

Which strengths do hemodialysis patients use to self-manage their everyday life?



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Abstract

Background: Hemodialysis patients are exposed to incisive implications on their everyday life due to their dialysis treatment. To maintain a satisfactory quality of life, they are required to engage in self-management activities to continuously care for their kidneys. For this purpose, hemodialysis patients need to be aware of internal and external strengths they can utilize for their everyday caretaking of their health even without medical assistance. Using their strengths to engage in self-management activities may empower the everyday coping behavior of hemodialysis patients. This study aimed to investigate which strengths hemodialysis patients use to self-manage their everyday life.

Methods: A qualitative study design was chosen. Semi-structured interviews were conducted with ten participants from a local kidney office in Münster, Germany. The sample consisted of mixed gender and varying ages ($M = 54.4$). Participants were asked about their personal background, their coping with the dialysis treatment, and their strengths. The interviews were audio recorded, transcribed verbatim, and analyzed using inductive coding.

Results: The findings show that participants use several self-management strategies ($n=5$), internal strengths ($n=7$), and external strengths ($n=2$). Self-management strategies evolved around managing practical issues to integrate the dialysis treatment into the everyday life of hemodialysis patients such as planning, organizing, and re-adjusting their lifestyle. Among the internal strengths it was most apparent that participants were able to accept their dialysis treatment, persist its implications, and to maintain a positive attitude. However, participants most frequently relied on their social environment as a source of support. Drawing from a variety of internal and external resources, participants were able to increase their levels of psychological, emotional, and social well-being.

Conclusion: The hemodialysis patients in this study indicated to employ a range of self-management strategies and strengths to cope with the impact of their dialysis treatment in their everyday life. The findings could be useful for the facilitation patient-centered care. Medical staff could tailor their healthcare according to patients' needs and wishes and hemodialysis patients may extend their repertoire of strengths and self-management strategies employed for their self-care behavior.

Introduction

Kidneys are important organs in the human body that perform essential functions for our survival. They not only filter the blood to remove wastes and fluids multiple times each day but also regulate our blood pressure and produce necessary hormones (Deutsche Gesellschaft für Nephrologie [DGfN], 2020). Although they are powerful and highly productive organs, they are also fragile and prone to damage for varying reasons. The most common risk factors and comorbidities associated with kidney damage include diabetes, hypertension, autoimmune disorders, a family disposition to kidney diseases, or an age of 60 and above (Kidneyfund, 2020; Roscosz et al., 2019). At the World Kidney Day 2019 it was stated that about 850 million people suffer from a kidney disease worldwide (DGfN, 2019a). In mild chronic conditions, a kidney disease can effectively be tackled with a conservative treatment including medications and professional surveillance (Ammirati, 2020; Bundesverband Niere e.V., 2020). However, as soon as more than 50% of the kidney tissue is damaged, patients are in need for a so-called renal replacement therapy consisting of either hemodialysis, peritoneal dialysis, or receiving a kidney transplant (DGfN, 2020; National Institute of Diabetes and Digestive and Kidney Disease [NIDDK], 2018). This study focuses on kidney patients receiving hemodialysis because of the high level of implications they experience in their everyday life. This is a treatment form that uses an external machine to stabilize the function of the kidneys by filtering the blood (NIDDK, 2018). The impact of a hemodialysis treatment for the patients can be detrimental and range from adhering to strict treatment regulations or drastic lifestyle adjustments to impairments in physical functioning (Sperschneider, 2008). To counteract the extent to which a hemodialysis treatment affects kidney patients in their everyday life, certain resources and strengths – internal and external – need to be enabled to facilitate their ability to self-manage their daily duties and responsibilities (Park et al., 2004; Lin et al., 2017). On the one hand, internal strengths can be characteristics of the individual patients such as persistence, knowledge or acceptance. On the other hand, external strengths most often constitute support from families, relatives, friends or healthcare providers (Kristjansdottir et al., 2018). The aim of this study therefore is to investigate which strengths hemodialysis patients use to self-manage their dialysis treatment in their everyday life.

The experience of both an advanced progression of their chronic disease as well as the requirement for a dialysis treatment represent incisive life events for kidney patients. Consequently,

they are faced with changes and challenges that impact their everyday life. This not only implies adjustments towards their lifestyle, but also means adapting to practical, psychological, physical, social, and emotional consequences (Morton et al., 2011; Roscosz et al., 2019; Yeo & Sawyer, 2005). For instance, to receive their dialysis treatment, patients are attached to a machine for at least three times a week and five hours per session on average (Roscosz et al., 2019; Sautenet et al., 2018). As a result, dialysis patients are exposed to a tightly fixed schedule (Morton et al., 2011), they experience a limited capacity to perform their everyday tasks, they are less able to travel (Urquhart-Secord et al., 2016), or they have difficulties to continue their work (Roscosz et al., 2019). Next to these practical implications, hemodialysis also poses a physical burden for the patients which is mainly caused by the blood filtration. Dialysis patients report increased levels of fatigue and the need for sleep, a lack of appetite (Urquhart-Secord et al., 2016), a reduction in their physical functions and a decline in physical functioning in general (e.g. the ability to perform everyday activities; Sperschneider, 2009; Lopes et al., 2014). These feelings of exhaustion and debility often interfere with or impact the social relations of dialysis patients. For instance, due to their tight schedule, time for friends or relatives is limited which leads to difficulties sustaining relationships (Lopes et al., 2014). Furthermore, they are less able to achieve family goals (Urquhart-Secord et al., 2016) and often become dependent on caregivers. This can not only harm their mental health but also lead to feelings of disappointment or inferiority. Additionally, patients on dialysis have a 15% annual mortality rate (Tong et al., 2015). This fact combined with the continuity of the treatment itself often lead to feelings of anxiety, depression, or hopelessness (Finkelstein & Finkelstein, 2000; Hatami et al., 2019; White & McDonnell, 2014). In advanced stages, patients even tend to deny adherence or continuation of their dialysis treatment and they oftentimes showed more interest in living well with their disease and the treatment than caring about their own mortality (Urquhart-Secord et al., 2016; Morton et al., 2010). The desire for a reasonable and acceptable quality of life - whilst coping with the consequences of the dialysis treatment and the effects of the chronic kidney disease - demands for strategies that individuals can apply to self-manage their everyday life besides the assistance of professional, medical care.

To maintain a satisfactory level of quality of life, patients need to engage in self-management activities every day to ensure continuous caretaking for their kidneys even without medical surveillance (Barlow et al., 2002; DGfN, 2019a). Barlow and colleagues (2002) define self-management as the ability of an individual to manage the symptoms and treatment, lifestyle

changes as well as physical and psychosocial consequences occurring with a chronic illness. They state that successful self-management also entails the ability to monitor one's condition to establish a continuous process of self-regulation (Barlow et al., 2002). In their review, Schulman-Green and colleagues (2012) propose a framework for the self-management of individuals with chronic diseases that may also describe self-management activities and strategies for dialysis patients. It consists of three categories of processes, namely focusing on illness needs, activating resources, and living with a chronic illness. Regarding their illness needs, dialysis patients need to acquire disease-specific knowledge to understand important aspects of the disease and to learn how to effectively recognize, monitor, and react to symptoms (Haris & Polner, 2018). Furthermore, they require skills to adhere to medication plans (Havas et al., 2016; Wild et al., 2017). Focusing on illness needs also entails the caretaking of patients' physical entity. This relates to dialysis patients because ideally they quit smoking, optimize physical activities, preserve a normal body weight, and adopt a healthy dietary lifestyle (DGfN, 2019b; Haris & Polner, 2018; Roscosz et al. 2019; Wild et al., 2017). Activating resources comprises the interaction of chronic patients with their social environment and supportive others (Lorig & Holman, 2003; Schulman-Green et al., 2012). In their review on preferences for self-management support of people with chronic kidney disease, Havas and colleagues (2016) explicitly mention that both engaging and sustaining social support and establishing effective relationships to medical professionals is important (see also White & McDonnell, 2014). This may include community activities, meeting with friends or family members to receive emotional support, or connecting well with members of one's healthcare team (Havas et al., 2016). Probably the most difficult category for dialysis patients is to adjust to living with their chronic illness and their continuous treatment. On the one hand, it implies making modifications to their lifestyle such as adjusting to dietary guidelines, exercising sufficiently, establishing new routines, or learning to plan ahead (Havas et al., 2016; Wild et al., 2017). On the other hand, it comprises developing a positive attitude and taking care of one's mental wellbeing. This likely affects the way in which dialysis patients engage in their treatment, healthcare, and the collaboration with their healthcare providers (Havas, et al., 2016). These processes of self-management describe possibilities and opportunities for dialysis patients to improve adjusting with illness-specific conditions and circumstances. Engaging in these activities may reduce the impact of the chronic illness on their daily life, slow down disease progression, and enable them to more effectively cope with the wide-ranging consequences (Barlow et al., 2002; Havas et al., 2017).

