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EUROPEAN KIDNEY PATIENTS' FEDERATION
CEAPIR



Living better with CKD – improving the quality of life of CKD patients on dialysis across Europe

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Terminology

The following terms can be found throughout this paper. For the purpose of this paper, the definitions are as follows:

Chronic kidney disease (CKD)	A long-term condition where the kidneys are damaged and can't filter blood in the way that they should.[1] There are several stages of CKD, ranging from mild loss of kidney function to complete kidney failure[2]
Advanced stage kidney disease	When chronic kidney disease has reached an advanced state and kidneys can no longer function on their own, and dialysis or transplantation are necessary to stay alive[3]
Renal replacement therapy	Includes treatments such as dialysis or transplantation, which replace the normal blood-filtering function of the kidneys
Symptom-based complications	The consequences and additional issues facing patients living with advanced stage kidney disease as a result of the disease itself, and its treatment





Executive Summary

Our kidneys are vital to our health, yet kidney disease is relatively common. In the EU alone, over 64,000 deaths are caused annually by diseases of the kidney,[4] bringing kidney disease in the top ten leading causes of death globally.[5] 8-10% of the population worldwide is affected by chronic kidney disease (CKD),[6] and over 2 million people now require renal replacement therapy to sustain life worldwide.[7] In 2040, kidney disease is expected to be amongst the top five leading causes of death globally.[8] However, a lack of access to renal replacement services in many countries has led to an estimated 2.3 – 7.1 milion premature deaths.[9] Despite the scale and impact of CKD, the level of policy attention it receives is low and it is often forgotten in broader health policy.

All people living with CKD, including advanced stage patients on dialysis and awaiting transplants, have the right to a good quality of life, however there is little recognition of the impact that the disease and its side effects can have. Given that the World Kidney Day Steering Committee has dedicated 2021 as the year of 'living well with kidney disease',[10] it is an opportune moment to highlight the struggles faced by patients living with CKD, including advanced stage patients on dialysis or receiving transplants. At the heart of this is a drive for plans and actions toward achieving person -centered wellbeing.[11]

The objective of this paper is to raise awareness about the devastating impact of advanced stage kidney disease on the quality of life of patients. In doing so, it makes three recommendations to European policymakers for changes that could improve the quality of life of individuals on dialysis.

Recommendation 1: Introduce disease-specific quality of life indicators, including patient-reported outcomes measures and patient-reported experience measures, as a key measure of success in dialysis care

Recommendation 2: Establish a Dialysis Quality Guarantee to ensure all patients receive high-quality dialysis care in countries where dialysis is fully establised

Recommendation 3: Support healthcare professionals (physicians and nurses) to focus on improving quality of life

These recommendations are based on evidence about the impact of advanced stage kidney disease on quality of life from individual interviews with clinical experts and patients from across Europe, including France, Spain and the United Kingdom.

This paper is intended as a constructive contribution to discussions on how to improve the quality of life of patients living with advanced stage kidney disease on dialysis while also managing the increasing pressure on services. Moreover, we hope that it will serve as a catalyst for policymakers to come together and take action to address the unmet needs of European patients who will have to rely on dialysis in the coming years.



Introduction

Our kidneys are vital to help us live. They filter our blood, clear toxins, and create hormones which help us lead healthy lives.[14] When our kidneys stop functioning it can be devastating, cutting lives short or damaging quality of life.

The primary clinical interventions for advanced stage kidney disease – dialysis and transplantation – are highly effective in keeping people alive,[15] often enabling them to lead active and productive lives. Transplantation is the gold standard and offers superior outcomes compared to dialysis, but limited availability makes it impossible to provide transplants for everyone who needs them. Therefore, there should also be a focus on quality of life for dialysis patients as their lives are impacted so significantly.

However, both dialysis and transplantation have their own limitations. Not all patients are suitable for a transplant and there is a shortage of donor kidneys. Dialysis – the focus of this paper – is both time-consuming for patients and costly to healthcare systems, and while there are now many types of dialysis available, access to them accross Europe varies.[16] For those patients who do go on dialysis, the impact on their quality of life can be considerable and is often overlooked in the drive to improve other clinical outcomes.

Patients living with CKD have been particularly affected by COVID-19, as they have been identified by health authorities as being clinically vulnerable with a need to shield themselves from potential infection for significant lengths of time. Aside from the higher risk of developing serious illness from COVID-19 due to a weakened immune system, the pandemic has also had an impact on the quality of care of patients living with CKD. Furthermore, COVID-19 will increase the CKD patient population in the future given that a side effect of severe COVID-19 is acute kidney injury.[17]

This paper explores the consequences for both patients and healthcare systems of the demand for dialysis. It sets out some of the major personal, societal and economic costs and suggests potential solutions to improve quality of life for dialysis patients, with a particular focus on their mental health[18] and those aspects of the disease and care which are modifiable.

Symptom-based complications associated with advanced stage kidney disease can include fatigue, sleep disturbance, nausea and CKD-associated pruritus (CKD-aP or itching), amongst others.[19] These often under-recognised issues are highlighted in the patient and clinician testimonials in this paper.

We hope this paper will provide a constructive contribution to policy discussions about how to further improve the quality of life of patients on dialysis in Europe, while effectively managing the increasing pressure on services.

