



Leading European Nephrology

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European Renal Association – European Dialysis and Transplant Association

Do we have the right tools, but the wrong language?

A study in the current issue of ckj [1] shows that information material on transplantation, even on the most popular websites, is too complicated and cannot be understood by the target group: the patients.

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According to the Pew Research Center, 72 percent of internet users looked online for health information within the past year. Of these online health seekers, 77 percent of people started their search at a search engine such as Google, Bing, or Yahoo [2]. It is known that patients utilize online resources to guide healthcare decision-making, especially if they suffer from serious illnesses that will most probably change their life, as an end stage renal disease. These patients search the web for information on renal replacement therapy, which is dialysis or transplantation.

A study of the Institute of Education Sciences [3] found out that the average reading level ranges between 7th and 8th grade. As such, the National Institute of Health recommends patient education materials to be written at approximately a 7th grade level [4].

The authors of the new ckj study [1] compared the readability of online living donor recipient materials versus the readability of deceased donor recipient material in the web – and came to an astonishing result: Readability analysis was performed in the top ten results from each Google search. Overall, the mean reading level for the Living Donor materials was 12.54 (range 9.2-17) and for the Deceased Donor materials, 12.87 (range 8.7-17, $P=0.73$), both corresponding to a university level. None of the sites met the 7th grade level recommended by the NIH.

“This circumstance should rouse us. We provide information the patients cannot understand. But how can we expect health awareness and compliance, if the messages we wish to convey are not understood?”, explains ckj editor-in-chief, Professor Alberto Ortiz.

ERA-EDTA draws the conclusion that patients’ materials have to be updated or newly developed. “We will keep this important insight of the study in mind, when we start to work on our new information brochure *The Inner Connection: The Kidneys at the heart of your health*, which will be



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launched at World Kidney Day”, promises Professor Carmine Zoccali, president of the ERA-EDTA.

[1] Eric P. Zhou et al. Online Patient Resources for Deceased Donor and Live Donor Kidney Recipients: A Comparative Analysis of Readability. CKJ 2017. Available from:

<https://academic.oup.com/ckj/advance-article/doi/10.1093/ckj/sfx129/4657174>

[2] Available from: <http://www.pewinternet.org/fact-sheets/health-fact-sheet>

[3] Kirsch, I.S. et al., Adult Literacy in America National Center for Education Statistics 2002.

[4] How to Write Easy to Read Health Materials Available from:

<http://www.nlm.nih.gov/medlineplus/etr.html>

About ERA-EDTA

With more than 7,500 members, the ERA-EDTA ("European Renal Association – European Dialysis and Transplant Association") is one of the biggest nephrology associations worldwide and one of the most important and prestigious European Medical Associations. It supports basic and clinical research in the fields of clinical nephrology, dialysis, renal transplantation and related subjects. It also supports a number of studies as well as research groups and has founded a special "Fellowship Programme" for young investigators as well as grant programmes. In order to involve young nephrologists in all its activities ERA-EDTA has the "Young Nephrologists' Platform" (YNP), a very active committee whose board includes members who are 40 years old or younger. Besides, it has established various working groups to promote the collaboration of nephrologists with other medical disciplines (e.g. cardiology, immunology). Furthermore, a "European Renal Best Practice" (ERBP) advisory board was established by the ERA-EDTA to draw up and publish guidelines and position statements. Another important goal of the ERA-EDTA is education: several series of CME-courses as well as the annual congress offer an attractive scientific programme to cover the need of continuous medical education for doctors working in the fields of nephrology, dialysis and transplantation. The association's journals, NDT (Nephrology, Dialysis, Transplantation) and CKJ (Clinical Kidney Journal), are currently the leading nephrology journals in Europe; furthermore NDT-Educational is the online educational journal, open for free to all uses, of the Society as well as the very important and useful feature of NDT-Educational "Literature Review". The ERA-EDTA Registry is a large epidemiologic database comparing countries by assessing nephrology practice throughout Europe. ENP, the European Nephrology Portal, is the latest new initiative of ERA-EDTA: here all those interested in the activities of the Society can find everything that is done, all in one place! Finally, ERA-EDTA is a member of the European Kidney Health Alliance (EKHA), a consortium of patients, nurses, foundations all related to renal issues that actively interacts with the European Parliament. For more information please visit www.era-edta.org