

PERCEIVED INFORMATION LEVEL AND EDUCATIONAL NEEDS IN DIALYSIS AND TRANSPLANTED PATIENTS

C. Isnard Bagnis¹, E. Speyer², D. Beauger³, Y. Caillé⁴, C. Baudelot⁴, S. Mercier⁴, C. Jacquelinet⁵, S. Gentile⁶, S. Briançon²;

¹Nephrology, Groupe Hospitalier Pitie Salpetriere et Chaire de Recherche en Education Therapeutique, paris, FRANCE, ²CHU Nancy, Po1e QSP2, Epidémiologie et Evaluation Cliniques et Université de Lorraine, Université Paris Descartes, Apemac, EA4360, Nancy, FRANCE, ³Laboratoire de Santé Publique, Université Aix-Marseille, Faculté de Médecine, Marseille, FRANCE, ⁴Renaloo, Paris, FRANCE, ⁵Agence de la Biomédecine, Saint Denis, FRANCE, ⁶Université Aix- Marseille et AP-HM, Laboratoire de Santé Publique, et Service Santé Publique et Information Médicale, Marseille, FRANCE.

Objectives:

ESRD patients need to make choices with regard to treatment and therefore need sufficient level of information. In order to improve self care and quality of life, not only knowledge but also counseling is critical. Part of it is provided through educational programs. This national study aimed at analyzing the way ESRD patients access information and participate to educational programs by describing their needs in terms of counseling.

A cross-sectional study by mailed self-administrated questionnaire, was performed on an ESRD representative sample constituted with 3386 dialysis patients and 3555 renal transplanted patients, aged of 18 years and more, treated for at least one year, included in one of the 21 (over 23) French regions taking part in the REIN registry in 2010. Data on the way ESRD patients may access information and educational programs as well as their needs in term of counseling, education, information were collected in addition of sociodemographic and medical data. Patients answered a French validated version of the **Health Education Impact Questionnaire**, a questionnaire used to evaluate impact of educational programs on 6 domains (Health directed behavior, positive and active engagement in life, emotional well-being, self-monitoring and insight, constructive attitudes and approaches, skill and technique acquisition, social integration and support, health service navigation). Self estimated adherence to treatments was evaluated both for immunosuppressive drugs in transplanted patients and for all other treatments in all.

Methods:

Results:

Perceived information level was high in dialysis and transplanted patients (enough information 39.3% vs 40.2%, p=0.04) both at diagnosis of the disease and along treatment steps. Both dialysis and transplanted patients felt they were **listened to** in 27.7% and 28.1% of the cases respectively). Despite attesting medical teams **considered their opinion** (27.7% and 28.1% respectively), dialysis and transplanted patients recognized they felt **involved into therapeutic choices** made in 26.2% and 32.5% of the cases respectively (p<0.0001).

49.4% and 32.6% of dialysis and transplanted respectively (p= 0.04) **never searched for information** on disease and treatment.

12.5% of dialysis patients and 5.6% of transplanted patients expressed **a need for help** in improving quality of their life with the disease (p=0.0001). 17.6% of the dialysis patients placed **pain as their major area of concern** and need for help (vs 10.4% of transplanted patients, p=0.0011). Dialysis patients (13.4%) mentioned more **trouble in expressing themselves** and sharing ideas on ESRD than transplanted patients (9.1%, p=0.0007). They wished **to exchange more** with other patients and patients support groups. Only 14.1% of dialysis and 19.5% of transplanted patients **confirmed they attended educational programs** (p<0.006). Transplanted patients were more enclined into attending group sessions than dialysis patients.

Very few patients knew what educational programs really are (12.7% and 19.1% respectively, p<0.004) and less than 10% remembered having being ever offered to participate.

Scores from the HEIQ questionnaires were significantly higher in transplanted patients compared to dialysis patients.

HEIQ scores in transplanted and dialysis patients adjusted on age.

	Transplanted N=1658 (57.0%)			Dialysis N=1251 (43.0%)			p**
	N	mean	SD*	N	mean	SD*	
Comportement en santé	1571	2,8	0,8	1145	2,3	0,9	<0,0001
Engagement positif et actif dans la vie	1573	3,1	0,6	1143	2,6	0,7	<0,0001
Bien-être émotionnel	1573	2,9	0,7	1154	2,3	0,8	<0,0001
Autocontrôle et réflexivité	1574	3,3	0,4	1158	3,1	0,5	<0,0001
Attitudes et approches constructives	1570	3,2	0,5	1145	2,8	0,7	<0,0001
Acquisition de compétences et de technique	1561	2,9	0,5	1135	2,8	0,6	0,0028
Intégration et soutien social	1585	3	0,6	1153	3	0,6	0,058
Orientation dans les services de santé	1571	3,3	0,5	1157	3,3	0,5	0,0885

* SD

HeIQ score varies from de 1 à 4 (4 being the best result); ** ANOVA adjusted on age

Adherence to treatments

	Transplanted N=1658 (57,0%)			Dialysis N=1251 (43,0%)			p**
	N	%/mean	SD*	N	%/mean	SD*	
Medical treatment							
Respect of prescription	181	11,3		177	15,1		0,0038
Difficulties with timing of drugs	164	10,3		110	9,4		0,4277
Unpleasantness to take the treatment	41	2,6		94	8,0		<0,0001
Changes made in immunosuppressive drugs							
Never	1334	89,3					
Less than once a month	131	8,8					
1 to 3 times a month	19	1,3					
Once a week	5	0,3					
More than once a week	5	0,3					
Changes in others treatments							0,0001
Never	1256	84,8		841	79,2		
Less than once a month	163	11,0		133	12,5		
1 to 3 times a month	35	2,4		48	4,5		
Once a week	21	1,4		23	2,2		
More than once a week	7	0,5		17	1,6		

* SD

** Chi-2 test

Conclusions:

In 2009, France has passed a law suggesting educational programs should be available for all chronic patients. Despite increasing offer, there is a need for more information on those programs. CKD patients feel provided with enough information but experience not enough involvement into therapeutic choices. This work raises issues related to the effective dissemination of educational programs among CKD patients in France.

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