About Chronic Kidney Disease and dialysis

About Chronic Kidney Disease (CKD)

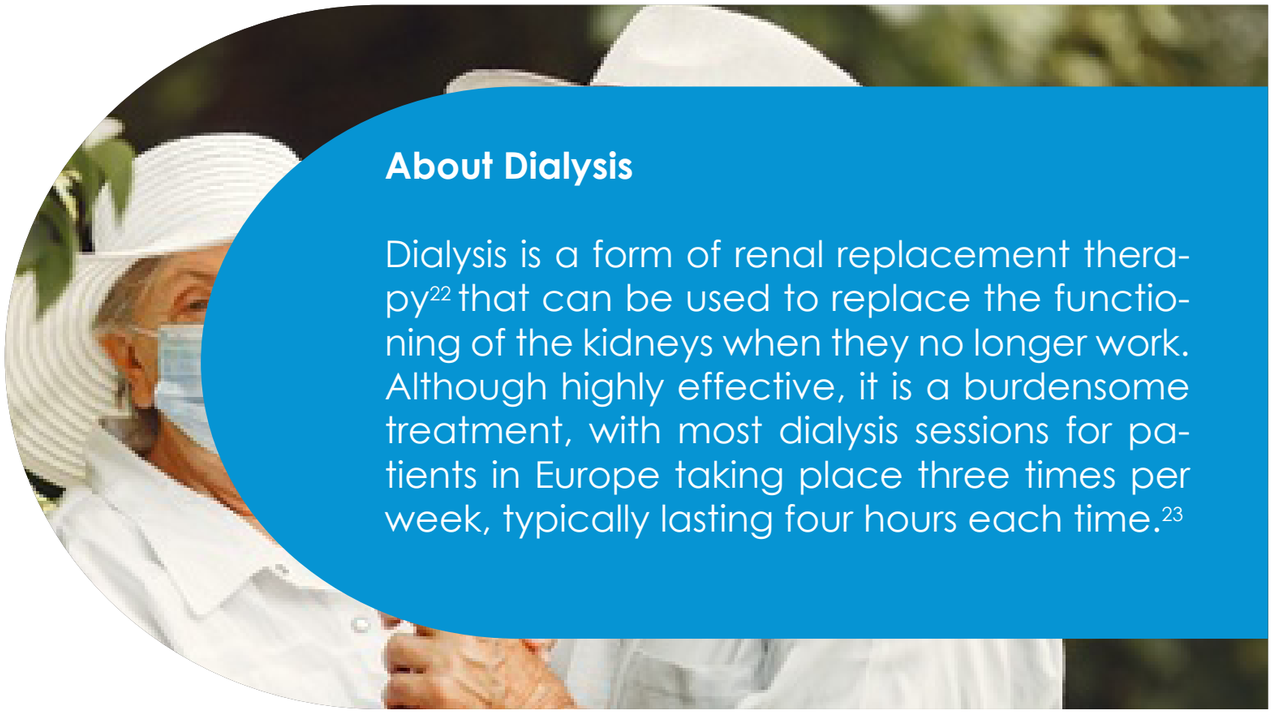
One in ten (10%) people worldwide is affected by chronic kidney disease (CKD).[6] Over 94 million people are living with CKD across Central, Eastern and Western Europe alone.9 This is similar to the size of the populations in Belgium, France and the Netherlands combined.

CKD can be categorised in five stages, from mild damage in stage 1 to complete kidney failure in stage 5.[20] In the most severe cases, patients need renal replacement therapy – either transplantation or long-term dialysis (or sometimes both in succession). Patients with advanced stage kidney disease have a high burden of physical and psychosocial symptoms, poor outcomes, and consequently cause higher costs of care for healthcare systems.[19]

"Patients living with CKD need to learn to live with the disease for their whole life. There is a need to have a holistic patient-centred approach to respond to the day-to-day struggles." **- Daniel Gallego Zurro, President, EKPF and ALCER**

This paper explores the consequences for both patients and healthcare systems of the demand for dialysis. It sets out some of the major personal, societal and economic costs and suggests potential solutions to improve quality of life for dialysis patients, with a particular focus on their mental health18 and those aspects of the disease and care which are modifiable.





About Dialysis

Dialysis is a form of renal replacement therapy[22] that can be used to replace the functioning of the kidneys when they no longer work. Although highly effective, it is a burdensome treatment, with most dialysis sessions for patients in Europe taking place three times per week, typically lasting four hours each time.[23]

There are two main types of dialysis: haemodialysis (HD) and peritoneal dialysis (PD). The former works by filtering blood through an external machine before it being returned to the body, while the latter involves inserting dialysis fluid into the abdomen to remove waste products from blood, with the peritoneum functioning as the filter. Most HD treatments are performed at a hospital, a doctor's office, or a dedicated dialysis centre,[24] which can often be far from patients' homes. Peritoneal dialysis is typically performed at home, however it is possible for haemodialysis treatment to take place at home too.

This paper explores the consequences for both patients and healthcare systems of the demand for dialysis. It sets out some of the major personal, societal and economic costs and suggests potential solutions to improve quality of life for dialysis.

Dialysis has a substantial financial cost for healthcare and social systems26,18 and this is likely to increase further as a consequence of improved life expectancy and growing prevalence of CKD.[16] In 2018 alone, over 81,000 new patients in Europe were accepted for renal replacement therapy for kidney failure.[25]

The impact of CKD and dialysis on quality of life

Dialysis helps keep people alive. However, patients living with advanced stage kidney disease often suffer with other co-morbidities and the process of dialysis has a significant impact on their quality of life.[16]

Encouragingly, there is now more data being collected about quality of life due to the introduction of specific measurement tools. The Kidney Disease Quality of Life Instrument (KDQOL), used in the United States, is a 36-question kidney disease-specific survey and is used to measure health-related quality of life, such as symptoms, burden of illness, social interaction, staff encouragement, and patient satisfaction.[27] It represents the gold-standard in quality of life measurement and could be adapted and adopted in Europe. For example, results from a continuous quality improvement program in Portugal have shown that there is a relationship between the number of off-target KPIs and health-related quality of life, which may be a consequence of improvements in disease-specific symptoms and functional capacity.[28]

The International Consortium for Health Outcomes Measurement (ICHOM) has developed a 'standard set' of outcomes that matter most to patients with Chronic Kidney Disease. Healthcare providers are urged to measure the suggested outcomes, ranging from vascular access survival and cardiovascular events, to fatigue and physical function, to understand how to improve the lives of patients. Quality of Life is also emphasised as a parameter to be measured for the 'standard set'.[29]

However, while there has been increased recognition over recent years of the importance of quality of life for patients living with CKD, this has not translated into standardized treatments and approaches that deliver supportive care for patients, both on and off dialysis.[19] Such measures would go a long way to helping with modifiable symptom-based complications that impact patients' quality of life.

