Self-management in chronic kidney patients

Research to the added value of a Disease Management Toolbox

Bachelor thesis Health Sciences, Erasmus University of Rotterdam
Janneke Smeets, intern at EKHA
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Management summary

Chronic kidney disease patients can engage in many forms of self-management behaviour to improve their quality of life and slow down the disease process. However, these self-management behaviours come with barriers and can therefore be challenging for some. The aim of this study is to map out which self-management behaviour kidney patients display, which barriers they experience and how a Disease Management Toolbox can contribute to the display of self-management behaviour and can be of added value. The main question is:

"What do patients with chronic kidney disease from stage 3 or 4 need in order to better self-manage their disease, using a Disease Management Toolbox?"

Methods
For this study, literature research was done on self-management behaviour in chronic kidney disease patients and existing tools for chronic kidney disease patients. In addition, 8 kidney patients, 7 nephrologists and 8 kidney nurses were interviewed. In total, 23 interviews were conducted with respondents from 12 different European countries.

Theoretical framework
Barriers to self-management in kidney patients are: lack of knowledge, lack of intrinsic motivation and lack of social support. In addition, a major challenge for kidney patients is their comorbidity. Due to the different barriers in self-management behaviour, it is important that there is a tool that can support kidney patients in (i) monitoring their blood glucose and blood pressure, (ii) maintaining physical activity, (iii) changing eating patterns, (iv) following complicated medication regimes, and (v) avoiding substances toxic to the kidneys. According to a study, there are 4 factors to consider when developing a self-management tool. The 4 factors are (i) having adequate knowledge about self-management behaviour, (ii) the characteristics of the patient and his/her personal motivation, (iii) promoting cooperation between patients and healthcare providers and (iv) the model and vision of self-management tools.

Existing tools
Examples of tools that provide information on CKD are:

<u>KDIGO</u>
The ISN in collaboration with KDIGO has developed a toolkit that focuses on early identification and timely interventions. This toolkit has several components, such as guides and infographics, education for health teams, resources for patients, articles and webinars. This toolkit is a good start for more screening and to create awareness of chronic kidney disease, but it does not address self-management. In addition, it is mainly intended for doctors and the information that is useful for patients only focuses on providing information.

Strong Kidney

ERA has developed a video clip explaining the functions of kidneys, how to detect kidney disease and what to do to keep your kidneys healthy. This is a general video to educate novice chronic kidney disease patients. This tool is also good for creating awareness, but it is not about self-management.

My Kidney Journey

Baxter has developed a resource aimed at chronic kidney disease patients and their families. This tool explains the role of the kidneys, stages of deterioration, expected symptoms and evaluates in detail each treatment option (from dialysis to transplantation). It also contains an extensive section on nutrition, exercise, mental aspects, travel and an information center with files. All this is intended to help the patient make an informed choice about the type of treatment, with multidisciplinary support. This tool provides a lot of information and education for many Europeans, but lacks the option to connect with healthcare providers or other patients. In addition, the information is mainly textual and does not make use of visualizations.

Patient Information

EDTNA/ERCA offers multilingual patient education documents through their website. The aim is to provide the best standard of care for people with chronic kidney disease and their families from different cultural backgrounds. They are not only useful for nurses who face language barriers, but also for new kidney nurses to use as a reference for chronic kidney disease patient education. The information provided is very helpful in getting more insights in kidney disease and care but the format is not one of a self-management tool, that actively helps people with kidney disease on a daily basis with the management of their disease.

Results

The areas in which kidney patients can use to self-manage to improve quality of life or slow down the disease process are physical activity, diet (less salt, less fat, protein under control), medication and blood pressure. According to the interviews with kidney patients, they add social support, taking rest and mental health to the components of self-management. However, discipline and motivation are needed to achieve this.

However, the barriers experienced by kidney patients regarding this behaviour are dialysis or transplantation, lack of guidance, maintenance of self-management behaviour, presence of discipline and level of information.

A Disease Management Toolbox can help overcome the barriers, provided it is low-threshold and individualized. The Toolbox will be an application that offers information, educates and provides a network of healthcare providers and patients. According to the nephrologists and kidney nurses, the information should contain visualizations and as little medical language as possible. It is also important that choice aids are offered and, for example, blood pressure can be monitored.

According to nephrologists and renal nurses, the best way to approach kidney patients about the Disease Management Toolbox is through healthcare professionals (nephrologists, kidney nurses, social workers, dieticians, etc.), kidney patient organizations and health insurance companies. Advertising the Toolbox through media or hospital waiting rooms is also important.

Preconditions

The preconditions for the Disease Management Toolbox are that it should be an online tool (most likely an application), which is low-threshold and individualized to the patient. The Toolbox should not only offer information, but also create interaction by providing a network of healthcare providers and patients. The monitoring of, for example, blood pressure or the amount of physical activity is also important here.

Conclusion

The conclusion is that a Toolbox should be developed that is accessible, individualized and easy to use, with the focus on informing the patient about the disease and helping them to carry out self-management behaviour.

Recommendations

This study has some limitations such as only kidney patients who are in stage 5 of chronic kidney disease were interviewed and all respondents were most likely to have been educated to a higher level because they are Dutch or English speaking. Finally, not all countries that are members of EKHA are represented. EKHA can take these limitations into account for follow-up research by interviewing respondents from different stages and more different countries. In addition, it can be tested whether the Toolbox can provide added value to existing information tools and the desired form (application) can be enquired about. Finally, it is important that EKHA can test if the Toolbox has an effect on the quality of life, the disease process and how therapy compliance kidney patients are.

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1. Introduction

One in 10 Europeans suffer from kidney impairment severe enough to impact their health status (Bikbov et al., 2020). Patients with chronic kidney disease have an increased risk of kidney failure and death from cardiovascular disease. The major problem with kidney disease is that people experience complaints that are not immediately attributed to reduced kidney function, such as reduced energy, difficulty with concentration, muscle cramps, swollen ankles and feet, etc. (National Kidney Foundation, 2021).