However, research and practice on chronic kidney disease and hemodialysis has almost exclusively focused on biological markers, adverse events, the delivery of health-related information, and physical implications such as setting up a medication plan or choosing the right treatment (Havas et al., 2017; Tong et al., 2015; Urquhart-Secord et al., 2016). Although these instances of caretaking are beneficial to the patients, they largely disregard their own healthcare preferences. For instance, Urquhart-Secord and colleagues (2016) mention that patients tend to weigh topics that focus on their daily living and well-being as more important. Additionally, dialysis patients show an increased willingness to sacrifice some aspects of healthiness (e.g. prolonged survival) for the freedom to travel or to relieve their caregivers (Tong et al., 2015). Building on this, research has found that patients report both a lack of individualized self-management support and a lack of explanation for the necessity of lifestyle adjustments. Instead of being excessively informed about disease-related information and facts, patients value emotional support, reinforcements to take care of their physical and mental health as well as learning how to more effectively engage in healthcare as equally important (Havas et al., 2017). Research has shown that these values could be satisfied by increasingly centering health services and caregiving around patients' needs. Patient-centered care yields positive outcomes regarding patients' adherence to the treatment, patient engagement and task orientation as well as an improved quality of life (Bauman et al., 2003; Tong et al., 2015). Consequently, empowering patients to partially become the managers of their disease - next to their healthcare providers - is beneficial and desirable. However, they need to be able to self-manage effectively to improve the coping with their chronic disease and the impact of their dialysis treatment on their everyday life as best as possible.

To this end, dialysis patients need to become aware of factors that may facilitate their day-to-day self-management. They are required to access their personal qualities or properties in their environment that help them to achieve effective self-management. The positive psychological approach proposed by Peterson and Seligman (2004) promotes that a focus on character strengths of an individual – defined as positive traits expressed by thoughts, feelings, and behavior – may enhance their general well-being and flourishing. Character strengths may activate and promote decision-making and behavioral change in favor of positive health outcomes (Rotegård et al., 2009). This view is supported by Kristjansdottir and colleagues (2018) who stress the importance to discover and use one's own strengths to comfortably live with a chronic disease. Pursuing to

concentrate on strengths is fundamental for chronic patients to identify their health-related needs and wishes (Kristjansdottir et al., 2018). However, strengths not only originate in individuals themselves, they may also arise from external sources. It has been found that external strengths include different forms of support from the cultural and social environment of patients. Positive external assistance from families, relatives, or friends may facilitate patients' activation of internal resources which in turn benefit their everyday engagement in self-management strategies (Rotegård et al., 2009). Research has shown that factors influencing the self-management of hemodialysis patients are, for instance, self-efficacy, patient's knowledge or the level of social support (Li et al., 2014). Wild and colleagues (2017) explain that a high level of self-efficacy is positively associated with improvements in health-related behaviors (e.g. medication and treatment adherence) and patient's self-care behavior (see also Lin et al., 2017). It was found that hemodialysis patients use a positive attitude and increased levels of hope to reduce stress, anxiety, and depression symptoms which enables them to become more problem focused (Rahimipour et al., 2015). Furthermore, a variety of strengths was found by Kristjansdottir and colleagues (2018) that promote the engagement in self-management strategies and patient's resilience when having a chronic illness. Among others, these are knowledge, positive emotions and optimism, supportive relationships, persistence, and the availability of emotional and practical support. Resilience in particular not only leads to less avoidance behavior and more coping with illness-related issues but also increases the level of social support received by hemodialysis patients (Hatami et al., 2019). Receiving social support enables their coping abilities by boosting their self-esteem and emotional stability which leads to an increase in self-care behaviors that positively impact their physical, psychological, social, and emotional well-being (Hatami et al., 2019). In fact, Rotegård and colleagues (2009) found a bidirectional relationship between internal and external strengths which demands for an emphasis on both to foster the everyday self-management of hemodialysis patients.

Previous research has already identified a range of strengths and self-management strategies employed by hemodialysis patients. However, this study aims to add to the existing body of research by further exploring which personal strengths and qualities as well as which environmental resources help hemodialysis patients to self-manage the consequences and the impact of their dialysis treatment on their everyday life. Based on this, the following research question is formulated: *“Which strengths do hemodialysis patients use to self-manage their everyday life?”*.

Methods

For this study, a qualitative research design was chosen. This served to gain insights into the thoughts, experiences, and opinions of hemodialysis patients regarding the strengths used to self-manage their everyday life. For this purpose, semi-structured interviews were employed to obtain rich and extensive information from the participants.

Participants

The sample population consisted of ten participants with mixed gender ($f = 4$, $m = 6$). Their age ranged from 36 to 68 years of age ($M = 54.4$, $SD = 10.92$). All participants were German and resided in and around Münster (North Rhine-Westphalia). Eight participants were retired from their jobs whereas only two of them still worked part-time.

Procedure

Because this research project involved human participants, a request for ethical approval was sent to the Ethics Committee of the Faculty of Behavioural, Management, and Social Sciences at the University of Twente, Enschede. The request was accepted and approved, and the recruitment of participants was initiated. Participants were recruited through convenience sampling at a local kidney office in Münster, Germany. Together with a kidney doctor at that office, the researcher approached several hemodialysis patients. After getting to know each other, the aim of the study was briefly explained and a short introductory letter (appendix I) was handed out. Every patient immediately agreed to voluntarily participate in the research project and contact information was exchanged. No material incentives were provided although a copy of the final version of this report was offered to everyone. Recruitment stopped as soon as ten participants confirmed to participate. Inclusion criteria for this study were: (1) an age of 18 and above; (2) voluntary participation; and (3) receiving hemodialysis as a treatment form. Participants were recruited regardless of their type of kidney disease because the study was designed to investigate which strengths hemodialysis patients use to self-manage the impact of their dialysis treatment on their everyday life. No exclusion criteria were identified. As a next step, the researcher contacted every participant individually via telephone to arrange an appointment for the interview. The interviews were

conducted via telephone because personal contact was not allowed at that point due to governmental regulations. Originally, face-to-face interviews were scheduled. Since the interviews were held at a distance, the informed consent form (appendix II) was handed out to the participants before the appointments via the kidney doctor at the office. At the beginning of the interviews, the participants were asked for questions, concerns, or if they wanted to withdraw from the study. Informed consent was otherwise checked verbally once more, and it was ensured that participants also signed the written consent form ahead of the interviews. Then, the interviews were conducted to discover which strengths hemodialysis patients use to self-manage the impact of their dialysis treatment in their everyday life. The duration of the interviews was between 30 to 60 minutes and they were recorded with a mobile phone. When all interviews were finished, the audio recordings were transcribed verbatim in German. Based on these transcriptions, a coding scheme was developed and applied to all interview transcriptions to generate the final results.

Interview

The interviews were semi-structured. To allow for a similar starting point, an interview scheme (appendix III) was created and applied to every interview with the participants. It served as a guideline for the interview and consisted of both explanatory parts and questions. The explanatory parts were supposed to facilitate the interview for the participants. They served to provide additional information about the aim of the study and the procedure of the interview and allowed for transitions between sets of questions regarding the topics of interest. The first set of questions aimed to get to know the participants and they were invited to introduce themselves as a person, to provide information about the background of their disease, and to explain what led to their dialysis treatment. Example questions were: *“What can you tell me about your current situation?”* or *“How did you respond when first learning about the need for dialysis treatment?”*. The second part concerned the self-management of the participants and investigated how they self-manage the impact and the consequences of the dialysis treatment in their everyday life. Questions such as *“What areas of your life are most affected?”*, *“What strategies help you to deal with the consequences?”*, or *“What aspects, factors, or persons are important for you to deal with dialysis?”* were asked to reveal additional information about the participants’ thoughts and experiences regarding their self-management of the dialysis treatment. The last set of questions focused on the topic of strengths. Particularly, it was explored which strengths participants use to self-manage

their dialysis treatment and why these strengths would facilitate their ability to self-manage the impact of their treatment. To gain insight into this topic, the researcher once more defined the term ‘strengths’ to the participants. Based on this, the participants were asked to think-aloud about which strengths they perceive to be helpful for their self-management. When they came up with a particular strength, follow-up questions were asked such as “*Which aspects of this strength are important for your self-management?*”, or “*Can you explain why this strength is useful for your self-management?*”. Whenever participants perceived the concept of strengths as being too difficult to understand, a list of strengths was used to facilitate generating insights (appendix IV).