Impact on daily life

The process of dialysis is very time-consuming for patients, making it difficult for many to continue with other parts of their life, including work. Patients on dialysis face multiple burdens, some of which are modifiable burdens which could be addressed to improve their quality of life. Amongst these modifiable burdens, patients identify determining the optimal length of time and frequency of HD for individual patients to reduce itching, fatigue, restless legs as a priority.[30]

Some examples of the burden facing patients on dialysis

- **Patients have to plan their lives around dialysis: a typical dialysis session lasts four hours (excluding transportation and waiting time), and takes place three times per week**
- **In some countries, dialysis centres are often located far from patients' homes: patients have to factor in time to allow for transport to and from dialysis sessions, and can be dependent on carers for this**
- **There is a very small window where patients feel well between dialysis sessions: in particular, fatigue is a common symptom for dialysis patients[31]**
- **Adapting diets limiting the types of food patients can eat to avoid complications such as hyperkalemia or hyperphosphatemia and fluid restriction**

The impact of advanced stage kidney disease on the quality of life of informal caregivers should not be ignored. Caregivers are family members who are tasked with responsibilities, such as transporting patients to and from dialysis sessions, ensuring the correct medication is administered and cooking meals that are palatable for patients on dialysis. Burnout, depression, fatigue and isolation are commonly reported in caregivers of patients living with CKD.[11]

Impact of symptom-based complications

People suffering from CKD and in particular advanced stage kidney disease also have to deal with symptom-based complications which are often left unidentified and therefore poorly managed, significantly diminishing quality of life and adding a higher burden to patients living with advanced stage kidney disease. Some symptom-based complications can include sleep disorders, depression, nausea and CKD-associated pruritus (itching or uremic prutitus). For instance, depression has an high prevalence on patients living with CKD, especially when under dialysis, and should be given adequate attention, having a great impact of quality of life.

"The restricted diet has a great impact on social life. Patients, who have not yet accepted their condition, may even decline invitations to the wedding of family members and friends to avoid encountering difficulties due to their diet. Additionally, when patients start dialysis, they suffer from anemia, itching, sarcopenia, sexual dysfunctions etc.,[33] all of which have a significant emotional impact, leading to stress, anxiety or even depression" – Daniel Gallego Zurro, President, of EKPF and ALCER

Non-exhaustive list of symptom-based complications as a result of CKD[19,33]		
Anemia	Anxiety	Anorexia
Constipation	Depression	Diarrhoea
Frailty and sarcopaenia	Immune deficiency	Nausea
Pain	Restless legs syndrome (RLS)	Sexual dysfunction
Sleep disorders	Uremic pruritus	Vomiting

"CKD-associated pruritus is one of the most important symptom-based complications when looking at patients' quality of life. Patients reporting this issue usually describe it as terrible, as it impacts their daily life even preventing them from sleeping in some cases." – Dr. Patricia de Sequera Ortiz, President, Spanish Association of Nephrology



Clinician and patient perspectives on quality of life

Dr Philippe Chauveau is a recently retired nephrologist and member of the French Society of Nephrology, as well as the European Renal Association-European Dialysis and Transplant Association (ERA-EDTA). He believes that a patient-centric approach to dialysis care is still missing, meaning that some patient needs remain unmet.

In his experiences of administering dialysis over more than 40 years, he found it frustrating to see so many patients' quality of life impacted by a life-saving treatment. To Dr Chauveau, success means seeing patients living full and happy lives with little impact from symptoms.

"Dialysis is a successful treatment, but it is not a cure. It offers the possibility that one's health condition will not worsen in the coming years."

Dr Chauveau believes that many nephrologists do not ask patients questions about quality of life, particularly since in Europe there are very few nephrologists per patient,[34] meaning their time with each patient is severely restricted. Although there are some existing questionnaires in Europe to measure patients' quality of life, these are often too long, difficult to share with patients and difficult to interpret. Dr Chauveau reports that in his experience, nephrologists and nurses in big dialysis centres often do not have time to liaise with patients on the questionnaires.

In Dr Chauveau's opinion, the structure of dialysis units and the way dialysis is delivered are also important factors impacting quality of life. In his view, adapting the delivery of care to patients' needs would allow nephrologists and nurses to be better placed in assisting their patients with a more holistic approach, having the opportunity to more closely discuss those symptom-based complications impacting quality of life.

"Patients are often the ones who need to adapt to the system, by having to reach dialysis centres often far from home, or having to go for appointments early in the morning or during the weekend."

A patient-centric approach to dialysis care can contribute to improving patients' quality of life. In Dr Chauveau's view, having dialysis centers closer to patients' homes is beginning to improve some patients' quality of life, as they have shorter transit times and sometimes a sense of community, ultimately leading to less missed dialysis sessions. Missed dialysis sessions lead to further utilisation of healthcare system resources, and result in patients reporting poorer physical and mental quality of life measures.

The patient's perspective: Faizan Awan, United Kingdom

Faizan (Fez) Awan lives in the United Kingdom and has received three kidney transplants throughout his life. An avid sports fan, Fez enjoys football and tennis, as well as comedy shows and movies. He is a volunteer patient ambassador at his local Kidney Patient Association, and for the UK's NHS Blood and Transplant service.

Fez has lived with kidney disease since birth, receiving his first kidney transplant at three years old. Fez, like many other advanced stage kidney disease patients, has been forced to undertake burdensome dialysis sessions (both peritoneal dialysis and haemodialysis). He suffered an array of challenging symptom-based complications that come with advanced stage kidney disease, medication and dialysis which severely impacted his quality of life, ranging from diet and fluid restrictions to fatigue and a lesser-known symptom, CKD-associated pruritus.

