THE USE OF A DIARY AND PEDOMETER FOR TREATMENT ADHERENCE IN PATIENTS WITH AUTOSOMAL DOMINANT POLYCYSTIC KIDNEY DISEASE AND CHRONIC KIDNEY FAILURE: A RANDOMIZED CONTROLLED STUDY

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OSPEDALE
SAN RAFFAELE

Autosmal Dominant Polycistic Kidney disease- ADPKD

Genetic disorder characterized by two genes mutations: **PKD1** (responsible for 78% of cases) and **PKD2** .Which means that in most cases, the disease runs in families. Sometimes, a genetic mutation occurs on its own (spontaneous), so that neither parent has a copy of the mutated gene.

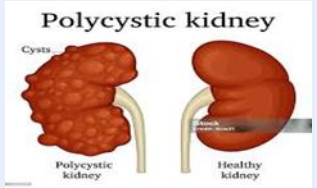
Epidemiology

12,5 milion in the word

4th cause of ESRD

Clinical Signs and Symptoms

Cyst in both kidneys with increase in number and size. The progression of the disease can lead to a gradual deterioration of renal function



Lower back or abdominal pain due to compression, hematuria, hypertension (60%), urinary tract infections, liver cysts, mitral prolapse and cerebral aneurysms.

Psychological symptoms:

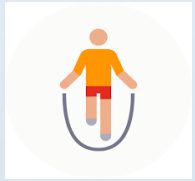
- Transmissibility of the disease
- Body image perception

Cornec-Le Gall, E., Alam, A., & Perrone, R. D. (2019). Autosomal dominant polycystic kidney disease. *Lancet* .

Promotion self-care in ADPKD patients

- Blood pressure monitoring

- Physical activity



- Pharmacological and dietary adherence

- Disease perception

- Quality of life

Brioni, et al. (2023)The Educational Aspect in Promoting a Low-Sodium Diet, Physical Activity and Therapy Adherence among Patients with Autosomal Dominant Polycystic Disease: A Literature Review. *Giornale Italiano di Nefrologia*

Delli Zotti et al. (2019). Psychological Assessment of a sample of women with ADPKD: quality of life, body image, anxiety and depression. *Giornale italiano di nefrologia*

Brioni, et al. Self-efficacy and self-management in patients in hemodialysis: a narrative review of multidisciplinary theories (2021). *Giornale italiano di nefrologia*

Brioni, E., Magnaghi, C., & Silingardi, M. (2020). Management of polyuria in autosomal dominant polycystic kidney disease after treatment with tolvaptan: an educational approach. Journal of Kidney Care.