Data analysis

After finalizing the interviews, the audio recordings were transcribed verbatim with the help of Microsoft Word. While interviewing and transcribing, initial notes were made to identify similarities in participants’ responses and to get a grasp of which themes were mentioned. The analysis was conducted with an inductive type of coding in which codes were obtained by iteratively working through the transcriptions. At first, all transcriptions were read over once. Then, the content was more thoroughly analyzed by working through every single transcription to create initial codes. 29 codes were found during the initial phase of content analysis. They were obtained by marking quotations in the transcriptions. For every quotation it was indicated whether they belonged to the category of self-management strategies or strengths to allow for a better focus while selecting and allocating new quotations. By doing so, every new quotation related to one of the categories was either added to an existing code or a new code was created. After finishing this step, the 29 initial codes were reviewed. Codes with similar content were combined to create groups of codes. For instance, the group of codes “being positive” is a combination of the initial codes “being friendly”, “thinking positive”, “having humor”, and “being joyful”. Allocating every single initial code to a group of codes resulted in having 14 codes constituting a preliminary coding scheme. In the end, the transcriptions were once more scanned with the preliminary coding scheme and it was checked whether these codes were consistent with the content of the transcriptions or whether new topics were found. However, no new findings did arise from this review and therefore the 14 codes were approved (appendix V). Based on the categories that were checked for during the interview and to relate the codes to the research question, they were divided into three categories: self-management strategies (5), internal strengths (7), and external strengths (2).

Results

After analyzing the ten interviews, 14 different codes were found to be relevant to answer the research question “Which strengths do hemodialysis patients use to self-manage their everyday life?”. These codes are related to the categories of self-management strategies (5), internal strengths (7), and external strengths (2). Due to the reason that some themes were more important to the respondents, they are described and listed according to their priority and frequency. The following tables 1, 2, and 3 display the identified codes and highlight a description, the frequency, and quotations to exemplify the content of the codes.

Self-management strategies

Five self-management strategies were identified during the analysis of the interviews (table 1). These strategies concerned the ability of the patients to self-manage their dialysis treatment in their everyday life and helped them to better cope with their daily challenges, duties and responsibilities. Namely, these self-management strategies are 1) “dealing with dialysis”, 2) “being active”, 3) “planning & organizing”, 4) “social comparison”, and 5) “protecting oneself”. Some of these strategies helped the respondents to better organize their daily life and to integrate the dialysis treatment into it. Others served to maintain a satisfactory level of quality of life so that respondents perceived their lives worth living despite the impact of the dialysis treatment on their everyday life.

The most frequently mentioned self-management strategy was labeled “dealing with dialysis” and it concerns all relevant aspects of their dialysis treatment (n=9). For instance, respondents mentioned to know about the importance of adhering to treatment regulations (e.g. dieting). Nevertheless, some respondents explained to suspend dietary regulations quite frequently. Granting themselves to make exceptions reportedly increased their emotional and psychological well-being and life satisfaction. In contrast to this, respondents diligently attended dialysis sessions. Almost all respondents described taking extra hours at dialysis (> 4 hours) as helpful to sustain higher levels of physical well-being. Some respondents mentioned to better understand the purpose and value of their dialysis treatment by acquiring knowledge and learning about dialysis in general. Others argued that having routine for their dialysis treatment facilitated adjusting their lifestyle (e.g. knowledge about procedures, regularity of dialysis sessions).

“Being active” was described as a self-management strategy to maintain normality (n=8). It included the engagement in activities leading to feelings of achievement and accomplishment beyond the impact of their dialysis treatment. Some respondents mentioned that staying physically active, exercising or simply being outside was helpful. Others explained that being able to do housekeeping, go working or helping others increased their self-worth and increased their psychological and emotional well-being. Furthermore, activities such as engaging in hobbies or traveling were referred to as relieving stress and distracting themselves from thoughts about their dialysis treatment.

Another self-management strategy that helped respondents to self-manage their everyday life was “planning & organizing” (n=8). This strategy is essentially about scheduling dialysis sessions and combining the time spent at dialysis with the private life. Relevant aspects mentioned by the respondents are planning to travel (e.g. knowing where dialysis can be done), getting along with other duties (e.g. work), or coordinating the circumstances of their dialysis treatment with their caretakers. Successfully applying this strategy was reported to lead to more time for pleasurable activities and social contacts which resulted in more effective recovery during leisure time.

Seven respondents described to frequently compare themselves with others to re-assess the severity of their own situation. Visualizing that others’ situations may be worse (e.g. having cancer) helped them to evaluate their own situation more positively. By doing so, they realized to at least have the opportunity to receive a form of treatment allowing for longer survival. The similarity to other dialysis patients and learning about their situation create a feeling of communality. Fellowship with other dialysis patients, exchanging feelings, worries or fears, or simply talking to others alleviated the burden to self-manage one’s own dialysis treatment. This reduced the feeling of being alone and respondents felt understood due to the similar situation.

The last self-management strategy employed by respondents was “protecting oneself” (n=6). It served to distance and protect oneself from matters and aspects of the dialysis treatment. For instance, some respondents occasionally rejected being ill and concealed their illness to other people. This helped to suppress true feelings or thoughts about their illness and the dialysis treatment. It was described as a form of coping with their situation because not showing their illness made it appear less salient and severe to respondents. Others explained that ignoring, forgetting, or masking their situation with humor relieved some of their burden.

Table 1*Self-management strategies*

Self-Management Strategies	Description	Frequency (n)	Quotations
Dealing with dialysis	Adhering to treatment regulations (e.g. drinking/eating, attendance); taking extra dialysis hours; learning about dialysis; adjusting lifestyle; having routine	9	R1: "I just do it [extra hours] and there is a saying: dialysis time is lifetime." R7: "I always have to be aware of dialysis appointments and private appointments and how I arrange it all. How do I have to change my personal behavior, also regarding drink intake so that I maybe can have a break that is one day longer."
Being active	Staying physically active, exercising; engaging in hobbies; being outside; doing household; helping others; working; traveling	8	R6: "For me it is important to also do something for other people (...) that encourages me to believe that I have achieved something in spite of the dialysis and that gives me a good feeling" R9: "I do everything on my own regarding craftsmanship, when something needs to be constructed (...) I cannot just sit there and do nothing all day, I always need to be active and do something."
Planning & Organizing	Scheduling dialysis sessions; coordination with relatives; planning traveling; getting along with duties (e.g. work); combining dialysis time with private life	8	R1: "There is little time left when I do dialysis for four and a half hours and I then decided to swap my sessions to the afternoon because I am more able to do something in the household in the morning than in the afternoon." R5: "When I book a journey, I always have to ensure that there is a possibility for dialysis or where can I do it. That's not always possible and we cannot travel anywhere we like."
Social Comparison	Comparing own situation with others; visualizing that others situation can be worse; "re-framing" their own situation, assessing it more positively; similarity to other dialysis patients; learning about their situation	7	R7: "There are also other persons here that have a disease they will die from. I do not have to deal with that in my situation and I personally regard their situation as more dramatic and then I think, they are worse off than me." R3: "Sometimes you just think it's trivial when someone is making a scene because they hurt their arm (...)."
Protecting oneself	Distancing from dialysis aspects; rejecting being ill; not telling/showing others about illness; suppressing true feelings & facts; ignoring illness;	6	R1: What is important to me is that it [illness, dialysis] is not visible for others. That would be very hard for me." R7: "So, I bury that and swallow it down and I do not allow that. That is a strategy that works well now and maybe someday it will all come to the surface and it will not work anymore, but for the moment this works very well for me."

Internal Strengths

Internal strengths represent respondents' individual characteristics that facilitate the self-management of their dialysis treatment in their everyday life (table 2). Most of the strengths identified during the interviews were ascribed to be internal strengths. Namely, these are 1) "being persistent", 2) "ability to accept", 3) "being appreciative", 4) "hope", 5) "being positive", 6) "trusting oneself", and 7) "faith".