CKD-associated pruritus, the medical term for itching, is an extremely frustrating symptom for people living with chronic kidney disease that has a profound impact on quality of life. CKD-associated pruritus is a very common condition in patients living with advanced stage kidney disease on haemodialysis with, according to studies, 37% of HD patients experiencing moderate to extreme CKD-associated pruritus.[35] However, CKD-associated pruritus often remains unreported by patients who may not know their itch is linked to the underlying kidney disease and undiagnosed by nephrologists, and therefore untreated.

"At one point in my life, itching became so strong and unbearable that it would prevent me from sleeping. I used to get up in the middle of the night to take showers, waking up my whole family. Furthermore, I found it very challenging to get up early in the morning to go to doctors appointments when I had been up and walking around the house all night because of the itch that was driving me insane."

While some progress has been made in the management of CKD-associated pruritus thanks to creams that sometimes provide temporary relief, there is currently no safe and effective treatment approved by the European Medicines Agency (EMA). CKD-associated pruritus can cause great discomfort all day long, but scratching the itch cannot be a solution nor a relief as it can lead to bleeding and infections.

Furthermore, patients are often uncertain on when and whom to report it to. CKD-associated pruritus is an important indicator of a poorer prognosis. Patients extremely bothered by itching also have the highest rates of mortality and hospitalisation, are more likely to withdraw from dialysis and miss dialysis treatments, are less likely to be employed, and are more likely to have a recovery time greater than 6 hours after dialysis sessions.[36] Among patients who miss dialysis sessions, those who report severe itchiness on average miss 2.6 more dialysis sessions per year compared to patients who do not suffer from CKD-associated pruritus.[37] In response to CKD-associated pruritus, patients often experience longer dialysis times or receive prescriptions for sometimes ineffective medicines or off-label remedies.

"When itching was so strong, I often had to resort to knives and forks to alleviate the discomfort. At that point, my medical team understood that itching had become unbearable for me."

Variations in the quality of dialysis care in Europe

There are significant variations in the quality of dialysis services across Europe that, if addressed, could contribute to better clinical outcomes as well as a better quality of life for all patients living with advanced stage kidney disease. These factors form the basis of our recommendations for better quality of life in the next section.

Variations in the quality of dialysis care occur in:

- **Access to dialysis services:** the extent to which people are able to receive dialysis
- **Patient choice in dialysis modality:** choice on where and which type of dialysis patients receive
- **Comprehensiveness:** the extent to which the services delivered to patients address the full range of a person's needs with a holistic patient-centred approach
- **Use of quality standards:** the extent to which the services delivered accord with established quality standards
- **Funding:** the extent of the resources provided to services to plan and deliver care. Variations in funding and its criteria are key to put in place the appropriate incentives to prioritise quality of care
- **Patient information:** the extent to which it is ensured that patients can make informed decisions about their care

Access to dialysis services

Easy and equitable access to dialysis services is a necessity for people who need dialysis. A lack of choice around the dialysis received, or how close to home it can be administered, can lead to poorer health outcomes, increased co-morbidities and higher risk of death.[38, 39, 40, 41]



Patient choice in dialysis modality

In general, many patients are calling for more choice on where and which type of dialysis they receive. In consultation with their healthcare professional about which type of dialysis is most appropriate for them, in some countries patients are able to decide whether they receive dialysis at home or in hospital. Home dialysis can empower patients on dialysis to take over part of their treatment and improve their quality of life by allowing for treatment to take place in the comfort of the patient's home, and in line with a schedule of their choice, having a potential positive impact of their working life too such as the ability to remain in work.[45,47] Flexibility surrounding dialysis treatments in healthcare centres can be difficult due to the scarce resources of nurses, amongst other issues.

Comprehensiveness

Advanced stage kidney disease impacts people in many ways but health systems and funding have traditionally been focused on providing dialysis services rather than managing physiological and psychological complications. There is a financial as well as a health dividend to be realised through better dialysis management and reduction of symptom-based complications, such as reducing the number of missed appointments and emergency interventions. As it stands, health systems are not organised to facilitate patient pathway thinking that can be reflected in clinical practice. It is therefore important that providers are encouraged to adopt a holistic approach to patient support and that corresponding and appropriate funding follows.

Quality of care

There are several measures that providers use to rate the quality of dialysis care they are delivering (such as haemodialysis adequacy, anemia measures, nutrition status, vascular access, infection control etc).[42] However, these do not measure patients' quality of life and therefore services are not ranked on a patient-centric approach basis. There is a recognised need to measure health-related quality of life and collect patient-reported outcome measures. Different tools have already been developed such as OptumTM SF-36v2 Health Survey, EQ-5D, PROMIS-Global Health, PROMIS-29 or RAND-36, but these are not in widespread use.

The nature of dialysis care means that patients may need to consult with a range of healthcare professionals, including nephrologists, dieticians, psychologists, nurses, cardiologists and pharmacists. It is important that assessments of quality take into account the extent to which services are able to meet the entirety of a patient's needs and not simply the process of dialysis. A multidisciplinary approach built around the patient, with data and information shared across disciplines, is currently lacking in many services.

Many European countries have introduced financial incentives to improve quality of care.[43] In France, for example, health authorities aim to encourage investment in quality care through the financial incentive for quality improvement (IFAQ) scheme.[44] This incentive-based approach links a provider's income to the achievement of nationally-set quality indicators, such as structure and organisation and, importantly, patient satisfaction. Similar pay-for-performance quality systems for dialysis are in place in the UK[49] and Czech Republic.[51] This model could serve as an example for other European countries. As a second step, in countries where dialysis bundles already exist, funding could be linked to quality measures and controls. This would ensure that the additional financial resources are used to improve patient care and their quality of life.

Funding

Funding policies for dialysis care vary across European countries and levels of reimbursement can depend on factors such as the site of care, type of dialysis being administered, frequency of the treatment and hospital budgets. In France, for example, there is a very diverse network of limited care centres which are very innovative in comparison to other European countries.[53] Regardless of the health system, funding policies that take into account symptom-based complications as well as the provision of dialysis would support improvements in quality of life.