Kidney disease is an irreversible process, once kidney disease is diagnosed there is no going back (Kidney Foundation, 2018a). chronic kidney disease is classified into 5 stages, ranging from mild complaints to immediate life-threatening (see figure 1). If chronic kidney disease is not treated, it ends up in stage 5, also called End-Stage Kidney Disease (ESKD). At this stage, kidney functions are severely impaired that the patient requires kidney replacement therapy (KRT) via dialysis or transplantation. (Nivel, 2019). Kidney transplantation is the best treatment option, but there is a severe shortage of donor kidneys. In addition, it is not certain that the donor kidney will be accepted in your body and it is possible that the donor kidney will be rejected (Mayo Clinic Staff, 2019). Dialysis is also not ideal, because as kidney patient has to dialyses 4 to 5 times a week in the hospital or at home. This takes a lot of time, is physically demanding and can lead to complications (Kidney Foundation, n.d.-a). A kidney patient therefore wants to postpone stage 5 as long as possible, because dialysis or transplantation has a high impact on the quality of life and significantly shortens life expectancy.

The main causes of chronic kidney disease are diabetes and hypertension. Diabetes causes damage to several organs, including the kidneys, and hypertension causes high blood pressure.

Figuur 1: De 5 stadia van chronische nierschade (E. Scheres, persoonlijke communicatie, 03-09-2021).

	NO CKD	CKD I	CKD II	CKD III	CKD IV	CKD V = ESKD
Kidney function	100%	> 90%	90-60%	60-30%	30-15 %	15-0 %
Kidney damage	*none*	*Slight*	*Worrying*	*Serious*	*Severe*	*Lifethreatening*

High blood pressure means that the kidneys cannot remove all waste from the body, which increases blood pressure even more and kidney disease can occur. (National Institute of Diabetes and Digestive and Kidney Disease, 2021). Both are critical to the functioning of the kidneys. Conversely, chronic kidney disease can also lead to high blood pressure and ultimately cardiovascular disease. (National Kidney Foundation, 2021). Due to the regular occurrence of underlying diseases that can have a different effect on kidney disease and its treatment, it is complicated to provide care to people with kidney disease. In addition, the treatment of chronic kidney disease is different for each patient.

Because chronic kidney disease causes vague symptoms and general practitioners do not immediately call the alarm, in most cases chronic kidney disease is only discovered when someone has only 30% of his/her kidney functions left. (Kidney Foundation, n.d.-b). As a result, kidney patients quickly reach stage 5 and it is important to slow down the disease process. Kidney patients could take action themselves to slow down the disease process by addressing a change in lifestyle, a different diet or high blood pressure (Nierstichting, 2019).

The Dutch National Institute for Health and Environment has calculated that health benefits can already be achieved in kidney patients if a maximum of 6 grams of salt per day is consumed

(Hendriksen et al., 2018). Research (Lin et al., 2013) shows that blood pressure control, blood sugar control and restriction of protein intake effectively contribute to slowing down the disease process of chronic kidney disease. Another study (Chen et al., 2011) describes that a self-management support intervention effectively slows down the kidney disease process. This intervention, also known as a tool, consists of providing healthcare services that enable patients to better manage their health such as providing health information, patient education, telephone support and the assistance of a support group. In addition to delaying the disease process, this way of support also reduces hospital admissions compared to kidney patients who do not use a self-management intervention.

In chronic kidney disease, self-management could help the patient to better control the disease and thereby improve quality of life and slow down the disease process. Showing good self-management behaviour is not for everyone, so it is important that there is a tool that can help patients with this. This research examines whether these aids are available and what kidney patients would like to see reflected in a tool. With these insights, advice is given to the internship organization about the possible added value and content of a ‘Disease Management Toolbox’.

1.1 Goal

The European Kidney Health Alliance (EKHA) is a European advocacy platform of the nephrology field that focuses on achieving effective prevention, more efficient care pathways and new and innovative treatments for kidney patients, resulting in appropriate, affordable and high-quality treatments for all Europeans. The aim of EKHA is to ensure that there is more attention and recognition for kidney disease at European (political) level, so that fewer people get kidney disease and kidney patients receive the best treatments. (EKHA, 2016).

In addition to prevention and innovation, EKHA believes it is important that patients can gain more control over their own disease through disease management. The question for EKHA is therefore whether the development of a tool to help patients with disease management can help with this and has added value compared to existing tools and information (E. Scheres, personal communication 09-03-2021). The assumption here is that a self-management tool for kidney patients can improve their quality of life and slow down the disease process.

EKHA wants this tool to be helpful to the patient, but also to facilitate informal caregivers and care providers such as general practitioners, nephrologists, renal nurses and other specialists in supporting kidney patients managing their disease. The tool should be helpful in pointing out who can do what to better manage kidney disease. The intended name of the tool is ‘Disease Management Toolbox’. In addition, the Toolbox aims to slow down the disease process, so that kidney patients are less likely to rely on dialysis or transplantation.

1.1.1 Research

This research focuses on the question whether the realization of the Disease Management Toolbox for kidney patients can promote self-management of patients and can add value to existing tools and information. The research consists on the one hand of literature research and on the other hand of qualitative research by questioning kidney patients about possible barriers in the field of self-management and how a possible Disease Management Toolbox can help to reduce the barriers. In addition, nephrologists and renal nurses provide input for the possible content of the Toolbox and how it can be used in the care of their patients. In this study, the focus is therefore on what kidney patients can do and achieve in the field of self-management.

1.1.2 Research question

The following research question arises from the existing literature and the research question from EKHA:

"What do patients with chronic kidney disease from stage 3 or 4 need, to better self-manage their disease, using a Disease Management Toolbox?".