The first internal strength, "being persistent", is multi-faceted and was described in terms of courage, perseverance, discipline, and persistence. All respondents mentioned to use this strength for their self-management ($n=10$). Respondents oftentimes described receiving a dialysis treatment as a burden for their lives and complained about numerous constraints. They specified to be brave, tireless, and constantly fighting the challenge that was imposed to them. This was essential for them to overcome difficult episodes in their lives. For instance, being courageous helped them to stay strong and positive for oneself and beloved others despite their treatment situation. Discipline served to increase treatment adherence and medication intake. Respondents explained to be perseverant by taking extra hours at dialysis which benefits their physical well-being and health outcomes. Lastly, respondents stated to be confronted to oblige to treatment regulations almost every day which is difficult to handle. However, being persistent helped to withstand thoughts of regret about their current situation and to endure arduous episodes in the everyday self-management of their dialysis treatment.

Next, the "ability to accept" was another internal strength that was mentioned by every respondent ($n=10$). To a certain degree, this strength relates to "being persistent" because it also helped to overcome difficult life episodes by accepting their dialysis treatment as a necessity. In other words, they accepted the impact of the dialysis treatment as a part of their life and they accepted to be dependent on it to survive. Respondents realized to at least receive help through their dialysis treatment, although alternative forms of treatment are unavailable (except transplantation). They mentioned to regard their treatment as an opportunity to stay alive rather than a curse. The awareness that their health situation is mostly unchangeable led respondents to accept their dialysis treatment as a given instead of complaining or grieving about it. The acceptance of their situation improved arranging important life matters with more ease and balanced their own ambitions and life goals to merge with the requirements of their dialysis treatment.

Nevertheless, respondents also displayed the ability for “being appreciative” (n=10). This strength mainly concerns thankfulness and gratitude regarding the technical advances and the possibility of a treatment allowing for prolonged survival. Respondents increasingly appreciate and acknowledge positive aspects of life due to their situation (e.g. friends, environmental support, nature, etc.). Furthermore, they appreciate a certain degree of well-being and reported to more consciously enjoy living in general.

Nine respondents declared to use “hope” for their everyday self-management. Their hope was mostly directed towards receiving a healthy transplant organ and leaving the dialysis treatment after a successful transplantation. This aspect was oftentimes combined with the hope to retrieve normality for their lives and to experience less complications. Some respondents desired to re-establish life conditions equal to those before the start of their dialysis treatment such as recovering physical capabilities, going back to work or being able to travel. Respondents tried to remain optimistic by hoping for the best to happen and to hope to their dialysis treatment to end one day when eventually receiving a transplant organ. However, they knew the chances are low because transplant organs are rare. After all, the hope for longevity was regularly mentioned.

Another internal strength was “being positive” (n=8). It entails being friendly or having humor as well as maintaining a positive attitude. Occasionally, this helped the respondents to overcome their burden and to suppress their psychological and emotional strain to a certain extent. More often they reported to make the “best out of a bad situation”. Respondents explained that the engagement in regular activities, enjoying pleasure time with friends and families, or not being too serious to oneself were helpful to self-manage the dialysis treatment in their everyday life.

The next internal strength is labeled “trusting oneself” which resembles the belief in oneself and one's abilities (n=6). This strength represents the belief in oneself to master the situation and not giving up on themselves. Furthermore, respondents regarded being honest to oneself, being self-determined and self-confident as important to cope with their situation in their everyday life. Trusting oneself helped to bravely face challenges and it raised awareness of other capabilities such as persistence and perseverance.

The least frequently mentioned internal strengths is “faith” (n=4). Being faithful and trusting in God was described as being supportive in difficult times. Engaging in activities such as praying helped to relieve pressure, stress, and to emit responsibility. Also, respondents expressed

their belief about being held, carried, guided or watched at by something or someone superior as a great source of support and relief to their situation.

Table 2

Internal Strengths

Internal Strengths	Description	Frequency (n)	Quotations
Being persistent	Being disciplined; being brave; being organized; not giving up; fighting the challenge; carrying on with life; dealing with the situation & circumstances; to overcome difficult episodes in life	10	R1: "(...) that I stand up every day again and still go to dialysis and that I keep my head up and still be joyful." R8: "Certain things that probably count as a resource that I have to fight and to never give up and to make the best out of the situation."
Ability to accept	Accepting the circumstances and the impact of dialysis; taking the challenge; there are not alternatives; accept dialysis as part of everyday life; the opportunity must be taken; nothing can be changed	10	R9: "You simply have to live with it, and you can do nothing about it. It is not possible to live without dialysis and I cannot decide to skip sessions for two weeks, that is just not possible because I am dependent on the treatment." R10: "I try not to see it as a punishment and try to accept it as something that helps me live longer and that keeps me alive. I do not moan about my situation but accept the things as they are and live with it."
Being appreciative	Thankful for the technical advances; appreciating & acknowledging positive aspects (e.g. friends, environmental support); appreciating well-being; enjoying living	10	R1: "I am thankful that we have dialysis machines because 60 years ago it was different. That is why I am thankful and there is always something worse and I am feeling quite well and that's why I am thankful." R3: "There is always something new that you can see or there are moments when something beautiful happens."
Hope	Hope to receive a transplant organ and that it works; hope for a non-complicated life; to retrieve normality; for longevity	9	R5: "When maybe one day there is a new kidney, then it will be possible again to also do a bigger journey, for instance to Canada, and that is what I am looking forward." R10: „I obviously hope to receive a transplantation. Hope dies last, however, the situation is critical to receive a transplant organ."

Table 2. Continued

Internal Strengths	Definition	Frequency (n)	Quotations
Being positive	Being friendly; having humor; thinking positive; not being too serious to oneself	8	<p>R3: “As long as I find something to laugh about there is still hope for me because when there was no joy at all that would be awful.”</p> <p>R6: “With humor and when someone is joyful, I also become joyful again and am able to forget about some thoughts that I sometimes have.”</p> <p>R8: The joy of life that I have despite the dialysis, that encourages me because I want to live and I want to make the best out of this situation that I am in and I still can celebrate and do such things and I do not lock myself into my house.”</p>
Trusting oneself	Being honest to oneself; being self-determined; believing in oneself to master the situation; not giving up	6	<p>R1: “Self-confidence, that I am able to carry it off. When you are ill, you first notice which strengths you possess, and I do not let myself down.”</p> <p>R7: “When there is a situation then it needs to be resolved and no one else can do it because there is no one else, it’s only me that can resolve it and it simply needs to be done.”</p>
Faith	Trust in God; support in difficult times; praying; beliefs about being held, carried, guided or watched at;	4	<p>R5: “But this deep trust, so that I know it will not go lower than in Gods hands and that I will be carried and picked up, that is always present for me.”</p> <p>R8: “When I have a problem or a situation, then I include these into my prayers and when I spoke about them, then I feel relief and it feels easier.”</p>

External Strengths

External strengths are defined as properties from the environment of the respondents that facilitate the daily coping with the dialysis treatment (table 3). Two external strengths were mentioned by the respondents: 1) their “personal environment” and 2) their “medical environment”.

The “personal environment” was the most important and most frequently mentioned strengths in this study overall (n=10). In total, it has been mentioned 61 times in ten interviews. Receiving support from their families, relatives, or friends was regarded as essential for the respondents to self-manage their dialysis treatment in their everyday life. It was explained that supportive others managed a wide range of practical issues for the respondents such as a driving service, shopping, or housekeeping in general. Due to these facilitative services, respondents had

more time to recover from their dialysis sessions. Furthermore, respondents experience benefits through the emotional and mental support from their personal environment. They described to feel understood, encouraged, and energized by the sympathetic support from their families, friends, or relatives. Being treated as a normal person without emphasizing their illness or dialysis treatment increased respondents' self-worth. Perceiving that life is worth living for the purpose of oneself and beloved others and experiencing their condolence encouraged respondents to cope with the burden of their dialysis treatment with more ease. Lastly, respondents valued the engagement in social activities with their personal environment. Sharing laughter, memories, and engaging in leisure time activities was explained to create pleasurable feelings and a positive atmosphere. Thus, respondents could temporarily escape the worries about their illness and the implications of their dialysis treatment. Taken together, respondents emphasized that their personal environment made them feel valued, trusted, taken care of, and treated as normal persons which enhanced their psychological and emotional well-being and their self-worth.

The other external strength constituted the “medical environment” (n=7). Respondents described that a good relationship to the doctors and nursing staff is important. They explained that receiving medical information and emotional support by the medical staff is helping them to better assimilate to regularly being dialyzed. Furthermore, having a routine for their dialysis treatment is perceived to be as important as a homelike feeling and being treated respectfully. Trusting the medical staff in their advice-giving, decision-making and their treatment management helped respondents to at least emit their medical responsibilities.