Patient information

Another key indicator for quality is the extent to which patients feel able to make informed decisions about their care. This is underpinned by access to high quality, timely and relevant information, enabling them to ask questions, seek advice and make appropriate treatment decisions. Patients do not always feel comfortable asking questions, may lack access to relevant information and may consequently under-report their symptoms, in turn reducing opportunities to enable effective management of complications. It has been found, for example, that less than half of patients in haemodialysis suffering from pruritus have reported their symptoms to their nephrologist and 25% did not report them to any healthcare provider.[46]

"Many of my decision-making and shared care conversations were around dialysis, but also transplantation. It was extremely important to have conversations around quality of life, taking into account which form of dialysis would suit me best bearing in mind my aspirations and other aspects of my life. Dialysis needs to work for patients, and not patients having to work around dialysis." **– Faizan Awan, United Kingdom**



Opportunities to improve the quality of life of patients on dialysis across Europe

Policy action at European and national levels could deliver significant improvements in the quality of life for patients on dialysis, including in the way in which dialysis services are organised. Examples include minimising the impact of modifiable symptom-based complications, patient empowerment over treatment decisions and enabling greater flexibility regarding when dialysis is delivered. Specifically, action is required in three areas:

Recommendation 1: Introduce disease-specific quality of life indicators, including patient-reported outcomes measures and patient-reported experience measures, as a key measure of success in dialysis care

• Introduce systematic quality of life measurement systems and the collection of patient-reported outcome measures (PROMs and PREMs) as a routine part of patient care, with clear criteria and metrics to evaluate the modifiable symptom-based complications and including data collection to gain more insights on how the quality of life could be improved
• Leverage the opportunities created by digital health to create resources which make it easier for patients to record their quality of life, access information to manage symptom-based complications and receive advice on how to describe issues to their clinical teams
• Use the data collected to evaluate improvements and deficits in patients' quality of life and develop action plans to address particular issues which patients may be facing, being able to identify and act on modifiable symptom-based complications
• Make aggregated data publicly available so that good practice may be identified and learned from
• Incorporate data on quality of life into funding mechanisms for dialysis services, rewarding providers achieving good quality of life and ensuring that existing care bundles do not create financial disincentives that limit access to support services for patients

The effectiveness of dialysis care is about more than just the laboratory values which might be recorded. Instead, how a patient feels and their ability to lead the life they wish to lead should be the central goal. It is important to have the correct quality of life measures available that can inform both decision-makers and physicians. However, good baselines must be established as, generally speaking, the quality of life of dialysis patients in comparison to general patients is much poorer.

Quality of life should be put at the forefront, ensuring that services are focused on the issues which matter most to patients.13 All services should be routinely collecting PROMs, and developing action plans to address any areas of identified deficit. The accurate assessment and treatment of bothersome symptoms in dialysis patients is essential if efforts to improve the care of this patient population are to be successful, and tools, such as the KDQOL, should form a routine part of dialysis care.48 Healthcare professionals could include straightforward quality of life-related questions in their routine conversations with their patients on, for example, side-effects, sleep quality or even itching issues.

Developments in digital health create opportunities to improve both the quality and efficiency of the collection of quality of life data, such as the development of mobile applications that can be easily used by dialysis patients to record their physical and mental health. Digital resources can also be used to educate patients on potential side effects, helping them identify issues early, as well as offering support on how to self-manage, when this is appropriate, or the best way to describe issues to clinicians.

In the Netherlands, an annual, validated quality of life questionnaire to collect PROMs from dialysis patients has been running since 2016.[12,50] It includes 42 questions about general quality of life and can only be completed online. Any patient included in the national Renine registry - 97% of dialysis patients in the Netherlands - can be invited to take part in the survey. While the survey currently focuses on dialysis only, there are future plans for it to be expanded to chronic kidney damage and to renal replacement treatment.

Recommendation 2: Establish a Dialysis Quality Guarantee to ensure all patients receive quality dialysis care in countries where dialysis is fully establised

• Develop clear standards, including on quality of life, on what constitutes a high quality dialysis service. Encourage dialysis centres to sign up to them, providing assurance to patients that their care will be high quality and to payers that resources will be used effectively
• Ensure appropriate funding for dialysis services, including ensuring that the support services and interventions which can improve quality of life are properly funded
• Conduct a future funding assessment to evaluate the impact of rising need for dialysis on funding requirements

• Work with key stakeholders, such as the European Kidney Health Alliance, to collect and publish data on adherence to key quality standards across Europe

The need for dialysis is set to further increase across Europe, due to changing demographics and the rising prevalence of advanced stage kidney disease. Although steps should be taken to reduce the number of patients who require dialysis by improving prevention and transplantation, it is inescapable that the pressures on dialysis services will grow.

Policy attention needs to be devoted to ensuring that future needs are met, with appropriate funding and strategies to maximise capacity and realise efficiencies. It is important that funding is based on the resources required to deliver a high quality, holistic service, enabling improvements in quality of life as well as the safe and effective delivery of dialysis.

Funding should also create room – and incentives – for innovation, encouraging services to adopt developments in treatment and care which can improve outcomes, convenience or efficiency. Innovation does not have to be expensive – and indeed changes in service provision can improve quality, reduce costs and create efficiencies – but it is important that sufficient flexibility is available to support changes in the way services are provided, including dialysis in the home, where these are justified. The implementation of quality of life assessments in routine clinical care, followed by interventions, has previously been the subject of calls to action from experts in the field.[19] Any findings stemming from how a patient's quality of life is being impacted should be incorporated in the management of dialysis patients.

