HEALTH EDUCATION
IN CKD



EKPF European Kidney Patients Federation
Hackhofergasse 8
1190 Wien
Viena
info@ekpf.eu
www.ekpf.eu

Administrative headquarters
FEDERACIÓN NACIONAL ALCER
Calle Constancia 35. Local 2
28002. Madrid
915 610 837
informacion@alcer.org
www.alcer.org

Coordination: Juan Carlos Julián • Editing: Roberto Ortiz • Drafting: Mónica Suengas

The need for health education in CKD

Prof. Raymond Vanholder point of view

Only 14% of Europeans on dialysis is treated at home. Home dialysis provides the best quality of life, lowest societal cost, and survival is at least equal to in-center HD. Education would be part of the solution.

Transplantation provides best quality of life at end stage kidney disease, best survival and lowest societal cost. Because of this you would expect it to have very high rates, but in reality is only 38%. There are of course huge differences among countries in transplantation. Spain and Netherlands doing very well. Only 38% of Europeans with advanced CKD is transplanted. Part of the problem with this is education.in transplantation.



Raymond Vanholder
President of the European Kidney Health Alliance (EKHA)

Education to prevent kidney failure

We know that prevention is healthy lifestyle. We have to control smoking, obesity, the lack of exercise and the salt, phosphate and sugar intake.

When we talk about education, we also talk about education and information for healthcare professionals, general population and policy makers.

General population has to be aware of chronic kidney disease. We are heavily in need of patient-friendly solutions. We need to measure the quality of information and whether it is given.

What aspects would CKD education improve for kidney patients?

• It is very important that patients become resilient and they say clearly what they want when communicating with doctors. They have to become stronger in telling what they want and what they would want to accomplish.

• There are very interesting projects such as EUPATI, which is an education platform that increases patients' engagement and has members from the EKPF.

• The level of health illiteracy among CKD patients is around 30-35%. Transplant education is more common and more patients are choosing to transplant, however they are not educated about other therapies and that must be corrected.We need specific education and we need to work together with the patient community, communities with high health illiteracy and specialists in education, because nephrologists are not very well trained for education.

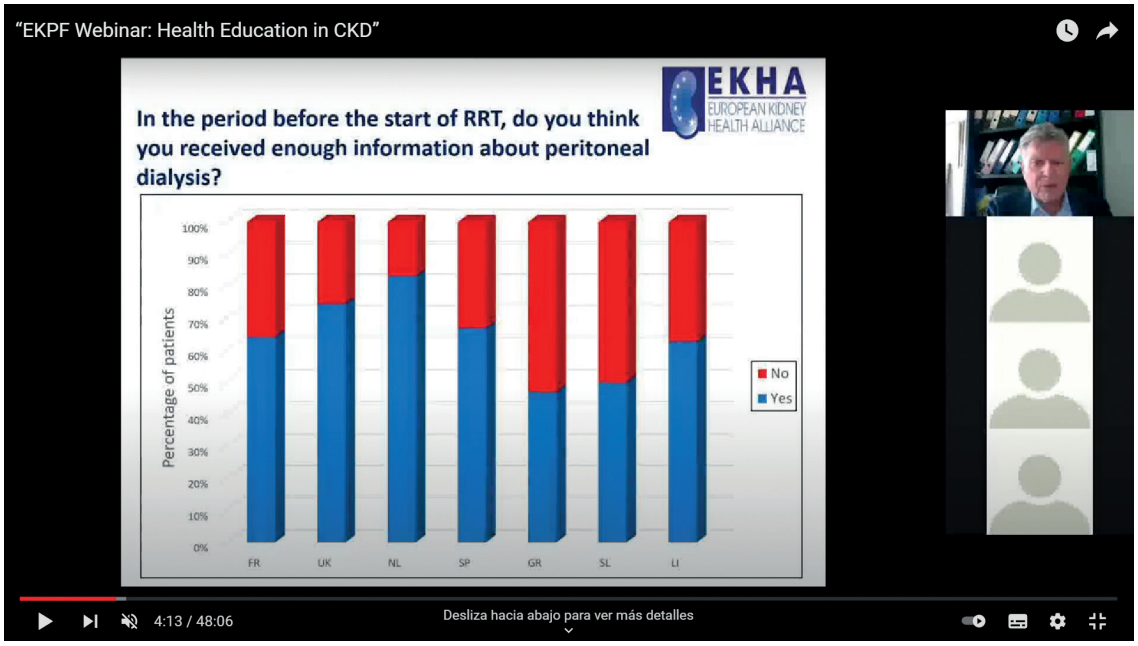
The best professionals to deliver education to patients may be the nurses, because they are closer to the patients and have other tools. We as doctors are not well trained.

Phisicians need to receive advice from education specialists because we, are not professionals and do not have training on this.

There is a study in which they were looking at elements that were contributing to self-care. The worst results were related to quality of life and to easy preventive measures such as diet and exercise. These aspects could be covered and are able to have an impact on the progression of the kidney.



A few years ago, the EKHA surveyed European renal replacement therapy patients about **their satisfaction with the information** they received about peritoneal dialysis. Dissatisfaction was 35%. There were also large differences between countries. The countries with the l**owest satisfaction are those with the lowest uptake of peritoneal dialysis. Also, lower income countries reported a lower percentage of patient information** on different treatments, so there is also an economic factor.