- CLINICAL TRIAL DESIGN: RCT
- AIMS

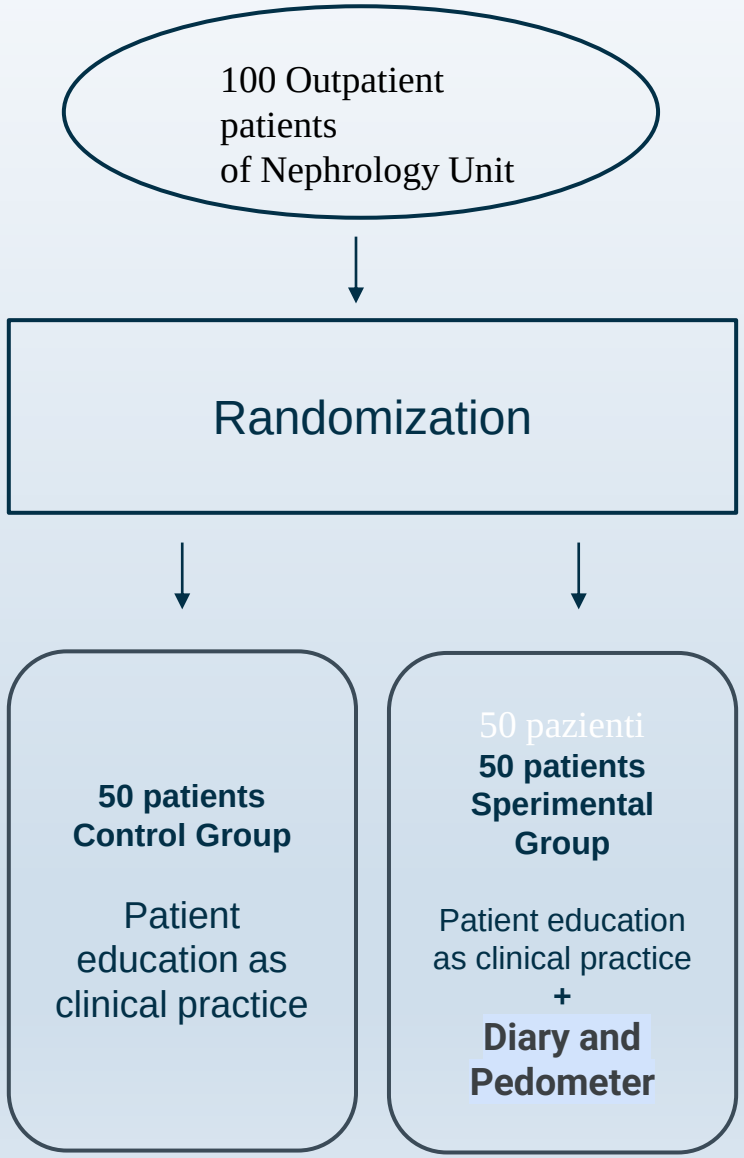
1. Investigate the effectiveness of an educational intervention dedicated to preserving renal function and slowing down the worsening of renal function through blood pressure control, maintenance of physical activity and promotion of adherence to drug therapy ADPKD patients
2. Investigate the quality of life and perception of the disease in ADPKD patients.

Inclusion criteria:

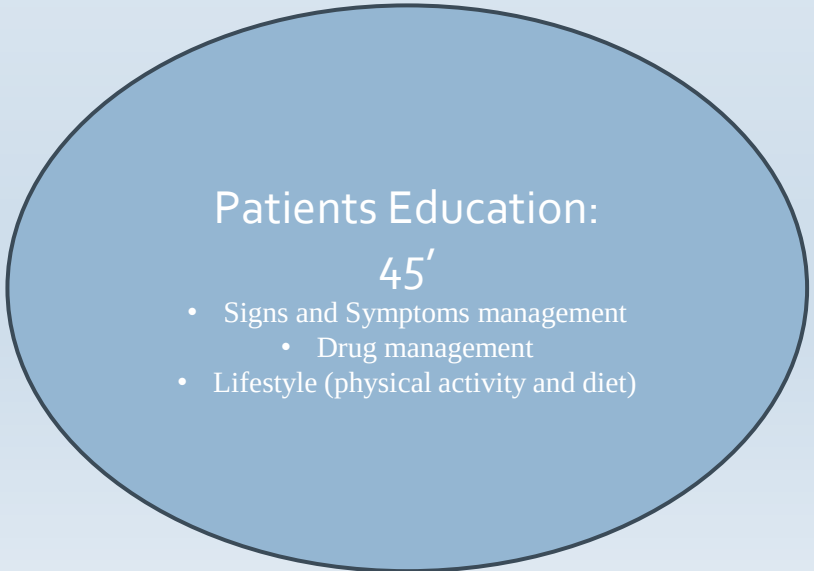
- Age > 18 years
- ADPKD
- Mobile phone with pedometer
- Informed consent signature

Exclusion criteria:

- Hemodialysis patients
- Kidney transplant patients
- Patients with psychiatric clinical conditions
- Pregnant or breastfeeding women



	Struments	V0	V1 + 7gg	V2 + 60gg
Signature of informed consent	Informed Consent	x		
Adherence to therapy	**MMAS-8** (Morisky Medication Adherence Scale)		x	x
Quality of life	**KDQOL-SF™** (Kidney Disease Quality of Life Short Form)		x	x
Perception of disease	**IPQ-R** (The Revised Illness Perception Questionnaire)		x	x
Blood pressure control	Automatic Sphygmomanometer		x	x
Physical activity	Pedometer (Gruppo sperimentale)		x	x