2018 guidance from the National Institute for Health and Care Excellence (NICE) on renal replacement therapy in the UK are a good example of guidelines introduced to ensure the quality of dialysis treatments. They aim to improve quality of life by making recommendations on planning, starting and switching treatments, and coordinating care.[52]



Although quality of life issues have a significant impact on patients, they are currently under-reported and therefore not addressed. For many people, dialysis is a necessity to prolong their life, but some of its positive impact on patients' lives can be lost, unless the complications of advanced stage kidney disease are managed in their entirety. Healthcare professionals should therefore be encouraged to have conversations around quality of life by asking patients relevant questions.

There is a longstanding perception amongst CKD patients that their illness has a substantial impact on their lives,[26] which can in turn lead to emotional and mental distress. Greater attention should be paid to the mental health of patients living with CKD, where emotional aspects such as sexual dysfunction, work and social integration are included in their care. Emotional aspects such as anxiety and depression are highly prevalent in patients undergoing renal replacement therapy, but are commonly forgotten among nephrologists.[18] Even those suffering from early stage CKD can feel significant physical and emotional effects, which is often underestimated by healthcare professionals.[21]

The high emotional and mental burden on caregivers should also not be forgotten. Tasks such as taking CKD patients for dialysis sessions on a regular basis, ensuring adherence to medication and other common caregiving responsibilities can take their toll. As mentioned previously, burnout, depression, fatigue and isolation are commonly reported in caregivers of patients living with CKD.[11]

Policymakers can support healthcare professionals working in dialysis services by ensuring that appropriate support is available for training and that policies recognise the importance of genuinely multidisciplinary team care, so that care plans can be informed by a full range of professional perspectives. To be effective, multidisciplinary team working needs to be adequately resourced and supported by appropriate infrastructure. This would enable team collaboration, as well as ensure that patients are benefitting from full support when they attend care in a dialysis unit, but can also have access to high quality remote care.

Healthcare professionals can also be supported by the use of digital resources, enabling patients to record and discuss quality of life issues and ensure that these are appropriately managed and documented in health records.

Conclusion

Patients living with CKD, in particular advanced stage kidney disease, can be exposed to a series of symptom-based complications that affect their quality of life. Some of them are modifiable and there are opportunities to improve their recognition and management. For that to happen, healthcare systems should start focusing on what matters most to patients living with advanced stage kidney disease, and prioritise improving the quality of life of patients on dialysis across Europe.

Ensuring that symptom-based complications are identified and managed is a first key step to create a holistic patient-centred approach, while services are organised in a way which better responds to patients' needs. Strengthened partnerships with patients in the development, implementation and evaluation of interventions for practice and policy settings, as advocated for by the World Kidney Day Steering Committee, are a crucial step towards improving quality of life.[11]



With this paper, we aim to draw European and national policymakers' attention towards the unmet needs of patients who have to rely on dialysis in the coming years, as they can play a central role in shaping the tomorrow of patients living with advanced stage kidney disease. Policy action and roll-out plans at European and national level can make a real difference to further improve the quality of life of patients living with CKD, including those on dialysis, across Member States. Improved quality of life for patients living with CKD will ultimately translate into improved health outcomes, and will ultimately reduce the impact on healthcare systems overall.

We call on European and national policymakers to put in place necessary regulatory frameworks to implement the three recommendations developed in this paper. We aim to build on the existing opportunities, and to contribute to the ongoing discussions around improving the quality of life of patients living with advanced stage kidney disease on dialysis across Europe, to ensure concrete actions and roll-out plans will be put in place.

ABOUT EKPF

EKPF is a non-profit entity that represents kidney patients at European level. EKPF represents over 75 million of people with kidney health conditions in Europe. Its membership brings together 27 national kidney patients federations from 26 different countries across Europe. Our Federation aims to raise End Stage Kidney Disease on the European public health agenda; promote the prevention of the disease; establish an early detection and a European quality standard in the treatment of patients with CKD; increase organ donation and transplantation; improve the well-being, treatment, social security and living conditions of all kidney patients and their carers and increase cooperation and information exchange with organizations and institutions involved in renal diseases. These aims shall be achieve by promoting a general kidney disease policiy to protect the interests of patients and their carers, monitoring EU developments and making legislative proposals, offering patients view and disseminating information and education and promoting medical, educational and social rehabilitation and integration of all kidney patients.

The Federation brings together European organizations and carries out activities to promote its aims such as the organization of conferences and training seminars, the development of research and studies or the publication of journals, among others.

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- **Faizan Awan** (Patient advocate, UK)
- **Dr Philippe Chauveau** (nephrologist, Aurad-Aquitaine and formerly Bordeaux Hospital University Center (CHU), France)
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- **Dr Patricia De Sequera** (President of the Spanish Association of Nephology, Spain)
- **Prof. Raymond Vanholder** (President of the European Kidney Health Alliance and President of the Chronic Disease Alliance, Belgium)
- **Fresenius Medical Care**
- **Vifor Pharma**