In addition, the following sub-questions are answered in order to provide a conclusive conclusion:

1. *Which self-management behaviour is good for kidney patients to improve quality of life or slow down the disease process?*
2. *Which barriers do kidney patients experience in applying self-management behaviour?*
3. *How can a Disease Management Toolbox help to prevent these barriers?*
4. *How can nephrologists and renal nurses best approach patients with the Disease Management Toolbox?*

1.1.3 Relevance

This research is relevant for EKHA, because it can contribute to better (self) care for people with chronic kidney disease. The results of the research consist of: an advice to EKHA about the added value and content of the Toolbox, what the points of attention are when developing a Toolbox and how a Toolbox can be offered to patients.

With the advice, EKHA can decide whether they will actually develop a Disease Management Toolbox for kidney patients. As this is a topic that EKHA was already working on, this research provides the in-depth knowledge with which they can make targeted decisions regarding the development of a Disease Management Toolbox. In addition, EKHA intends to publish an article based on the results of this research.

2. Theoretical framework

2.1 Quality of life

Quality of life is divided into six categories according to the World Health Organization (1998); physical, psychological, level of independence, social relationships, environment and personal beliefs. According to a study by Da Silva-Gane et al. (2012) on quality of life in patients with kidney transplants and different types of dialysis, it can be concluded that the physical health of dialysis patients is very low compared to the average population. Also, the mean on the 'life of satisfaction scale' of novice dialysis patients was very low. From this it can be concluded that kidney transplants or kidney dialysis do not improve the quality of life kidney patients. That is why it is important to try to postpone ESKD for as long as possible and to offer kidney patients a better quality of life.

2.2 Self-management

To at least improve the psychological quality of life of chronic kidney patients, the patients themselves can adopt certain behaviours that help them to control side effects of their chronic disease. (Lee et al., 2016). Examples of these behaviours include monitoring blood glucose and blood pressure, maintaining physical activity, changing eating patterns, following complicated medication regimens, and avoiding toxic substances to the kidneys. (Narva et al., 2015). This kind of behaviour is part of disease management.

Disease management focuses on particular on delivering high-quality care across the entire continuum rather than just treating specific symptoms associated with the disease. (Ellrodt, 1997). Self-management is disease management by patients themselves. Self-management is generally understood as an intervention that includes techniques, tools and programmes to help patients choose and maintain healthy behaviours. In addition, there is a fundamental transformation of the patient-caregiver relationship to a collaborative one. (McGowan, 2012). It is also defined as a patient being an active participant in his/her disease process. Self-management is very important for patients with chronic diseases, because only the patient can be responsible for his/her daily care throughout the entire disease process (Lorig & Holman, 2003). According to a study by Rastogi et al. (2008) on disease management in kidney disease, managing patients with kidney disease at an early stage is therefore very valuable.

Exhibiting good self-management behaviour is not for everyone and can involve some obstacles. Barriers to self-management in kidney patients include: lack of knowledge, lack of intrinsic motivation and lack of social support. In addition, a major challenge for kidney patients is their co-morbidity. Co-morbidity is the presence of one or more conditions in addition to the main disease or multiple chronic diseases in one patient. Since kidney patients experience many different symptoms and have underlying causes such as diabetes and hypertension, co-morbidity is common. However, co-morbidity makes the application of self-management behaviours difficult, as the behaviours may need to be modified based on other underlying diseases (Bowling et al., 2017).

2.3 Self-management tool development

According to Ong et al. (2013), there are 4 factors to consider when developing a self-management tool. These factors can help or hinder the degree of self-management. The 4 factors are:

(i) Having adequate knowledge about self-management behaviour. This includes not only having information about chronic kidney disease, but also being able to apply this information to the kidney disease patient's own condition in order to take good steps in self-management behaviour. Kidney patients indicate that they have limited knowledge about the domains or they do not know how to apply the behaviour to their specific symptoms.

(ii) The characteristics of the patient and his/her personal motivation. Here it is important to note that each type of patient influences self-management behaviour and the use of aids differently. The right tools for the right type of patient will maximize the desired goals.

(iii) Promoting cooperation between patients and healthcare providers. Collaboration can support the decision-making process. Self-management tools should incorporate the principles of decision support and conflict with supportive patient-provider cooperation to promote self-management behaviour.

(iv) The model and vision of self-management tools. Here it is important that the tool is adaptable to different forms of technology or settings. It is desirable that different types of patients with different needs and access can use and adapt such tools in their self-management process.

Provided these factors are taken into account, a well-fitting device can help kidney disease patients improve self-management.

2.4 Self-management tool

Because of the various barriers to self-management behaviour, it is important that there is a tool that can support kidney patients in (i) monitoring their blood glucose and blood pressure, (ii) maintaining physical activity, (iii) changing eating patterns, (iv) following complicated medication regimes and (v) avoiding substances toxic to the kidneys (Narva et al., 2015). Currently, there are many 'kidney-related' organizations that have been developing tools to disseminate information and education around chronic kidney disease. Some are discussed below.

2.4.1 KDIGO

The International Society of Nephrology (ISN), in collaboration with Kidney Disease Improving Global Outcomes (KDIGO), has developed a toolkit that focuses on early identification and timely interventions. This toolkit has several components, including guides and infographics, education for health teams, resources for patients, articles and webinars. (Shlipak et al., 2021). This toolkit is a good start for more screening and to create awareness of chronic kidney disease, but does not address self-management. In addition, this is mainly meant for doctors and the information that is useful for patients mainly focuses on providing information.

2.4.2 Strong kidney

The European Renal Association (ERA) has developed a video clip explaining the functions of kidneys, how to detect kidney damage and what to do to keep your kidneys healthy. This is a general video to educate novice chronic kidney disease patients. This video is available in 26 European languages and will be used for a congress by ERA. (ERA, 2021). This tool is also good for creating awareness, but it is not about self-management.