Characteristics of the study sample

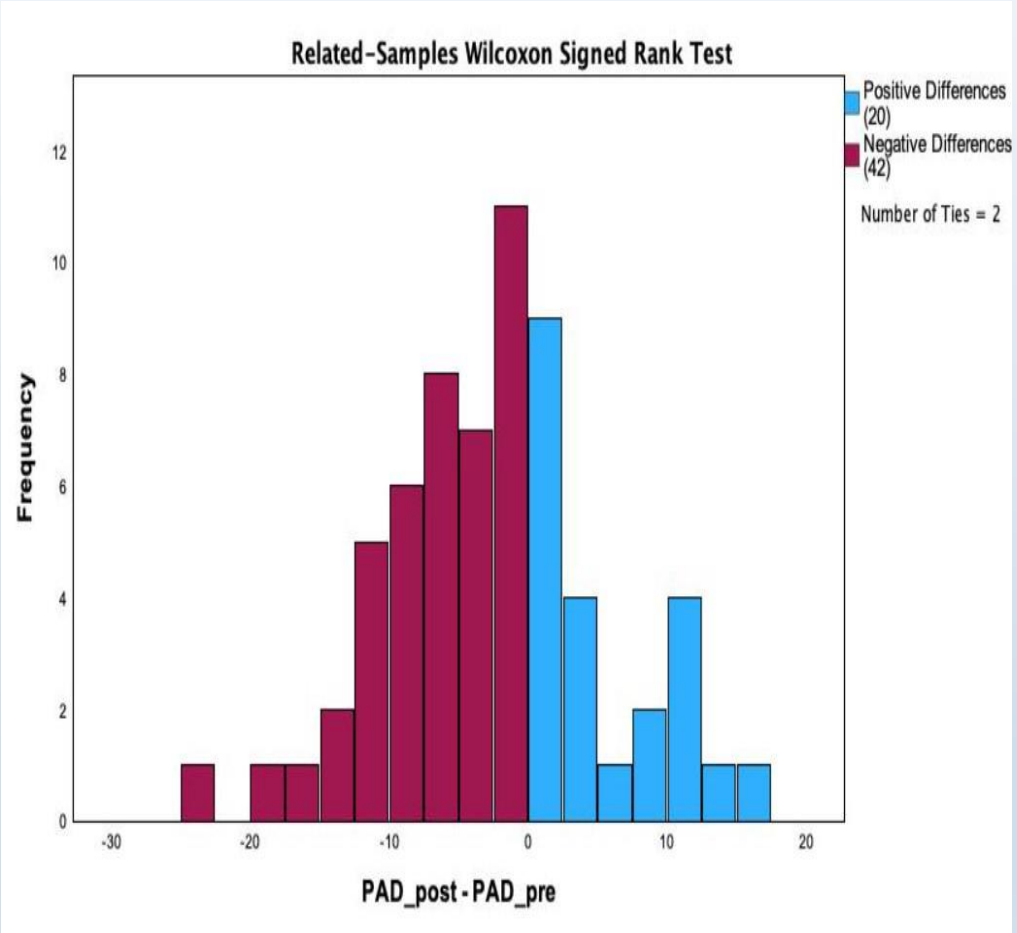
Experimental Group	n = 28
Control Group	n = 37
Patient enrolled	**n = 65**

Demographic characteristics of sample		
Gender	M	34 (52,3%)
	F	31 (47,7%)
Age	Media	45,6 ± 9,9
Marital status	married	70,8 %
	Single / divorced	29,2 %
Births		**0 = 43.1%** 1 = 20,0% 2 = 27,7% 3 = 4,6% 4 = 4,6%
Family members with ADPKD		sì 80,3% no 19,7%

(n=65)	**Media**	**Std. Deviation**
Age	45,66	9,98
BMI *(Body Max Index)*	24,04	5,70
Weight	74,726	14,95
VISCERAL FAT	7,12	3,69
FAT	26,09	9,83
MUSCLE	32,05	6,74
PAD *(diastolic blood pressure)*	127,33	15,03
PAS *(systolic blood pressure)*	84,16	11,41
FC *(heart rate)*	72,33	11,80
Creatinine in the blood	1,73	0,61