References

1. NHS. Chronic Kidney Disease. https://www.nhs.uk/conditions/kidney-disease/.
2. Kidney Research UK. Stages of Kidney Disease. https://kidneyresearchuk.org/kidney-health-information/stages-of-kidney-disease/.
3. Mayo Clinic. End-stage renal disease: symptoms and causes. https://www.mayoclinic.org/diseases-conditions/end-stage-renal-disease/symptoms-causes/syc-20354532.
4. Eurostat. Deaths due to kidney diseases in the EU. https://ec.europa.eu/eurostat/web/products-eurostat-news/-/EDN-20200319-1.
5. World Health Organization. The top 10 causes of death. https://www.who.int/news-room/fact-sheets/detail/the-top-10-causes-of-death.
6. World Kidney Day. Chronic Kidney Disease. https://www.worldkidneyday.org/facts/chronic-kidney-disease/.
7. Couser, W.G., Remuzzi, G., Mendis, S., and Tonelli, M. (2011). The contribution of chronic kidney disease to the global burden of major noncommunicable diseases. Kidney Int. 80.
8. Foreman, K.J., Marquez, N., Dolgert, A., Fukutaki, K., Fullman, N., McGaughey, M., Pletcher, M.A., Smith, A.E., Tang, K., Yuan, C.W., et al. (2018). Forecasting life expectancy, years of life lost, and all-cause and cause-specific mortality for 250 causes of death: reference and alternative scenarios for 2016–40 for 195 countries and territories. Lancet 392.
9. Bikbov, B., Purcell, C.A., Levey, A.S., Smith, M., Abdoli, A., Abebe, M., Adebayo, O.M., Afarideh, M., Agarwal, S.K., Agudelo-Botero, M., et al. (2020). Global, regional, and national burden of chronic kidney disease, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. Lancet 395.
10. World Kidney Day. 2021 WKD Theme. https://www.worldkidneyday.org/2021-campaign/2021-wkd-theme/.
11. Kalantar-Zadeh, K., Kam-Tao Li, P., Tantisattamo, E., Kumaraswami, L., Liakopoulos, V., Lui, S.F., Ulasi, I., Andreoli, S., Balducci, A., Dupuis, S., et al. (2021). Living well with kidney disease by patient and care-partner empowerment: kidney health for everyone everywhere. Kidney Int. 99.
12. van der Willik, E.M., Hemmelder, M.H., Bart, H.A.J., van Ittersum, F.J., Hoogendijk-van den Akker, J.M., Bos, W.J.W., Dekker, F.W., and Meuleman, Y. (2021). Routinely measuring symptom burden and health-related quality of life in dialysis patients: first results from the Dutch registry of patient-reported outcome measures. Clin. Kidney J. 14.
13. Wang, Y., Snoep, J.D., Hemmelder, M.H., van der Bogt, K.E.A., Bos, W.J.W., van der Boog, P.J.M., Dekker, F.W., de Vries, A.P.J., and Meuleman, Y. (2021). Outcomes after kidney transplantation, let's focus on the patients' perspectives. Clin. Kidney J. 14.
14. National Institute of Diabetes and Digestive and Kidney Diseases. What Is Chronic Kidney Disease? https://www.niddk.nih.gov/health-information/kidney-disease/chronic-kidney-disease-ckd/what-is-chronic-kidney-disease.
15. American Kidney Fund. Treating kidney failure. https://www.kidneyfund.org/kidney-disease/kidney-failure/treatment-of-kidney-failure/.
16. Himmelfarb, J., Vanholder, R., Mehrotra, R., and Tonelli, M. (2020). The current and future landscape of dialysis. Nat. Rev. Nephrol. 16.
17. Kolhe, N. V., Fluck, R.J., Selby, N.M., and Taal, M.W. (2020). Acute kidney injury associated with COVID-19: A retrospective cohort study. PLoS Med. 17.
18. Taylor, F., Combes, G., and Hare, J. (2016). Improving clinical skills to support the emotional and psychological well-being of patients with end-stage renal disease: A qualitative evaluation of two interventions. Clin. Kidney J. 9.
19. Davison, S.N., Levin, A., Moss, A.H., Jha, V., Brown, E.A., Brennan, F., Murtagh, F.E.M., Naicker, S., Germain, M.J., O'Donoghue, D.J., et al. (2015). Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: Developing a roadmap to improving quality care. Kidney Int. 88.
20. American Kidney Fund. Stages of Chronic Kidney Disease (CKD). https://www.kidneyfund.org/kidney-disease/chronic-kidney-disease-ckd/stages-of-chronic-kidney-disease/.
21. Baker, A., King, D., Marsh, J., Makin, A., Carr, A., Davis, C., and Kirby, C. (2015). Understanding the physical and emotional impact of early-stage ADPKD: Experiences and perspectives of patients and physicians. Clin. Kidney J. 8.