Table 3*External Strengths*

External Strengths	Description	Frequency (n)	Quotations
Personal Environment	Family support; supportive relatives; supportive friends; engagement in social activities; emotional back-up & support; trust; caretaking; employer support; understanding & empathic; having someone to rely on; source of energy; being treated as a normal person, not as someone with an illness; sharing laughter and memories	9	<p>R5: “Because I have an employer that treated me very well and loyal from the beginning on and did not impose obstacles on me. My family does also deal with my situation very well because they do not allow to be restricted by the implications of my dialysis treatment.”</p> <p>R8: “I am happy to have such a great environment, my friend, my parents that are very helpful. My friends never give me the feeling to be ill but instead treat me like a normal person and I think that also helps me live better.”</p>
Medical Environment	Relationship to doctors & nursing staff; having routine for dialysis; homelike feeling; medical information & emotional support; being treated respectfully;	7	<p>R1: “I need to come here three times a week and they are all very friendly and it feels like my second home and I think that the people really make a difference.”</p> <p>R4: “The staff and the doctors, there are no difficulties and that is very important for me that I know when I go there, I can feel very well and that is assured.”</p> <p>R7: “Then we have the doctors that I come along with very well, to have a good conversation which is also important. Then I get the feeling that they also take their time for me as a patient which does not come naturally these days.”</p>

To conclude the results, it was apparent that respondents relied on internal and external strengths to self-manage the impact of the dialysis treatment on their everyday life. Most often, respondents referred to their personal environment as a source of support. However, it was noticeable that respondents rather engaged in positive thoughts and attitudes instead of surrendering to the burden of their dialysis treatment. This facilitated their engagement in self-management activities to alleviate the strain put on their everyday lives.

Discussion

The objective of this study was to investigate which strengths kidney patients use to self-manage the impact of their dialysis treatment on their everyday life. It was found that every respondent could identify several self-management strategies as well as a range of internal and external strengths that they apply to cope with their daily life. Some respondents have developed unique mechanisms for their everyday self-management, but similarities among the responses were more apparent.

The findings of this study suggest that respondent's self-management strategies largely focus on practical issues facilitating the integration of the dialysis treatment into their everyday lives. Respondents emphasized the importance to arrange dealing with their dialysis treatment and the necessity to plan and organize their lifestyle. The self-management of their treatment regimen (e.g. dialysis attendance) or the acquisition of relevant knowledge were perceived to be essential to incorporate their dialysis treatment into their daily life. Previous research with chronic kidney patients has shown that acquiring disease-specific knowledge leads to better health-related outcomes (Narva et al., 2016) and lower rates of hospitalization and mortality (Haris & Polner, 2018). Being educated about their disease yields higher participation in activities such as preventing unhealthy dietary habits (Haris & Polner, 2018; Roscosz et al. 2019; Wild et al., 2017), improved blood pressure control, or engaging in care decisions and planning (Narva et al., 2016). This links to another self-management strategy centering around the coordination of dialysis sessions with respondent's private life. Commitments to plan and organize their weekly schedule yielded the opportunity to obtain some degree of regularity and normality for their lives. Due to complex treatment regimens, kidney patients are required to plan ahead and establish routines such as regular medication intake (Havas et al., 2016, Wild et al., 2017). Both of these self-management strategies reportedly improved respondent's life satisfaction through having more time to spend on their own interests or their social environment. This turned out to increase their overall well-being. These findings suggest that especially patients starting a dialysis treatment could benefit from immediately receiving advice to improve coordinating their everyday life.

However, respondent's self-management strategies also evolved around improving their emotional, psychological, physical, and social well-being. Engaging in activities with the aim to stay physically and socially active helped them taking care of their physical constitution and gave

meaning to their lives. This increased their physical well-being, self-worth and life satisfaction. When caring about illness needs, optimizing physical activity, exercising, and taking care of one's physical entity was shown to improve health outcomes (Haris & Polner, 2018; Schulman-Green et al., 2012; Wild et al., 2017). The importance of physical engagement became even more apparent due to respondents feeling faint during dialysis sessions and recreation time. Lorig and Holman (2003) confirmed that patient interaction with their social environment is beneficial for their emotional and psychosocial well-being. To this end, research on a Jordanian sample of hemodialysis patients has shown that a positive reappraisal strategy was preferred to cope with stressors caused by their dialysis treatment (Ahman & Al Nazly, 2014; Gurklis & Menke, 1995). This resembles the results of the present study because most respondents frequently contrasted their own situation with others experiences of dealing with a dialysis treatment or another disease. This helped them to re-frame their own situation and to assess it more positively. However, some respondents reported to distance themselves from dialysis aspects by suppressing true feelings and facts to protect themselves from psycho-emotional harm. Others even went as far as ignoring or rejecting their illness. Ahman and Al Nazly (2014) found that hemodialysis patients engaged in distancing behavior to cope with their dialysis-related burden. Both strategies – positive reappraisal and distancing – served to reduce levels of stress and perceived burden. This can be achieved by facilitating motivational and cognitive changes such as reduction of ego involvement or findings alternative channels of gratification (Ahman & Al Nazly, 2014, Lazarus & Folkman, 1984).

A set of internal strengths was discovered during the analysis of the interviews. These served as resources for their psycho-emotional coping and facilitated engaging in self-management strategies. For instance, being persistent empowered respondents to believe in themselves to master their situation better. This not only improved their self-management of treatment related aspects but also served as a psychological buffer to adverse events caused by their dialysis treatment such as physical limitations or thoughts of regret. Respondent's persistence in approaching dialysis implications was beneficial for self-management strategies such as being active or organizing their lives. These findings also relate to trusting oneself and believing in one's abilities to deal with their challenges. Although using different terms, research has shown that high levels of self-efficacy positively influence health-related self-care behavior and improve self-management activities (Li et al., 2014; Lin et al., 2017; Wild et al., 2017). However, persistence has frequently been referred

to as an internal strength used for dealing with chronic illness conditions. Kristjansdottir and colleagues (2018) propose that persistence promotes the engagement in self-management strategies of chronic patients and boosts their resilience (see also Cal et al., 2015; Lee et al., 2013). There is evidence that being resilient leads to less avoidance behavior, more coping with illness-related issues and an increased level of social support (Hatami et al., 2019). Although some respondents reported having difficulties complying to dialysis aspects, the majority was able to use persistence (e.g. overcoming challenging life episodes) to adopt resilient behavioral patterns. This promoted their engagement to self-manage the practical and emotional consequences of the dialysis treatment on their everyday life.

Respondents appeared to generally accept being exposed to their dialysis treatment and its implications. Due to the necessity of receiving dialysis treatment, acceptance explicitly served to relieve stress and some of their emotional burden. Poppe and colleagues (2012) found that acceptance predicted increases in health-related physical and mental quality of life. This facilitated adjusting to the difficulties and impairments of having a chronic kidney disease. In another study, acceptance has been explained to consists of two components: the acknowledgment of negative experiences and the integration of the illness into the everyday routine to restore a sense of living (Chan, 2013). Chan proposes that this so-called “active” form of acceptance may lead to reduced levels of depression, improved adaptive coping and an enhanced quality of life. However, acceptance may also be expressed negatively through resignation, passivity for coping engagement, negative cognitions and affects (Chan, 2013). This conforms to the present findings because respondents experienced their dialysis treatment as being restrictive and described difficulties to engage in active coping (see also Chan et al., 2009). Nevertheless, the majority reported being able to employ an active form of acceptance. Adaptive coping was expressed by regularly engaging in proactive social and physical activities instead of exerting passivity. Also, respondents demonstrated adapting to psycho-emotional constraints by adopting protective behavioral patterns.

This study also revealed that respondents used a range of internal strengths helping them to maintain a positive attitude and positive emotions. Namely, they explained that being appreciative, having hope, or being positive were particularly helpful for their psychological and mental well-being. Induced by their positivity, respondents were able to self-manage their everyday life with a higher degree of joy and appreciation for pleasurable activities and social relationships. Additionally, they were increasingly able to acknowledge positive aspects of their lives. These

findings resonate in the literature. It has been shown that a positive attitude and emotions, optimism, generally taking care of mental well-being as well as increased levels of hope yield positive effects on the self-management ability of dialysis patients (Havas et al., 2016; Kristjansdottir et al., 2018; Rahimipour et al., 2015). These factors may reduce stress, anxiety, and depression symptoms. They even lead to an improved self-care behavior through the engagement in self-management activities, higher patient activation, or collaboration with healthcare providers (Havas et al., 2016; Hibbard & Mahoney, 2010; Rahimipour et al., 2015).