2.4.3 My kidney journey

In addition to general education tools, Baxter (a company that aims to improve patient care through innovation) has developed a tool aimed at chronic kidney disease patients and their families. This tool explains the role of the kidneys, stages of deterioration, expected symptoms and evaluates in detail each treatment option (from dialysis to transplantation). It also contains an extensive section on nutrition, exercise, mental aspects, travel and an information center with files. All this is intended to enable the patient to make an informed choice about the type of treatment, with multidisciplinary support. This tool is not only comprehensive, but is also available in more than 30 languages, 19 of which are European. (Living with Chronic Kidney Disease | Baxter Kidney Care, n.d.). This tool provides a lot of information and education for many Europeans, but lacks the option to interact with healthcare professionals or other patients. In addition, the information is mainly textual and does not include visualizations.

2.4.4 CKD Patient information

EDTNA/ERCA, an umbrella organization for nephrology nurses, offers multilingual patient education documents through their website. The aim is to provide the best standard of care for patients with chronic kidney injury and their families from different cultural backgrounds. They are not only useful for nurses who face language barriers, but also for new kidney nurses to use as a reference for chronic kidney disease patient education. (EDTNA/ERCA, n.d.). The information provided is very helpful in getting more insights in kidney disease and care but the format is not one of a self-management tool, that actively helps people with kidney disease on a daily basis with the management of their disease.

2.5 Contribution of a self-management tool

The studies mentioned above show that self-management behaviour in chronic kidney disease patients is very important. This self-management behaviour can be improved by using tools or programmes with a potentially more positive course of disease. According to Richards et al. (2007), the use of a self-management tool can reduce healthcare costs for chronic kidney disease patients and slow down the disease process. Rocco (2009) also shows that significant cos savings and improvement in medical outcomes can occur when using a disease management tool. Existing tools meet many of the components of a Disease Management Toolbox, and these tools can provide important input and serve as examples. However, a number of components that EKHA would like to see in a toolbox are missing from existing tools.

3. Methods

3.1 Literature review

To conduct this study, a literature review was conducted using Google Scholar to answer sub-question 1 about which self-management behaviours can improve the quality of life of kidney patients and slow down the disease process. Google Scholar was used to search for existing scientific literature on the subject. The search criteria are that it is in a scientific journal or comes from a scientific source. The search terms used for this literature review are; chronic kidney disease, disease management, self-management, quality of life, slow down disease process, diet, fluid intake, lipid intake, salt intake, physical activity, hypertension, blood pressure control and all possible combinations of these terms.

3.2 Interviews

In addition, interviews were conducted with kidney patients, nephrologists and renal nurses. These interviews were conducted online (via Zoom). These 3 different respondents were chosen because nephrologists have the most knowledge about chronic kidney disease, nurses have the most contact with kidney patients and kidney patients have a lot of experience about their disease and how to manage it. The respondents were approached through the internship supervisor at EKHA who has close contact with different disciplines and organizations affiliated to EKHA.

3.2.1 Respondents

Ten kidney disease patients in stage 5 of chronic kidney disease were approached. Stage 5 patients were chosen because they have some knowledge of their disease, have a lot of experience with the consequences of chronic kidney disease and how they deal with it based on self-management. These kidney disease patients are Dutch or English speaking and come from as many different countries as possible affiliated to EKHA; including Belgium, France, Germany, Ireland, Netherlands, United Kingdom, Denmark, Italy, Spain, Portugal, Bosnia, Estonia, Turkey, Russia and Uzbekistan. The diversity in nationality of interviewees is important, as the scope of the study is Europe-wide. People living with kidney disease who are (to varying degrees) active in EKHA or EKHA partners were chosen because they may be more knowledgeable about self-management, deal with bottlenecks, can give better advice about an aid and can give more specific answers during the interviews.

For interviewing the healthcare workers, 10 nephrologists and 10 renal nurses were approached. Nephrologists and renal nurses from different European countries were also chosen. They are Dutch or English speaking and involved in the subject of ‘disease management’ around kidney patients, by being active in EKHA or partner affiliated to EKHA, such as the Dutch Kidney Foundation, the European Dialysis and Transplant Nurses Association and the European Renal Association. This number of interviews was chosen because it allows the research to be sufficiently reliable, but also feasible in a 5-month internship period.

The ethics of conducting the interviews have been considered. Prior to conducting the interviews, informed consent was given according to European Directive 2001/20/EC. Informed consent was given by asking for verbal permission from the person where the research will be carried out; that this person was been informed about the nature, significance, implications and risks of the research. (European Commission, 2001). Subsequently, the interviewer indicated that the privacy of the interviewee would be guaranteed, by not allowing the privacy-sensitive information to be recognizably included in the transcripts. Permission was also requested beforehand to make an audio recording for transcribing the interviews. The transcripts have only been shared with EKHA and the Erasmus University of Rotterdam. The audio recordings were not shared and immediately deleted after the transcripts were completed. Throughout the interview process, there was no covert research where deception could have occurred and no harm was done to the interviewer or interviewee. In addition, no coercion of participation was imposed on the interviewees, as the interviewer gave the interviewee the choice beforehand whether or not to participate.

3.2.1 Topic lists

Prior to the interviews, topic lists were drawn up with all important questions asked to the respondents. The same topic list was used for the interviews with the kidney patients. The same topic lists were used for the interviews with the nephrologists and renal nurses (see appendix 1). These topic lists have been drawn up on the basis of theoretical concepts that emerged are: quality of life, self-management, disease management, delay of disease process and tool/toolbox. These concepts play a role, because the degree of disease management or self-management can have a great impact on the quality of life and the disease process of chronic kidney disease patients. In addition, self-management behaviour can be improved by using a tool, or in this study a toolbox. The interviews are semi-structured, with topic lists as a tool to extract the most important answers. Deviations from this were made depending on the answers given by the interviewee and the possibility of the interviewer asking further questions.