Family members in dialysis	50,8%
Transplanted family members	44,6%

	Pre-educational intervention		Post- educational intervention		
Sample (n= 65)	**Media**	**Std.Deviation**	**Media**	**Std. Deviation**	***P value***
BMI	24,12	5,76	23,83	5,65	0,625
Peso corporeo	74,95	15,07	74,65	14,84	0,142
VISCERAL FAT	7,17	3,73	6,64	3,61	0,180
FAT	26,10	9,99	25,20	10,25	0,178
MUSCLE	32,07	6,84	31,26	8,80	0,193
PAD	84,24	11,57	81,43	11,08	0,006
PAS	127,50	15,20	125,02	14,14	0,085
FC	72,60	11,78	72,14	10,34	0,709
MORISKY QUESTIONNAIRE	5,94	1,43	5,95	1,22	0,384
KDQOL-SF™					
• *Care Satisfaction*	75,64	19,83	88,01	17,18	<0,001
• *Staff Encouragement*	85,65	17,84	91,66	15,90	0,019
• *Conditioning of disease (on life)*	71,27	19,84	66,44	19,60	0,05
IPQ-R					
• *Consequences of the disease*	17,26	3,61	18,28	3,81	0,017



Experimental Group (use of diary and pedometer)

	Pre-educational intervention		Post-educational intervention		
Sample (n=28)	**Media**	**Std. Deviation**	**Media**	**Std. Deviation**	***P value***
PAD	85,69	10,77	81,89	10,38	0,028
VISCERAL FAT	8,71	3,71	7,00	3,82	0,050
WEIGHT	80,10	15,40	79,17	15,29	0,010
MORISKY QUESTIONNAIRE	60,4	1,26	6,07	0,85	0,876
KDQOL-SFTM					
• *Care Satisfaction*	74,42	25,84	89,85	15,68	0,014
• *Sexual function*	94,38	9,77	87,50	18,07	0,027

Average number of daily steps taken:
6952

Blood Pressure	Gimpel et al. (2019) showed that an healthy lifestyle including physical activity and maintenance of normal weight should be promoted in all patients with autosomal dominant polycystic kidney disease
Weight	Nowak et al. (2018) The study showed that a higher BMI is associated with a greater annual percent change in kidney volume.
Sexual function	Duca et al. (2019).The review showed that physical inactivity in patients with CKD is considered a major risk factor for erectile dysfunction in men and failure to achieve orgasm in women
Satisfaction with the perceived quality of care and encouragement of the staff	Lopez -Vargas et al. (2016). This systematic review which includes 26 studies totaling 5403 patients evaluated the use of educational interventions to prevent the progression of kidney disease.

Gimpel et al.(2019) International consensus statement on the diagnosis and management of autosomal dominant polycystic kidney disease in children and young people

Nowak, K. L., et al. (2018). Overweight and Obesity Are Predictors of Progression in Early Autosomal Dominant Polycystic Kidney Disease. Journal of the American Society of Nephrology: JASN, 29(2), 571–578.

Duca, Y., et al (2019). Erectile dysfunction, physical activity and physical exercise: Recommendations for clinical practice. Andrologia, 51(5),

Lopez-Vargas, P. A., Tong, A., Howell, M., & Craig, J. C. (2016). Educational Interventions for Patients With CKD: A Systematic Review. American journal of kidney diseases : the official journal of the National Kidney Foundation, 68(3), 353–370

Limits

- Single-center study
- Small sample
- No long-term follow (es. after 1 year)

Implications to clinical practice

- Patient and caregiver education (structured interventions)
- Digital health tools
- Personalization of care

Conclusions

Structured educational interventions can increase patient awareness of disease.

These educational interventions can be used as prevention and treatment strategies for chronic diseases through the patient's participation in their own treatment path through adherence to the prescribed pharmaco-dietary indications. Physical activity monitored with a pedometer proved effective in improving some clinical parameters (such as blood pressure). Finally, educational interventions promoted the nurse-patient relationship, increasing satisfaction with the care received.

THANK YOU

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