One strength mentioned by only a few respondents was faith. It served to pass some burden on to a superior entity (e.g. God). This appeared to be an emotional and mental support for coping with the implications of their dialysis treatment. Faith seems to empower respondents to carry on with their lives. This conforms to research because for both chronic patients and kidney patients undergoing hemodialysis faith or spirituality served to improve resilience, illness acceptance, and positively impacted their general health and self-management behavior (Unantenne et al., 2013; Valcanti et al., 2012). Unantenne and colleagues (2013) furthermore stated that religious coping may benefit hemodialysis patients by providing comfort, giving meaning and purpose to their lives, and enhancing intimate relationships to God or other persons.

In the literature, evidence has also been found for the supportive nature of both the personal and the medical environment of chronic patients and dialysis patients for their self-management. This largely conforms to the findings of the present study. It was emphasized that different forms of environmental support yield improvements for patient's coping behavior. Most notably, emotional and social support from relatives or friends enhances the general well-being of dialysis patients (Havas et al., 2016; Kristjansdottir et al. (2018); Li et al., 2014). The findings from the present study show that respondents regard their personal environment as a source of energy and trust. They reported to rely on their caretakers and spend pleasurable time with their social contacts. Narva and colleagues (2016) stated that social support leads to improvements for dietary habits and physical activity. This was evident because respondents felt encouraged to engage in social gatherings or to enjoy company whilst being active outside. Additionally, the social environment reinforces the caretaking of their mental health and boosts their self-esteem which leads to increased self-care behaviors in hemodialysis patients (Hatami et al., 2019). In a study conducted by Havas and colleagues (2017), chronic kidney patients mentioned to value emotional and social

support as more important as being excessively informed about disease-related information and facts.

Next to this, the medical environment was found to be a fundamental source of support for respondents as well. They gained knowledge to become familiar with dialysis routines and procedures. This proved to be essential for their decision making in regard to their self-care behavior and treatment adherence (Narva et al., 2016). Respondents also reported improvements for their emotional and social well-being when being treated respectfully and by having a homelike feeling during their dialysis sessions. Establishing effective relationships to medical professionals and members of the healthcare team facilitates the coping of dialysis patients (Havas et al., 2016; White & McDonnell, 2014). For hemodialysis patients this could imply to more confidently claim the consideration of their own needs and wishes for their treatment and to be included proactively in making important decisions. This may positively impact respondent's self-determination and influence their self-management behavior (e.g. adherence, organization).

Strengths and limitations

During the process of this research project, some strengths and limitations were identified. The first strength of this study is that respondents received their dialysis treatment under similar conditions because they were all recruited in the same local kidney office. They used the same dialysis machines, were supervised by the same medical staff receiving the same quality of support, catering, and assistance. This allowed to set a common baseline for this study because confounding variables such as different treatment modalities or practices could be ruled out. As a result, the findings of this study allow for more meaningful results especially for some self-management strategies (e.g. dealing with dialysis). However, there is also a disadvantage to the similar treatment conditions. Due to the sample receiving their dialysis treatment in the same kidney office, the findings on the external strength medical environment could be distorted due to similar experiences respondents had with their medical staff or doctors. Their judgements about the medical environment could therefore conform to a certain degree. For future research it is recommended to recruit participants in multiple locations with similar environments (e.g. same company but different cities). By doing so, the opinions and experiences from other kidney offices will be obtained and generalizing the findings to larger populations might be facilitated.

Another strength is the different level of experience with dialysis treatments for every respondent. Some of them did only receive hemodialysis whilst others already experienced a kidney transplantation or peritoneal dialysis. This was found to be beneficial due to the qualitative design of the study and allowed for extensive and rich responses about respondent's self-management experiences. Future research projects with a qualitative approach on this topic are advised to recruit a largely heterogenous sample regarding variables such as age and gender. By doing so, more extensive insights could be obtained that might compensate for difficulties understanding abstract concepts (e.g. strengths).

However, some respondents reported to have an extensive history of diseases throughout their lives and comorbidities were prevalent. Participants were primarily recruited on the fact that they received hemodialysis and their previous experiences with other diseases could not be controlled for. This limits the findings of this study to a certain degree because this caused some ambiguity in the explanations of some of the respondents. Sometimes, it appeared to be difficult for them to exclusively relate their self-management strategies or strengths to coping with their dialysis treatment and instead they explained that these served to cope with another health-related challenge. For future studies on this research topic it is advisable to control for participants course of disease beforehand to obtain more distinct results.

During the interviews, a list of strengths was used as a supportive tool when respondents perceived the term strengths as being too abstract or difficult to grasp. Applying this list to the interviews via telephone was more complicated than expected. Despite being instructed about the list, respondents were unclear how to use this tool. Definitions were attached to the listed strengths which conversely caused too much steering while working with the list. Consequently, respondents refrained from imposing their own meaning to the strengths and free association was therefore prevented. This led to a loss of potentially valuable insights. Having a list of strengths was still helpful to showcase examples when respondents struggled talking about their own strengths. However, for future research projects, it is recommended to remove the definitions from the list. Only providing labels (e.g. bravery) grants respondents more freedom in their responses and facilitates relating the labels to themselves

It was sometimes also difficult for respondents to relate the concept of strengths to both self-management strategies and their dialysis treatment. Therefore, some responses were kept general which reduced the extent of insight gained. Nevertheless, based on the structure of the

interview scheme, some important aspects about these concepts were mentioned in earlier stages of the interview. The interviewer could draw back on these insights and clarify the relation between self-management strategies, strengths, and the dialysis treatment with the help of participant's own words. The interviewer could also reserve some space to discuss the meaning of the aforementioned concepts first or to provide examples. In any case, the relation between the core concepts and their meaning should be clarified more carefully before going into details.

The last limitation to this study is the fact that – due to governmental regulations – the interviews were conducted via telephone. This complicated the procedure of the interviews to some extent. For instance, while using the list of strengths, effective information provision was hindered by the lack of manually pointing out relevant aspects and to direct respondents in their use of the list. It was noticeable that using the list could be facilitated when conducting the interviews face-to-face. This constraint caused a loss of potential information and it could otherwise have been avoided. Additionally, most respondents preferred to be interviewed during their dialysis sessions while being in an open room with other patients at the kidney office. This caused considerable background noises as well as occasional interruptions by the medical staff (e.g. measuring blood pressure). Also, some respondents disliked being interviewed via telephone but liberally still agreed to participate. This all amounts to a limitation for the present study because more comprehensive insights could be generated by interviewing respondents face-to-face in a separate room and without disturbances. It is assumed that participants might disclose themselves more when being in front of their interviewer.

Conclusion

This study generated valuable insights into the health-related self-care behavior of hemodialysis patients. It highlighted the importance of using both internal and external strengths to facilitate everyday self-management activities. Respondents emphasized that receiving social support, persisting and accepting treatment implications as well as maintaining a positive attitude stood out most.

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Appendices

Appendix I: Introductory letter

Participants wanted for bachelor thesis!

My name is Sebastian Stewing and I am a psychology student at the University of Twente in Enschede.

Due to the reason that I have a chronic kidney disease, I am interested to know how other patients cope with their illness.

Within the scope of my bachelor thesis, I commit myself to investigate which strengths hemodialysis patients use to cope with their everyday life.

Therefore, I need participants who:

- Receive hemodialysis as their treatment (regardless of their age)
- Are willing to be interviewed for max. 1 hour
- For the time between 16th March and 19th April 2020

I would appreciate when you support my work; and I am flexible when arranging appointments

Just in case you have any question, feel free to contact me:

Appendix II: Informed Consent Form

Informed Consent Form

Which strengths do hemodialysis patients use to self-manage their everyday life?

Thank you for participating in my study! This is a research project conducted by Sebastian Stewing, a bachelor student in the psychology program of the University of Twente, Enschede. I invite you to participate in this study to investigate which strengths kidney patients use to self-manage the impact and the consequences of their dialysis treatment in their everyday life.

You will participate in an interview that will take between 30 and 60 minutes. At first, you will be asked some general questions about your previous experiences with both your kidney disease and the dialysis treatment. Building on that, we will elaborate on how you self-manage the impact of the dialysis treatment in your daily life and which strengths you use to handle the influences of your current health situation. Hereby, the focus will be on the strengths that you use which - for our purpose - can be defined as your personal, individual qualities and resources or properties in your environment that help and facilitate your coping with the dialysis treatment. To provide you with a brief outlook, I will ask you questions such as “In which way/how do you deal with the consequences of dialysis?” or “Which strengths do you use to self-manage your dialysis treatment?”.