Monika-Lichodziejewska-Niemierko
Head of the Peritoneal Dialysis Unit Department of Nephrology Transplantology and Internal Medicine University Hospital of Gdańsk, Poland
Vice Chair EuroPD

Prof. Monika Lichodziejewska-Niemierko

Keys to pre-dialysis education and the importance of shared-decision making

Slow the progression of ESRD:

The progression of the disease depends on particularities of kidney disease but also on treatment and adherence to diet and medication and lifestyle indications.

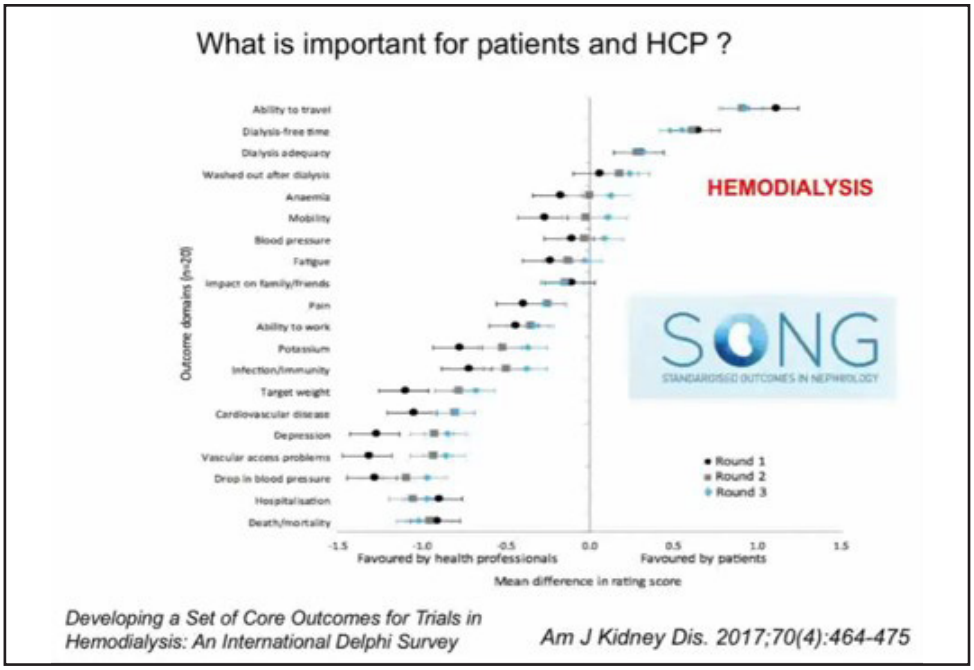
If we talk about education or training or information, we need to talk about slowing the progression and talking about education early in CKD. Specifically, in the end stage kidney disease and the options we can have.

Kidney Replacement Therapies:

Transplantation is the best possible treatment but not for everybody.

Dialysis, home therapy treatment, and palliative and supportive care are other options.

The need for health education in CKD



Education to prevent kidney failure

- Most important patient-reported outcomes are not the same as health professionals' priorities, we need to think that medical goals and patient goals may be different and we need to understand each other. The health professional knows the medical evidence, and the patient knows what is important for them.
- Quality of life (QoL) is very important; treatment cannot just be about surviving. Patient's challenge is to maintain the meaning of life.
- Patients should be honestly taught and informed about all possible options. We need to take into consideration patients' preferences to offer the best QoL.
- Nurses are perfect and fantastic at teaching, but this does not mean that doctors should skip this. Doctors should be closer and always open for patients who want to ask questions.
- El afrontamiento emocional juega un papel importante en la progresión de la enfermedad y esto rara vez es detectado por los nefrólogos. Algunos pacientes tardan un tiempo en darse cuenta de que su vida va a cambiar por completo y se trata de un problema emocional que puede jugar un papel muy importante en la progresión de la enfermedad.



Shared decission making

- Shared-decision making is a key component of patient-centered health care. It is a joint process in which a healthcare professional works together with another person to reach a decision about care. It involves choosing tests and treatments based both on evidence and on the person's individual preferences, beliefs and values.

- We have so many options and we have to look at each person individually.

- We talk a lot about elderly people because is the group of patients that normally enter treatments for end stage kidney disease, especially dialysis. But an elderly patient may also be very different and we are not talking about the age, but rather about fitness. Patient goals may be very different.

The three essential elements of shared-decision making:

- Recognizing and acknowledging that a decision is required;
- Knowing and understanding the best available evidence;
- Incorporating the person's values and preferences into the decision.
- This is what we call patient-centered vision of care for ESKD
- Quality of life is one of the most important things that could drive the choice of treatment.

David Marshal
Moderator

It has to be an informed decision making. I like to be informed of all my options so then I can talk to my team and decide what is the best one for me.



in transplantation. Spain and Netherlands doing very well. Only 38% of Europeans with advanced CKD is transplanted. Part of the problem with this is education.

If you could give just one advice to improve health education to kidney patients, what would it be?

“Educate health care professionals. Educate the educator”

Monika Lichodziejewska-Niemierko
Raymond Vanholder

GOLD SPONSOR

Baxter

VIFOR PHARMA

FRESENIUS MEDICAL CARE

astellas

SILVER SPONSOR

DIAVERUM

NOVARTIS

UNION THERAPEUTICS

HANSA BIOPHARMA

BRONZE SPONSOR

Bristol Myers Squibb