In the interviews with patients, we asked about their knowledge of quality of life and self-management and possible barriers regarding self-management behaviour. Next, the need for a tool to support self-management behaviour and the patient’s vision of such a tool were asked. In the first place, this will provide further support for sub-question 1 by indicating what kidney patients do themselves based on self-management behaviour and to create a better picture for the other sub-questions. Sub-question 2 will focus on the barriers experienced by the kidney patients regarding the self-management behaviour they apply. Sub-question 3 will explain what kind of tools kidney patients are looking for to overcome their barriers. Not only the type of aid will be considered, but also the most important categories and functions that the aid must contain.

In the interviews with the nephrologists and renal nurses, we also asked what they thought was important in terms of quality of life and self-management for kidney patients. The content of the toolbox and how specialists can best provide it to ensure that kidney patients are well informed was then discussed. Through these interviews, part of sub-question 3 is answered, not only highlighting the patients’ side, but also what the specialists consider important in a toolbox. Subsequently, sub-question 4 is answered through these interviews by asking which parties they consider most important that can interfere in offering and advertising this device to patients. The main question is answered by summarizing the answers to the sub-questions and giving a clear overview of what behaviour is good for kidney patients in terms of self-management and making this clear through a Disease Management Toolbox that is made available to every kidney patient.

3.2.2 Coding

After conducting and recording the interviews, they were transcribed by the interviewer and then translated into Dutch using a free online program. After this, the transcripts were coded using open and selective coding. Open coding was used to link text fragments to theoretical concepts which, according to the theoretical framework, are important in relation to chronic kidney disease; such as quality of life, self-management/disease management, delay in the disease process, barriers, tool/toolbox and care providers. Therefore, the appropriate text fragments can be quickly retrieved to link to the sub-questions. For example, for sub-question 1 we looked at the concept of self-management, for sub-question 2 at the barriers linked to self-management, for sub-question 3 we looked at the tool code and for sub-question 4 we looked at the care providers linked to the tool. Selective coding was then used by linking the text fragments containing the same code, for example by putting all text fragments with the code ‘quality of life’ together. This made it easy to search back for certain concepts and created a clear overview to apply the interviews in the report.

4. Results

4.1 Which self-management behaviour is good for kidney disease patients to improve quality of life or slow down the disease process?

4.1.1 Literature review

There is evidence that lifestyle changes can reduce the risks of common diseases, such as hypertension, obesity, diabetes, cardiovascular disease and chronic kidney disease. Since many of these diseases are associated with chronic kidney disease, it is important that kidney disease patients engage in regular physical activity. Furthermore, there is little evidence that physical activity has direct beneficial effects on kidney disease in chronic kidney disease patients, but it is beneficial in preventing high blood pressure or obesity, which may eventually lead to less rapid deterioration of kidney function. (Daugirdas, 2011).

Another aspect of lifestyle changes as part of self-management behaviour that kidney disease patients can apply is nutrition. First, it is important to eat less salt, according to a study by McMahon et al. (2012) on the effect of salt on chronic kidney disease patients. This shows that blood pressure decreases significantly when kidney patients eat a maximum of 6 grams of salt per day. This is therefore important for kidney patients, because they need to keep their blood pressure down to prevent hypertension and reduction in kidney function. In addition, the reduced intake of fats is as important lifestyle change for kidney patients. In fact, there is a direct link between high fat intake and causing chronic kidney disease. (Pei et al., 2020). Third, the amount of protein intake is very important to control for chronic kidney disease patients. Especially in stage 3 or 4, it is important for kidney patients to control their protein intake and reduce it by half, so that their disease process can be slowed down. (Fouque & Aparicio, 2007).

In addition to dietary adjustments, medication plays a major role in chronic kidney disease. Doctors prescribe medication to (i) prevent further kidney disease, (ii) treat symptoms caused by kidney disease, (iii) prevent protein loss, (iv) prevent cardiovascular disease and (v) prepare kidney patients for dialysis or transplantation. When kidney patients reach stage 5 and receive dialysis or transplantation, they usually have to continue taking the same medications and other medications are added. Most kidney patients require a combination of these types of medication, and it is important that the medication is taken as prescribed. It follows that medication adherence is an important part of self-management behaviour for chronic kidney patients. (Kidney Foundation, 2018b).

Several studies show that consistent antihypertensive therapy slows the rate of progression of kidney failure. This means that the disease process of chronic kidney disease is slowed down when chronic kidney disease patients take care of and control their blood pressure. (Wühl & Schaefer, 2008). As mentioned in the theoretical framework, hypertension is both a cause and an effect of chronic kidney disease, which makes it very important to control blood pressure. Blood pressure control is closely related to the other forms of self-management behaviour. Kidney disease patients can control their blood pressure by (i) being physically active, (ii) maintaining a normal body weight, (iii) limiting alcohol consumption, (iv) reducing sodium (salt) intake, (v) ensuring adequate potassium intake and (vi) consuming a diet rich in fruits, vegetables, low fat dairy products and containing less saturated fat. (Whelton et al., 2002).

4.1.2 Qualitative research

4.1.2.1 Patient perspective

For this study, eight kidney disease patients (five men and three women) from Cyprus, Denmark, Ireland, the Netherlands, Spain and Turkey were interviewed. All eight patients were in stage 5 of chronic kidney disease, seven of whom have undergone one or more dialysis options and two of whom are currently on haemodialysis at home. The other six patients have had one or more transplants.