During the interview, audio recordings will be made which serve as a data collection tool for the researcher to access the information gathered at a later point in time. However, these audio recordings will contain sensitive, personal information that will only be accessed by the researcher. The audio recordings will be transcribed as soon as possible after the interviews and your personal identifiable information will be anonymized. Nevertheless, fragments of information (e.g. quotes) from the interviews will be used as proof of evidence in the research report. In this case, it will be ensured that the anonymized data will be treated confidentially, and that the information cannot be traced back to you as the participant. The audio recordings will be saved by the researcher for the duration of the research project and will immediately be deleted after they have been transcribed into written, anonymized form.

Your participation in this research study is completely voluntary. You may choose not to take part in the research at all. When you engage in the research study, you may decide to withdraw from it at any given time without giving a reason for it. When you feel uncomfortable to answer questions, you can refuse to respond without giving a reason. You will not be penalized in any form when withdrawing from the study.

When you decide to withdraw from the study, you have questions, comments, complaints, or concerns, you may always contact the primary researcher:

Sebastian Stewing

When you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher, please contact the Secretary of the Ethics Committee of the Faculty of Behavioural, Management and Social Sciences at the University of Twente:

ethicscommittee-bms@utwente.nl

Statement of Consent

This research project has been reviewed and approved by the Ethics Committee of the Faculty of Behavioural, Management and Social Sciences at the University of Twente, Enschede.

With your signature, you give consent to the information stated above and to the following points. You receive a copy of the signed informed consent form:

- You are at least 18 years old
- You have read and understood the study information, or it has been read to you. You have been able to ask questions about the study and your questions have been answered to your satisfaction

- Your participation in this study is voluntary and you have been informed to refuse answering questions or withdrawing from the study at any time without having to give a reason
- You understand that taking part in this study involves an audio recording of the interview, the transcription of the audio recordings, and the use of anonymized quotes in the research report that cannot be traced back to you.
- You understand that the information you provide will be used for the undergraduate research project titled “Which strengths do kidney patients use to self-manage their dialysis treatment?” only and merely the researcher and supervisors of the research project will have insight into sensitive, personal information.
- You understand that the personal information collected that might identify you as a person (e.g. name, place of residence) will not be accessible to anyone other than the researcher.
- You give permission for the audio recordings and transcriptions that you provide to be archived by the researcher for the data collection of this research project. The audio recordings will be deleted as soon as they have been transcribed. Only the anonymized transcriptions will be saved.
- You have the right to request access to, and rectification or erasure of personal data.
- You have read and understood the points and statements of this form
- You have been given a copy of this informed consent form signed by the researcher.

To be signed by the **participant:**

Name of participant

Signature

Date

To be signed by the **researcher:**

Name of researcher

Signature

Date

Appendix III: Interview Scheme

Interview Scheme - Hemodialysis Patients

Hi, my name is Sebastian and I will be asking you questions about your thoughts, experiences, and opinions about the strengths that you use to cope with the dialysis treatment. For the purpose of this interview, the term ‘strengths’ will be defined as, for instance, your personal, individual qualities and resources or properties in your environment that help and facilitate the coping with the dialysis treatment. More specifically, I will investigate how these strengths contribute to your self-management and your ability to cope with the consequences of the dialysis treatment in your everyday life.

During this interview, you can withdraw from it at any time without giving any reason. We can take breaks whenever you like. Also, you do not have to respond to a question that makes you feel uncomfortable in any way. To listen back to the interview later, I would like to make an audio recording during the interview.

If you feel comfortable to begin with the interview, I will also start the audio recording now.

To begin with, I would like to invite you to **introduce yourself**.

Some probes:

- What can you tell me about your current situation?
 - What is your name?
 - How old are you?
 - What is your family status?
 - What is your employment status?

 - What kind of illness are you affected by?

- For how long are you receiving a dialysis treatment?
- How did you respond when first learning about the need for dialysis treatment?

Thank you for introducing yourself. I would now like to ask you some questions about your **coping with the impact and the consequences** of the dialysis treatment in your everyday life.

- What areas of your life are most affected?
 - How does it impact your everyday life?
 - Can you tell me more about the consequences?
- In which way/how do you deal with the consequences of dialysis?
 - What do you find easy?
 - What do you find difficult?
- Can you describe how you currently manage the consequences of dialysis?
 - What have you tried so far to manage these?
 - What is important for you in managing these?
 - How often do you think about dialysis?
 - Can you give an example?
- What strategies help you to deal with the consequences?
- What aspects/factors are important for you to deal with dialysis?
- What/who is helpful for you?
 - Can you give an example?
 - How does this help you?
- What would you need to deal well with dialysis?

We now talked about your experiences with the self-management of the consequences regarding your dialysis treatment. Thank you for your insight and thoughts so far! I would now like to switch the focus to the topic of **‘strengths’**. Strengths can also be useful for the self-management of the dialysis treatment in your everyday life. I would like to explore this topic together with you. As mentioned earlier, ‘strengths’ are those things that help you to better self-manage the consequences of the dialysis treatment on your everyday life. Due to the reason that the term

strengths is quite abstract, I brought a list with a range of strengths that I would like you to have a look on.

- Which strength do you recognize that you use to self-manage the dialysis treatment?
 - Which aspects of this strength are important for your self-management?
 - Can you give me an example of a situation in which you use this strength?
 - Can you explain why this strength is useful for your self-management?
 - In what way/to what extent did you experience difficulties to apply this strength for your self-management?
 - To what extent did the use/importance of this strength for your self-management change over time?
 - Can you tell me why?

- These questions can be applied to every strength that arises during the inspection of the strengths list –

Summarizing questions:

- Can you label five strengths that you use the most? (*if many were mentioned*)
- What strengths could you imagine to use for your self-management in the future?
 - Can you give a reason why this/these strengths may be useful for your self-management?
 - What would you need for this/these strengths to be useful for your self-management?

Possible other questions:

- Which strengths did you use to:
 - Familiarize yourself with the consequences of dialysis?
 - Adapt your lifestyle to the impact of dialysis?
 - Establish a relationship to your dialysis treatment?

Appendix IV: List of strengths

This list serves as a supportive tool in case that you perceive the concept of strengths as being too abstract or difficult to understand. During the interview we might eventually come back to this list to facilitate talking about the strengths that you use for the self-management of your dialysis treatment in your everyday life. Please have this list available next to you during the interview.

Wisdom: strengths that help you gather and use knowledge

- *Creativity* [originality, ingenuity]: Thinking of novel and productive ways to do things; includes artistic achievement but is not limited to it.
- *Curiosity* [interest, novelty-seeking, openness to experience]: Taking an interest in all of ongoing experience; finding all subjects and topics fascinating; exploring and discovering
- *Judgment* [open-mindedness, critical thinking]: Thinking things through and examining them from all sides; not jumping to conclusions; being able to change one's mind in light of evidence; weighing all evidence fairly.
- *Love of learning*: Mastering new skills, topics, and bodies of knowledge, whether on one's own or formally; obviously related to the strength of curiosity but goes beyond it to describe the tendency to add systematically to what one knows
- *Perspective* [wisdom]: Being able to provide wise counsel to others; having ways of looking at the world that make sense to oneself and to other people.

Courage: strengths that help you exercise your will and face

- *Bravery* [valor]: Not shrinking from threat, challenge, difficulty, or pain; speaking up for what is right even if there is opposition; acting on convictions even if unpopular; includes physical bravery but is not limited to it
- *Persistence* [perseverance, industriousness]: Finishing what one starts; persisting in a course of action in spite of obstacles; “getting it out the door”; taking pleasure in completing tasks
- *Integrity* [authenticity, honesty]: Speaking the truth but more broadly presenting oneself in a genuine way; being without pretense; taking responsibility for one's feelings and actions
- *Zest* [vitality, enthusiasm, vigor, energy]: Approaching life with excitement and energy; not doing things halfway or halfheartedly; living life as an adventure; feeling alive and activated.

Humanity: strengths that manifest in caring relationships with others. These strengths are interpersonal and are mostly relevant in one-on-one relationships

- *Love*: Valuing close relations with others, in particular those in which sharing and caring are reciprocated; being close to people.
- *Kindness* [generosity, nurturance, care, compassion, altruistic love, “niceness”]: Doing favors and good deeds for others; helping them; taking care of them.
- *Social intelligence* [emotional intelligence, personal intelligence]: Being aware of the motives and feelings of other people and oneself; knowing what to do to fit in to different social situations; knowing what makes other people tick.

