Renal development and cystic diseases

ADPKD DIAGNOSIS IN EUROPE: PATIENT REPORTS OF SYMPTOMS AT RECOGNITION AND POST DIAGNOSIS SUPPORT

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Introduction and aims

A pan-European survey of ADPKD (autosomal dominant polycystic kidney disease) patients was performed to explore patients' perspectives of methods of diagnosis and the modalities and adequacy of support provided at the time. The aim was to investigate the variation in patient pathways pre/peri-diagnosis and highlight differences in patient support across European countries.

Methods

This mixed method, semi-quantitative survey sampled ADPKD patients (N=730, 53% male, average age 45) across all stages of chronic kidney disease (CKD) (see Table 1) and was carried out within 9 European countries (see Table 2). Within this sample population, 67% were diagnosed <15 years ago, 9% had received a kidney transplant and 19% were currently receiving dialysis. Network recruitment was used to prepare telephone and web-based interviews and final data were collected via an online questionnaire developed in association with Tess Harris, President of PKD International.

Table 1. Respondents by CKD stage

CKD stage	% respondents
1	26
2	31
3	17
4	11
5	15

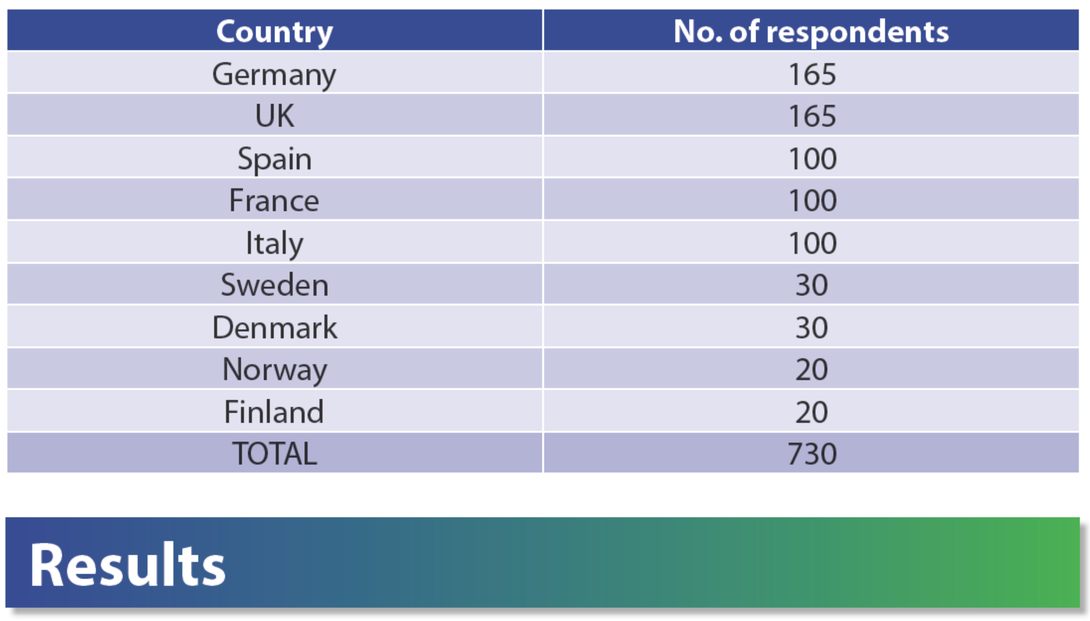
Table 2. Respondents by country

Country	No. of respondents
Germany	165
UK	165
Spain	100
France	100
Italy	100
Sweden	30
Denmark	30
Norway	20
Finland	20
TOTAL	730

Results

70% of patients were diagnosed between ages of 25–40 (average 31y) with some variation by country and gender. Common symptoms provoking diagnosis included: urinary symptoms (haematuria 24%, UTI 22%), hypertension (29%), family history of ADPKD (20%) and abdominal and/or back pain (both 14%): see Figure 1. Hypertension and UTI were the most commonly found symptoms at the time of diagnosis (35% and 25% respectively). 32% of respondents were not aware of any relatives who had been diagnosed with ADPKD or a kidney-related problem.