The interviews with the patients revealed that forms of self-management behaviour for them are: (i) medication adherence, (ii) being physically active, (iii) adhering to diet (less salt, less fluid), (iv) taking rest, (v) social support, (vi) blood pressure monitoring and (vii) keeping track of mental health. All eight patients unanimously agreed on this, only in some patients these self-management behaviours played a greater role than in others. For one patient, this kind of self-management behaviour did not feel like a big change, but a way of life without too much effort to adapt. For the other patients, the self-management behaviour did have an impact on their daily lives to varying degrees.

"I think disease management for me is something that I have been involved in all my life. So, I don't think about it much, it's just something I do." (Interview 3)

Mental management of the disease was mentioned by several patients as an important element of self-management. In this respect, 3 patients indicated that it is important to know how to deal with chronic kidney disease, what exactly it means to have chronic kidney disease. To achieve this self-management behaviour, two patients indicated that discipline and motivation are needed. When this is lacking, it becomes a big challenge to maintain this kind of behaviour, because for many patients it is a big change compared to how they used to live. The degree of discipline and motivation is also very different for each patient. Finally, the kidney patients indicated that self-management behaviour ultimately differs from patient to patient, but they did note that their quality of life is positively influenced when they engage in certain forms of self-management behaviour.

"it is important that you take responsibility for your own illness and health. Don't just say 'the doctor told you to do it' and become dependent on the doctor." (Interview 2)

4.1.3 Conclusion

Self-management behaviours that can improve quality of life for kidney disease patients or slow down the disease process is, according to the scientific literature: (i) physical activity, (ii) consuming less salt, (iii) consuming less fat, (iv) controlling protein intake, (v) taking medication in a timely manner and (vi) controlling blood pressure. According to the qualitative study, the kidney patients agree with this, but they also add (i) social support, (ii) taking rest and (iii) mental health to components of self-management behaviour. However, achieving these forms of self-management behaviour requires discipline and motivation from the patients themselves.

4.2 What barriers do kidney disease patients experience in adopting self-management behaviours?

4.2.1 Patient perspective

In the interviews, we asked about the biggest challenges and barriers kidney patients experience in managing their disease. Important themes that emerged were (i) dialysis or transplantation, (ii) lack of guidance, (iii) maintaining self-management behaviour, (iv) the presence of discipline and (v) the level of information. Thus, there are multiple barriers experienced by the patients themselves, with all bottlenecks being mentioned by multiple kidney patients.

Three kidney patients said they found the transition to dialysis or transplantation and rehabilitation from transplantation the biggest challenge. During dialysis, more attention has to be paid to issues such as taking the right medication, adhering to dietary restrictions and regular hospital visits for treatment or monitoring. This also causes patients to be very restricted in their freedom during dialysis, with a few patients stating that they had to plan everything carefully before they could go. In addition, there were a number of kidney patients who had very little energy during dialysis and could not do much. For these people, the transition to transplantation has been a great improvement, with these patients indicating that the treatment option of dialysis should actually be skipped.
"Being able to move and leave is really difficult, because I can't just get up and leave without having to plan it." (Interview 3)

Half of the kidney disease patients said they had difficulties with the level of information about their chronic kidney disease. They felt that although enough information is made available, it is difficult to extract and understand the information intended for them, both for theoretically and practically trained people. In addition, one patient indicated that she often looks for information herself, for example on diet, but she got totally lost on the internet because there was too much information. Not only is the amount of information impossible to keep track of, but different websites provide different information on the same subject. It is important to note that the level of information received from the hospital can vary greatly from one European country to another, as was shown in one of the interviews where it was indicated that the healthcare system in the country concerned is very poorly organized, and no information about the disease was given from the hospital after the diagnosis. This, in turn, is related to the lack of counselling immediately after the diagnosis of chronic kidney disease. When there is no support, receiving information is often absent as well.
"I think it is extremely important for new patients to have someone to guide them and explain to them what it means to deal with an illness, to get the best treatment or the best lifestyle, taking into account their illness." (Interview 5)

A number of kidney patients thought it was important that the patient had discipline to apply the lifestyle changes. They themselves often refer to having discipline, but sometimes they also find it difficult to maintain the lifestyle changes. This may be because they don't feel like it, have no energy or find it difficult to continue the diet in other people's homes. The latter applies not only to diet, but also to taking medication on time according to the rules.

4.2.2 Conclusion

Kidney patients experience (i) dialysis or transplantation, (ii) lack of guidance, (iii) maintenance of self-management behaviour, (iv) the presence of discipline and (v) the level of information as the biggest bottlenecks to adopting self-management behaviour.

4.3 How can a Disease Management Toolbox help to prevent these barriers?

4.3.1 Patient perspective

Seven out of eight kidney patients said they would like to use a tool if it could help them improve their self-management behaviour. One kidney patient personally had no need for a tool, but can understand that there are other patients who would like to use it. All patients were of the opinion that such a tool should be established as long as the tool is easily accessible and individualized. A few of the patients indicated that there is a big difference in types of patients, from patients who understand a lot and do their own research, to patients who do not understand much and are very ignorant. This last type of patient should be taken into account in the realization of a tool. One patient also indicated:

"One size does not fit all." (Interview 1)

It was difficult for the patients to indicate how they would like a tool to be designed. Nevertheless, five patients indicated that they would like to see an online platform in the form of an application. However, patients who do not own a smartphone and elderly people (which largely make up the kidney patient population) should be taken into account. Still, according to many, this should not be a reason not to develop the tool.

The kidney patients were asked what kind of components they find important in a self-management tool. The following issues emerged:

(i) Providing information. It is important that not only information is available on types of self-management behaviour for patients, but also general information on what chronic kidney disease is and what, for example, the different forms of dialysis are. In the area of self-management behaviour, several patients indicate that they would like information on (i) diet with recipes, (ii) medication and tips on how to avoid forgetting to take medication, (iii) exercise with examples of exercises or keeping track of steps and (iv) blood pressure with how to measure it. So, it goes beyond just providing information, because patients do not find that enough or they still do not know what they can change in their lifestyle.

