van de studie. Ik kreeg de gelegenheid om vragen te stellen en ik heb op al mijn vragen een bevredigend antwoord gekregen.	o	o
	o	o

Naam deelnemer	Naam onderzoeker
Datum:	Datum:
Handtekening	Handtekening

List of figures and tables

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