Figure 1. Symptoms provoking diagnosis of ADPKD in respondents



The type of support offered post-diagnosis was variable; support group referrals were highest in Spain and Italy (56% and 46% respectively) and lowest in Denmark (17%). The proportion of patients receiving a leaflet/booklet about the disease from the doctor ranged from 95% in Denmark to 7% in Spain and 5% in Italy. Genetic testing of family members was most common in Spain and Italy (11% and 5% respectively). 36% of patients had only a conversation with the doctor and received no additional information.

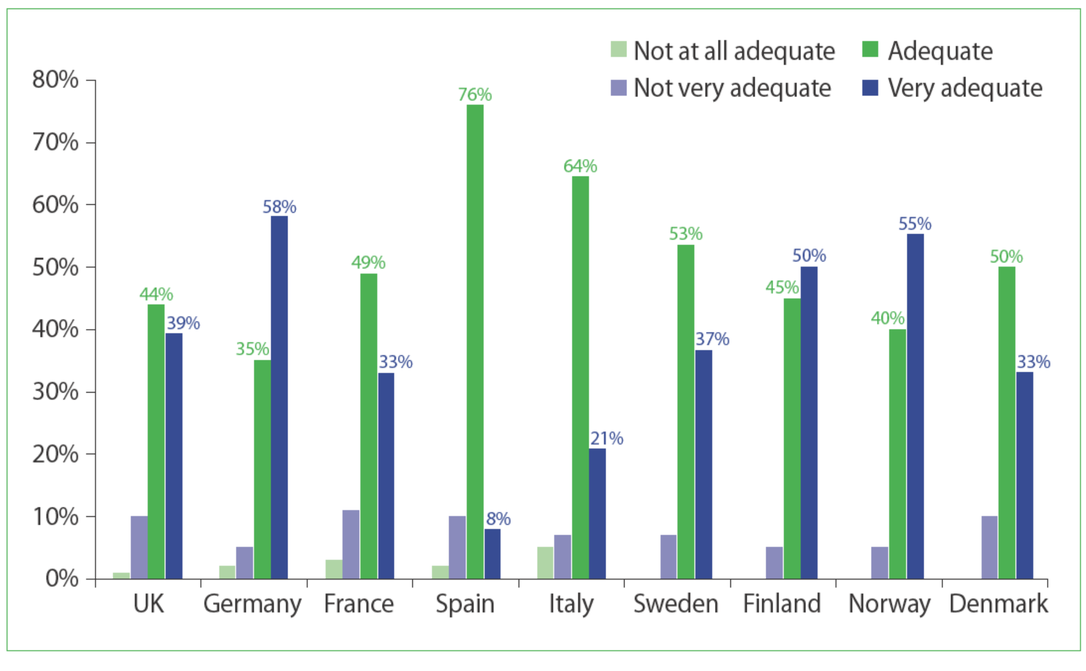
Table 3. Respondents by country

Country	% of respondents referred to support group	% of respondents given information in leaflet/ booklet
Germany	38	32
UK	36	15
Spain	56	7
France	27	39
Italy	46	5
Others	22	72

79% of patients across Europe were diagnosed by nephrologists, 9% by general physicians, 6% by urologists and 3% by radiologists. The proportion diagnosed by a nephrologist was 99% in Norway, Sweden, Denmark and Finland but fell to as little as 64% in Italy (where 19% were diagnosed by a urologist and haematuria was the most important symptom provoking diagnosis).

Patients were asked how adequate was the information received at diagnosis; only 36% rated this in the highest category available, and this proportion varied between countries from 55% in Norway to 21% in Italy and 8% in Spain (see Figure 2).

Figure 2. Opinion on information received at diagnosis



Conclusions

This survey allows the symptoms leading to ADPKD diagnosis to be quantified, although it was dependent on patient memory. 32% of patients had no knowledge of a family disease history, more than the 25% figure sometimes given in the literature[1], and very few had access to family genetic testing. The specialties of the physicians making the diagnosis varied between countries.

Countries which provide information through HCPs, and/or more written material, appear to offer less referral to support groups and vice versa. Although it would be best to provide support group access and written information in parallel, few European patients have access to the fullest range and quality of support/information around the time of diagnosis.

References:

1. Grantham JJ. N Engl J Med 2008;359:1477–1485.

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