(ii) Educating patients. This involves the sharing of knowledge and information by healthcare providers or other parties and has to do with providing information, as there are many patients who have little idea of what this disease that they will have for the rest of their lives means for them in practice. One patient also indicated that education can help with what patients can expect and that these expectations ease the process.

(iii) Providing a network. Patients indicated that they find a network of different specialists and kidney patients very important. A few kidney patients had experience of getting in touch with other patients in the early stages of their disease from which they derived great value. In addition, it can help a patient at an early stage to get in touch with someone at a later stage to get an idea of what dialysis is like, for example.

“It is the fear of the unknown, if you know what is coming and how to deal with it, it is half the battle.” (Interview 6)

“Sometimes you have your family with you, but sometimes it helps to talk to someone who has the problem themselves.” (Interview 8)

4.3.2 Caregiver perspective

Eight renal nurses were interviewed (2 men and 6 women) from Denmark, Germany, Lithuania, the Netherlands, Slovenia and Spain. Of these nurses, two are recently retired and one is currently not active as a nurse anymore, but as a manager in the nephrology sector. In addition, five of the eight nurses are active in different nephrology related organizations within Europe such as EKHA, the Dutch Kidney Foundation and the European Association of Kidney Nurses.

Seven nephrologists were interviewed (3 men and 4 women) from Belgium, Germany, Georgia, the Netherlands, Russia and Turkey. Of these nephrologists, one is recently retired and the other six are currently working as nephrologists. Furthermore, five of the seven nephrologists are active in various nephrology related organizations, such as EKHA, national societies and the European Nephrology Professional Association.

In addition to the ideas for a tool from kidney patients, the nephrologists and kidney nurses were asked what they think is important in a self-management tool for kidney patients. Many health care providers also indicated the points mentioned by the kidney patients. However, there are a number of additional issues that the nephrologists and kidney nurses feel need to be considered when developing a tool, such as (i) visualizing information, (ii) making the information as ‘non-medical’ as possible, (iii) providing choice aids for patients and (iv) monitoring symptoms so that patients can keep track of themselves.

Firstly, they agreed with the kidney patients that providing information in a tool is very important, and the information should be well adapted to the patient's situation and needs. Not only should the information be understandable, but it should be visualized. By using videos, pictures and cartoons, information can be more understandable and there is less of a language barrier, according to a number of care providers. In addition to visualization, it is therefore important that the information provided is not offered in too medical a manner. This can be a challenge for healthcare providers themselves, but they do indicate that many kidney patients do not understand ‘too medical’ language, but regularly 'nod' anyway.

One renal nurse said that she finds the assistance in making choices for the renal patients very important. She said that there are a lot of choices that a kidney patient has to make throughout his or her disease process such as whether or not to take medication or the type of treatment in stage 5 chronic kidney disease. According to this nurse, a kidney patient does not always have to follow what the healthcare providers consider to be the best option because, for example, medication can have unpleasant side effects, so the patient can also choose not to take this medication. The same applies to the type of treatment at stage 5. Healthcare providers may have a preference for home dialysis, for example, but ultimately it is up to the patient whether they prefer home dialysis or hospital dialysis.

> *“I think it is good to involve patients in the decision-making process about taking the medication, but it is also important to support them in their daily lives about the decision to take the medication, but also how to live and deal with the side effects.” (Interview 1)*

Finally, many health professionals indicated that monitoring symptoms can be important for kidney patients, such as monitoring blood pressure, heart rate and intake of fluids. If patients can keep track of this themselves, it makes them more aware of how they are doing and can prevent hospital visits or ring a bell to visit a specialist sooner.

4.3.3 Conclusion

According to kidney patients and caregivers, a Disease Management Toolbox can help overcome the barriers to adopting self-management behaviours, provided that the Toolbox is easily accessible and individualized. According to most respondents in this study, the Toolbox should be an application with the components (i) providing information, (ii) providing education and (iii) providing a network. According to the care providers, it is important that the information is visualized, that as little medical language as possible is used, that patients are offered choice aids and that certain components can be monitored, such as blood pressure.

4.4 How can nephrologists and renal nurses best approach patients with the Disease Management Toolbox?

4.4.1 Caregiver perspective

According to the health professionals, 'making kidney patients aware of the existence of a tool' is an important aspect of developing and using a self-management tool for kidney patients. There are many ways to do this (i) through healthcare providers informing their own patients, (ii) through kidney related organizations or (iii) through health insurance companies. It is also important that the tool is advertised through various media channels, but also in the waiting rooms of GPs or hospitals.

The first and according to the healthcare providers the most important aspect of making kidney patients aware of a device was through their healthcare providers. Many nephrologists consider nurses to be the most important, as they are in close contact with the patient and have more time to elaborate on their self-management behaviour and could possibly explain this device. In addition, nurses believe that social workers, psychiatrists and dieticians should play a greater role in the treatment of chronic kidney disease patients and thus in their self-management. They could then also address the specific needs of a kidney patient in more detail and show this using the tool.

According to nephrologists and renal nurses, kidney-related organizations such as patients' associations already have many tools and information for both kidney patients and healthcare professionals. These tools mainly contain education and information with little interaction. In addition, patient associations have a network of kidney patients and this network can be used to spread information about a tool. It is therefore very important that these sources are used when developing and distributing a new tool.

Finally, a few health care providers indicated that health care insurances could also play a greater role in the prevention of care and especially in slowing down the disease process of chronic kidney disease.

According to these health care providers, health care insurances should have more of an objective: to ensure prevention and to limit health care costs. In addition, (almost) all citizens in the EU and therefore kidney patients are members of a health insurance company, which gives them a wide range to inform kidney patients about an aid.