22. Gilbert, J., Lovibond, K., Mooney, A., and Dudley, J. (2018). Renal replacement therapy: Summary of NICE guidance. BMJ 363.
23. Kidney News. Frequent Long Dialysis: Why Do Length and Frequency Help? https://www.kidneynews.org/kidney-news/features/frequent-long-dialysis-why-do-length-and-frequency-help.
24. Healthline. Dialysis: Purpose, Types, Risks, and More. https://www.healthline.com/health/dialysis.
25. Kramer, A., Boenink, R., Stel, V.S., Santiuste de Pablos, C., Tomović, F., Golan, E., Kerschbaum, J., Seyahi, N., Ioanou, K., Beltrán, P., et al. (2021). The ERA-EDTA Registry Annual Report 2018: a summary. Clin. Kidney J. 14.
26. Clarke, A.L., Yates, T., Smith, A.C., and Chilcot, J. (2016). Patient's perceptions of chronic kidney disease and their association with psychosocial and clinical outcomes: A narrative review. Clin. Kidney J. 9.
27. Hays, R.D., Kallich, J.D., Mapes, D.L., Coons, S.J., and Carter, W.B. (1994). Development of the Kidney Disease Quality of Life (KDQOLTM) Instrument. Qual. Life Res. 3, 329–338.
28. Neri, L., Ponce, P., Matias, N., Stuard, S., and Cromm, K. (2020). Clinical target achievement is associated with better quality of life among dialysis patients: results from a continuous quality improvement program in a Portuguese healthcare network. Qual. Life Res. 29.
29. International Consortium for Health Outcomes Measurement. Chronic Kidney Disease Standard Sets. https://connect.ichom.org/standard-sets/chronic-kidney-disease/.
30. Manns, B., Hemmelgarn, B., Lillie, E., Dip, S.C.P.G., Cyr, A., Gladish, M., Large, C., Silverman, H., Toth, B., Wolfs, W., et al. (2014). Setting research priorities for patients on or nearing dialysis. Clin. J. Am. Soc. Nephrol. 9.
31. Jhamb, M., Weisbord, S.D., Steel, J.L., and Unruh, M. (2008). Fatigue in Patients Receiving Maintenance Dialysis: A Review of Definitions, Measures, and Contributing Factors. Am. J. Kidney Dis. 52.
32. British Medical Journal. Covid-19 and chronic kidney disease: It is time to listen to patients' experiences. https://blogs.bmj.com/bmj/2020/08/28/covid-19-and-chronic-kidney-disease-it-is-time-to-listen-to-patients-experiences/.
33. Vanholder, R., Annemans, L., Bello, A.K., Bikbov, B., Gallego, D., Gansevoort, R.T., Lameire, N., Luyckx, V.A., Noruisiene, E., Oostrom, T., et al. (2021). Fighting the unbearable lightness of neglecting kidney health: the decade of the kidney. Clin. Kidney J.*
34. Sharif, M.U., Elsayed, M.E., and Stack, A.G. (2016). The global nephrology workforce: Emerging threats and potential solutions! Clin. Kidney J. 9.
35. Sukul, N., Karaboyas, A., Csomor, P.A., Schaufler, T., Wen, W., Menzaghi, F., Rayner, H.C., Hasegawa, T., Al Salmi, I., Al-Ghamdi, S.M.G., et al. (2021). Self-reported Pruritus and Clinical, Dialysis-Related, and Patient-Reported Outcomes in Hemodialysis Patients. Kidney Med. 3.
36. Sukul, N., Karaboyas, A., Rayner, H.C., Csomor, P.A., Schaufler, T., Wen, W., Menzaghi, F., Hasegawa, T., Chen, Y., Salmi, I. Al, et al. (2018). Pruritus and Clinical Outcomes in Hemodialysis Patients: Results from the International DOPPS. 1, 2018.
37. Ramakrishnan, K., Bond, T.C., Claxton, A., Sood, V.C., Kootsikas, M., Agnese, W., and Sibbel, S. (2013). Clinical characteristics and outcomes of end-stage renal disease patients with self-reported pruritus symptoms. Int. J. Nephrol. Renovasc. Dis. 7.
38. Moist, L.M., Bragg-Gresham, J.L., Pisoni, R.L., Saran, R., Akiba, T., Jacobson, S.H., Fukuhara, S., Mapes, D.L., Rayner, H.C., Saito, A., et al. (2008). Travel Time to Dialysis as a Predictor of Health-Related Quality of Life, Adherence, and Mortality: The Dialysis Outcomes and Practice Patterns Study (DOPPS). Am. J. Kidney Dis. 51.
39. Diamant, M.J., Harwood, L., Movva, S., Wilson, B., Stitt, L., Lindsay, R.M., and Moist, L.M. (2010). A comparison of quality of life and travel-related factors between in-center and satellite-based hemodialysis patients. Clin. J. Am. Soc. Nephrol. 5.
40. Rucker, D., Hemmelgarn, B.R., Lin, M., Manns, B.J., Klarenbach, S.W., Ayyalasomayajula, B., James, M.T., Bello, A., Gordon, D., Jindal, K.K., et al. (2011). Quality of care and mortality are worse in chronic kidney disease patients living in remote areas. Kidney Int. 79.
41. Thompson, S., Gill, J., Wang, X., Padwal, R., Pelletier, R., Bello, A., Klarenbach, S., and Tonelli, M. (2012). Higher mortality among remote compared to rural or urban dwelling hemodialysis patients in the United States. Kidney Int. 82.
42. Kallenbach, J. (2011). Management of quality in dialysis care. Rev. Hemodial. Nurses Dial. Pers. 8th Ed.
43. Eckhardt, H., Smith, P., and Quentin, W. (2019). Pay for Quality: using financial incentives to improve quality of care.
44. Haute Autorité de Santé. L'incitation financière pour l'amélioration de la qualité (IFAQ). https://www.has-sante.fr/jcms/c_493937/fr/l-incitation-financiere-pour-l-amelioration-de-la-qualite-ifaq.
45. Muehrer, R.J., Schatell, D., Witten, B., Gangnon, R., Becker, B.N., and Hofmann, R.M. (2011). Factors affecting employment at initiation of dialysis. Clin. J. Am. Soc. Nephrol. 6.
46. Rayner, H.C., Larkina, M., Wang, M., Graham-Brown, M., van der Veer, S.N., Ecder, T., Hasegawa, T., Kleophas, W., Bieber, B.A., Tentori, F., et al. (2017). International comparisons of prevalence, awareness, and treatment of pruritus in people on hemodialysis. Clin. J. Am. Soc. Nephrol. 12.
47. Nie, Y., Witten, B., Schatell, D., Assari, S., Ding, X., Saran, R., and Bragg-Gresham, J.L. (2020). Changes in employment status prior to initiation of maintenance hemodialysis in the USA from 2006 to 2015. Clin. Kidney J. 13.
48. Weisbord, S.D., Fried, L.F., Arnold, R.M., Rotondi, A.J., Fine, M.J., Levenson, D.J., and Switzer, G.E. (2004). Development of a symptom assessment instrument for chronic hemodialysis patients: The dialysis symptom index. J. Pain Symptom Manage. 27.
49. Department of Health & Social Care (2021). Integration and innovation: working together to improve health and social care for all. https://www.gov.uk/government/publications/working-together-to-improve-health-and-social-care-for-all/integration-and-innovation-working-together-to-improve-health-and-social-care-for-all-html-version.
50. Nefrovisie. National request for PROMs for dialysis patients. https://www.nefrovisie.nl/nieuwsbrief/start-landelijke-uitvraag-proms-voor-dialysepatienten/.
51. Government of the Czech Republic. Decree No. 268/2019. https://www.zakonyprolidi.cz/cs/2019-268#p1.
52. National Institute for Health and Care Excellence (2018). Renal Replacement Therapy and Conservative Management Guidelines.
53. Commission des affaires sociales du Sénat (2020). L'insuffisance rénale chronique terminale: une prise en charge à réformer au bénéfice des patients. http://www.senat.fr/fileadmin/Fichiers/Images/commission/affaires_sociales/2020-03-04_Diaporama_IRCT.pdf.



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