Justice: strengths that help you connect in community or group-based situations

- *Citizenship* [social responsibility, loyalty, teamwork]: Working well as a member of a group or team; being loyal to the group; doing one's share.
- *Fairness*: Treating all people the same according to notions of fairness and justice; not letting personal feelings bias decisions about others; giving everyone a fair chance.
- *Leadership*: Encouraging a group of which one is a member to get things done and at the same time maintaining good relations within the group; organizing group activities and seeing that they happen.

Temperance: strengths that help you manage habits and protect against excess

- Forgiveness and mercy: Forgiving those who have done wrong; giving people a second chance; not being vengeful.
- Modesty and humility: Letting one's accomplishments speak for themselves; not seeking the spotlight; not regarding oneself as more special than one is.
- Prudence: Being careful about one's choices; not taking undue risks; not saying or doing things that might later be regretted.
- Self-regulation [self-control]: Regulating what one feels and does; being disciplined; controlling one's appetites and emotions.

Transcendence: strengths that help you connect to the larger universe and provide meaning.

- Appreciation of beauty and excellence [awe, wonder, elevation]: Noticing and appreciating beauty, excellence, and/or skilled performance in all domains of life, from nature to art to mathematics to science to everyday experience
- Gratitude: Being aware of and thankful for the good things that happen; taking time to express thanks.
- Hope [optimism, future-mindedness, future orientation]: Expecting the best in the future and working to achieve it; believing that a good future is something that can be brought about
- Humor [playfulness]: Liking to laugh and tease; bringing smiles to other people; seeing the light side; making (not necessarily telling) jokes
- Spirituality [religiousness, faith, purpose]: Having coherent beliefs about the higher purpose and meaning of the universe; knowing where one fits within the larger scheme; having beliefs about the meaning of life that shape conduct and provide comfort.

Notes:

- (1) This list of strengths originates in the 24 character strengths as used in the VIA survey. These descriptions were taken from:

Park, N., Peterson, C., & Seligman, M. E. P. (2004). Strengths of Character and Well-Being. *Journal of Social and Clinical Psychology*, 23(5), 603–619. <https://doi.org/10.1521/jscp.23.5.603.50748>

- (2) During the interview, a German translation of the 24 character strengths was used. This translation was retrieved from:

<https://developmenthub.eu/development-tools-3/fae/be/via/>

Appendix V: Final coding scheme

Code	Description	Quotations
<i>Dealing with dialysis</i>	Adhering to treatment regulations (e.g. drinking/eating, attendance); taking extra dialysis hours; learning about dialysis; adjusting lifestyle; having routine	R1: "I just do it [extra hours] and there is a saying: dialysis time is lifetime." R7: "I always have to be aware of dialysis appointments and private appointments and how I arrange it all. How do I have to change my personal behavior, also regarding drink intake so that I maybe can have a break that is one day longer."
<i>Planning & Organizing</i>	Staying physically active, exercising; engaging in hobbies; being outside; doing household; helping others; working; traveling	R6: "For me it is important to also do something for other people (...) that encourages me to believe that I have achieved something in spite of the dialysis and that gives me a good feeling"
<i>Being active</i>	Scheduling dialysis sessions; coordination with relatives; planning traveling; getting along with duties (e.g. work); combining dialysis time with private life	R9: "I do everything on my own regarding craftsmanship, when something needs to be constructed (...) I cannot just sit there and do nothing all day, I always need to be active and do something." R1: "There is little time left when I do dialysis for four and a half hours and I then decided to swap my sessions to the afternoon because I am more able to do something in the household in the morning than in the afternoon."
<i>Social comparison</i>	Comparing own situation with others; visualizing that others situation can be worse; "re-framing" their own situation, assessing it more positively; similarity to other dialysis patients, learning about their situation	R5: "When I book a journey, I always have to ensure that there is a possibility for dialysis or where can I do it. That's not always possible and we cannot travel anywhere we like." R7: "There are also other persons here that have a disease they will die from. I do not have to deal with that in my situation and I personally regard their situation as more dramatic and then I think, they are worse off than me."
<i>Protecting oneself</i>	Distancing from dialysis aspects; rejecting being ill; not telling/showing others about illness; suppressing true feelings & facts; ignoring illness;	R3: "Sometimes you just think it's trivial when someone is making a scene because they hurt their arm (...)." R1: "What is important to me is that it [illness, dialysis] is not visible for others. That would be very hard for me." R7: "So, I bury that and swallow it down and I do not allow that. That is a strategy that works well now and maybe someday it will all come to the surface and it will not work anymore, but for the moment this works very well for me."

Code	Description	Quotations
<i>Being persistent</i>	Being disciplined; being brave; being organized; not giving up; fighting the challenge; carrying on with life; dealing with the situation & circumstances; to overcome difficult episodes in life	R1: "(...) that I stand up every day again and still go to dialysis and that I keep my head up and still be joyful." R8: "Certain things that probably count as a resource that I have to fight and to never give up and to make the best out of the situation."
<i>Ability to accept</i>	Accepting the circumstances and the impact of dialysis; taking the challenge; there are not alternatives; accept dialysis as part of everyday life; the opportunity must be taken; nothing can be changed	R9: "You simply have to live with it, and you can do nothing about it. It is not possible to live without dialysis and I cannot decide to skip sessions for two weeks, that is just not possible because I am dependent on the treatment." R10: "I try not to see it as a punishment and try to accept it as something that helps me live longer and that keeps me alive. I do not moan about my situation but accept the things as they are and live with it."
<i>Being appreciative</i>	Thankful for the technical advances; appreciating & acknowledging positive aspects (e.g. friends, environmental support); appreciating well-being; enjoying living	R1: "I am thankful that we have dialysis machines because 60 years ago it was different. That is why I am thankful and there is always something worse and I am feeling quite well and that's why I am thankful." R3: "There is always something new that you can see or there are moments when something beautiful happens."
<i>Hope</i>	Hope to receive a transplant organ and that it works; hope for a non-complicated life; to retrieve normality; for longevity	R5: "When maybe one day there is a new kidney, then it will be possible again to also do a bigger journey, for instance to Canada, and that is what I am looking forward." R10: „I obviously hope to receive a transplantation. Hope dies last, however, the situation is critical to receive a transplant organ."
<i>Being positive</i>	Being friendly; having humor; thinking positive; not being too serious to oneself	R3: "As long as I find something to laugh about there is still hope for me because when there was no joy at all that would be awful." R6: "With humor and when someone is joyful, I also become joyful again and am able to forget about some thoughts that I sometimes have." R8: The joy of life that I have despite the dialysis, that encourages me because I want to live and I want to make the best out of this situation that I am in and I still can celebrate and do such things and I do not lock myself into my house."

Code	Description	Quotations
<i>Trusting oneself</i>	Being honest to oneself; being self-determined; believing in oneself to master the situation; not giving up	R1: "Self-confidence, that I am able to carry it off. When you are ill, you first notice which strengths you possess, and I do not let myself down."
<i>Faith</i>	Trust in God; support in difficult times; praying; beliefs about being held, carried, guided or watched at;	R7: "When there is a situation then it needs to be resolved and no one else can do it because there is no one else, it's only me that can resolve it and it simply needs to be done." R5: "But this deep trust, so that I know it will not go lower than in Gods hands and that I will be carried and picked up, that is always present for me."
<i>Personal environment</i>	Family support; supportive relatives; supportive friends; engagement in social activities; emotional back-up & support; trust; caretaking; employer support; understanding & empathic; having someone to rely on; source of energy; being treated as a normal person, not as someone with an illness; sharing laughter and memories	R8: "When I have a problem or a situation, then I include these into my prayers and when I spoke about them, then I feel relief and it feels easier." R5: "Because I have an employer that treated me very well and loyal from the beginning on and did not impose obstacles on me. My family does also deal with my situation very well because they do not allow to be restricted by the implications of my dialysis treatment."
<i>Medical environment</i>	Relationship to doctors & nursing stuff; having routine for dialysis; homelike feeling; medical information & emotional support; being treated respectfully;	R8: "I am happy to have such a great environment, my friend, my parents that are very helpful. My friends never give me the feeling to be ill but instead treat me like a normal person and I think that also helps me live better." R1: "I need to come here three times a week and they are all very friendly and it feels like my second home and I think that the people really make a difference." R4: "The staff and the doctors, there are no difficulties and that is very important for me that I know when I go there, I can feel very well and that is assured." R7: "Then we have the doctors that I come along with very well, to have a good conversation which is also important. Then I get the feeling that they also take their time for me as a patient which does not come naturally these days."