4.4.2 Conclusion

According to healthcare professionals, the best way to approach kidney patients about the Disease Management Toolbox is through (i) nephrologists, kidney nurses and other healthcare professionals who deal with chronic kidney patients, (ii) kidney patient organizations that kidney patients are members of, and (iii) health insurance companies. Advertising the Toolbox through media or hospital waiting rooms is also important.

5. Discussion

5.1 Conclusion

“What do patients with chronic kidney disease from stage 3 or 4 need in order to better self-manage their disease, with help of a Disease Management Toolbox?”

For patients with chronic kidney disease, it is important to display self-management behaviour in different areas such as physical activity, nutrition, medication and blood pressure. These self-management behaviours can improve quality of life and slow down the disease process. However, kidney disease patients experience many barriers to engaging in self-management behaviours, such as dialysis or transplantation, lack of counselling, maintaining self-management behaviours, the presence of discipline and the level of information. A Disease Management Toolbox can help with these barriers by providing clear information and offering a network of healthcare providers and kidney patients. It is important that this toolbox is accessible, individualized and easy to use for every type of patient.

There are already a number of resources in the literature about chronic kidney disease for patients. The Disease Management Toolbox will complement these by offering a personal tool that not only provides information, as with existing tools, but also provides a network to get in touch with care providers and other kidney patients. In addition, monitoring blood pressure, for example, would be a good addition so that patients themselves can get a better idea of how they are doing. Finally, it is also important that the Toolbox reaches kidney patients; healthcare providers, patient associations and health insurers will have to play a major role in this.

5.2 Positive aspects

For this research, kidney patients, nephrologists and kidney nurses were interviewed to find out what self-management behaviour of chronic kidney patients is and how a tool can help. A total of 23 interviews were conducted across the three types of people mentioned. This is a good number of interviews to get a starting insight into these topics, which is shown by the overlap in the answers given. In addition, it is positive that not only patients were interviewed, but also the healthcare professionals involved (nephrologists and kidney nurses) to create a more complete picture of self-management and how it is currently being addressed. Respondents also came from a variety of countries of origin, namely Belgium, Cyprus, Denmark, Germany, Georgia, Ireland, Lithuania, the Netherlands, Russia, Slovenia, Spain and Turkey. This has ensured a more complete picture of self-management across Europe.

5.3 Limitations

This research also has its limitations, such as the type of respondents and the domain. Also, the literature review can be extended by looking at more tool examples to get a broader picture of existing offerings (information and tools). Furthermore, only kidney patients who are in stage 5 of chronic kidney disease were interviewed. This means that the ideas of kidney patients in the other stages were not included in the study, which may distort the answers to the sub-questions. However, most patients do not find out they have chronic kidney disease until stage 4 or 5, which makes it difficult to include patients from earlier stages in this study. Furthermore, all respondents were Dutch or English speaking, which made it likely that most of the respondents were highly educated and therefore did not represent all kidney patients. Finally, the domain covered by this study is (almost) the whole of Europe. Although interviews were conducted in 12 countries, not all countries of EKHA were represented.

5.4 Recommendations

This study is a first step towards developing a Disease Management Toolbox for chronic kidney disease patients. It has provided a first picture of what kidney patients, nephrologists and renal nurses think is important in terms of self-management and how a Disease Management Toolbox might help. For a more complete picture, EKHA could do follow-up research consisting of more respondents, respondents from different stages and respondents from more different countries. In addition, more literature research can be done on existing information tools and the advantages and disadvantages can be mapped out. It can be tested whether the information that should be in the toolbox, as shown in this research, would be sufficient to give a tool added value. The desired form (application) can then also be enquired about.

The preconditions of a Disease Management Toolbox according to this research are that the Toolbox must be accessible in its use and individualized to the needs of a patient. In addition, the tool should contain information on various chronic kidney disease related topics and it is important that there is a network of kidney disease patients and caregivers to contact. All these conditions will have to be taken into account by EKHA as recommendations for the design and content of a Disease Management Toolbox. Finally, it is important to test whether the Disease Management Toolbox has an effect on the quality of life and the disease process. This could include whether or not kidney patients show more therapy compliance behaviour.

6. Appendices

6.1 Topic lists

6.1.1 Patients

- Can you tell me about your CKD diagnose? (Stage of the disease)
- What does quality of life in relation to your disease mean to you?
- Are you familiar with the terminology disease management?
- What does disease management of CKD mean for you?
- What is the biggest challenge in managing your disease?
- Do you experience any barriers concerning disease management of CKD?
- Would you like any kind of help, by means of some tools, to better your self-management/disease management?
- What kind of tool would you like, to help you with your disease management?
- What should the tool look like?
- What should be the main categories of the tool?
- Do you think a tool like this can help in improving quality of life?
  - If yes: why
  - If no: why
- Would you use the tool if it helped with slowing down your disease process?
- What will be the best way to inform you about this toolbox.
- Which caregivers should and could contribute to disease management of CKD patients? In what way?

6.1.2 Nephrologists/Renal nurses

- What does disease management of CKD patients mean to you?
- What are the differences between self-management of the disease in the various stages of CKD?
- How do your patients manage their CKD?
- What is the biggest challenge in managing CKD?
- How do you help your patients with their CKD disease management?
- Do you experience any barriers concerning disease management of CKD patients?
- Which caregivers should and could contribute to disease management of CKD patients? In what way?
- Would you like any kind of help, by means of some tools, to better the disease management of CKD patients? And for patients in which state of the disease?
- What kind of tool would you like, to help with the disease management?
- What should the tool look like?
- What should be the main categories of the tool?
- Will the tool help better the quality of life of CKD patients?
  - If yes: why?
  - If no: why?
- Will the tool slow down the disease process of CKD patients?
  - If yes: why?
  - If no: why?
- What will be the best way to inform CKD patients about this toolbox?

7. Resources

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