

Renal development and cystic diseases

ADPKD IS A BARRIER TO EMPLOYMENT IN EUROPE

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Introduction and Aims

A survey of 730 autosomal dominant polycystic kidney disease (ADPKD) patients was performed to explore the social and economic impact of this disease and how this varies across European countries.

Methods

This mixed method, semi-quantitative survey sampled ADPKD patients (N=730, 53% male) across all stages of chronic kidney disease (CKD) (see Table 1) and was carried out within 9 European countries (see Table 2). The age range of respondents was 18–82 years, average 45 (see Table 3); 19% were retired and 10% were students.

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

Table 3. Respondents by age group

Age	% respondents
18–24	7
25–34	22
35–44	27
45–54	17
55–64	14
65–74	12
74+	1

Results

Patients who had been in employment were asked whether they had informed their employer of their diagnosis; 19% answered 'no'. 48% had told their employer at the time of diagnosis, but 15% had only done so when in CKD stage 3–5 (see Figure 1).

41% had seen no effect on their career, while 32% said their employer had been sympathetic and made an effort to accommodate them. However, 13% were working part-time or freelance, 7% had had to change jobs, re-train or otherwise compromise their career and 5% had lost employment (see Figure 2). In Germany, only 23% said that disclosure had no effect on their career, while 42% said their employer was sympathetic.

Figure 1. Percentage of respondents who had informed employers of disease status.

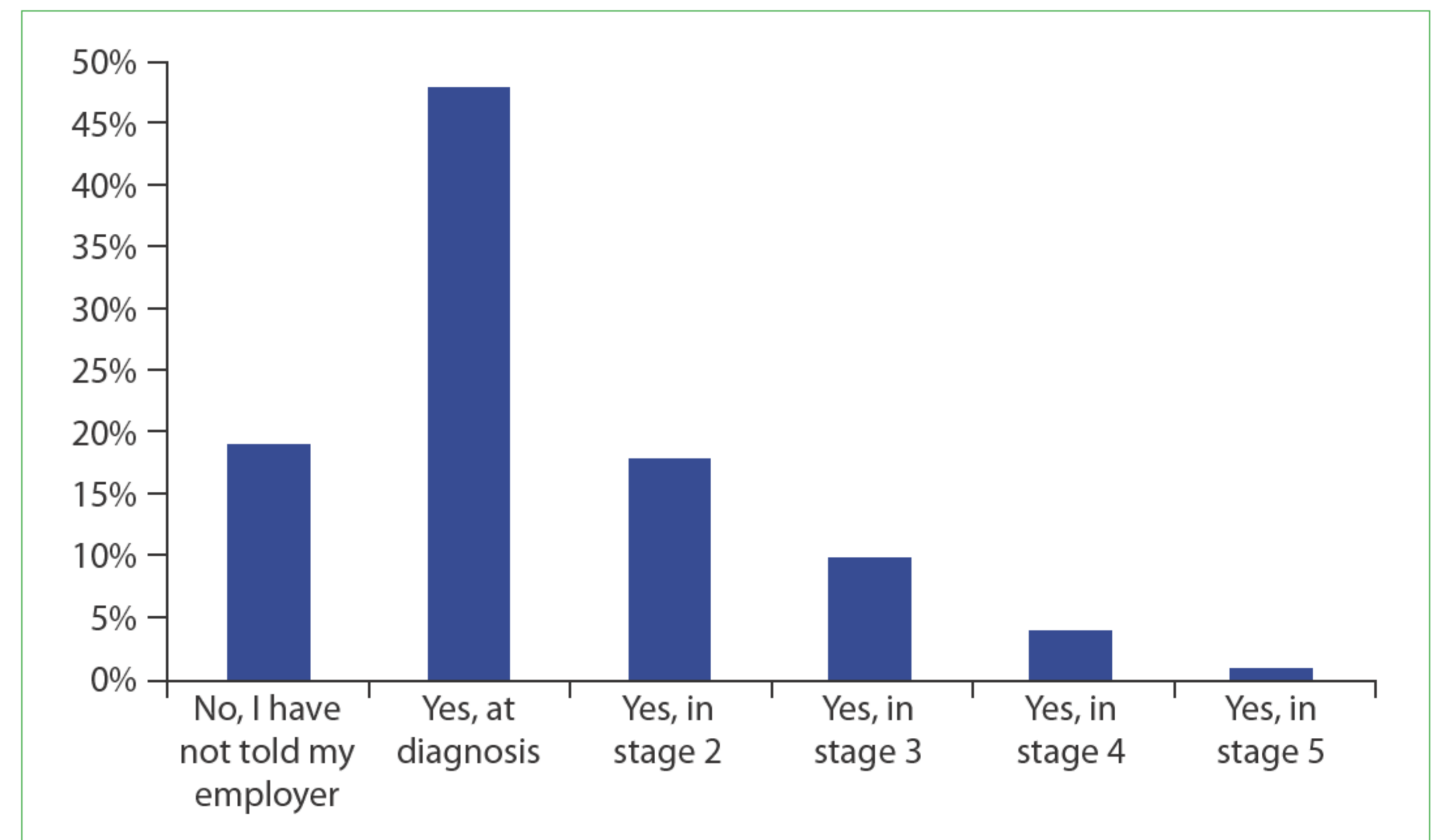
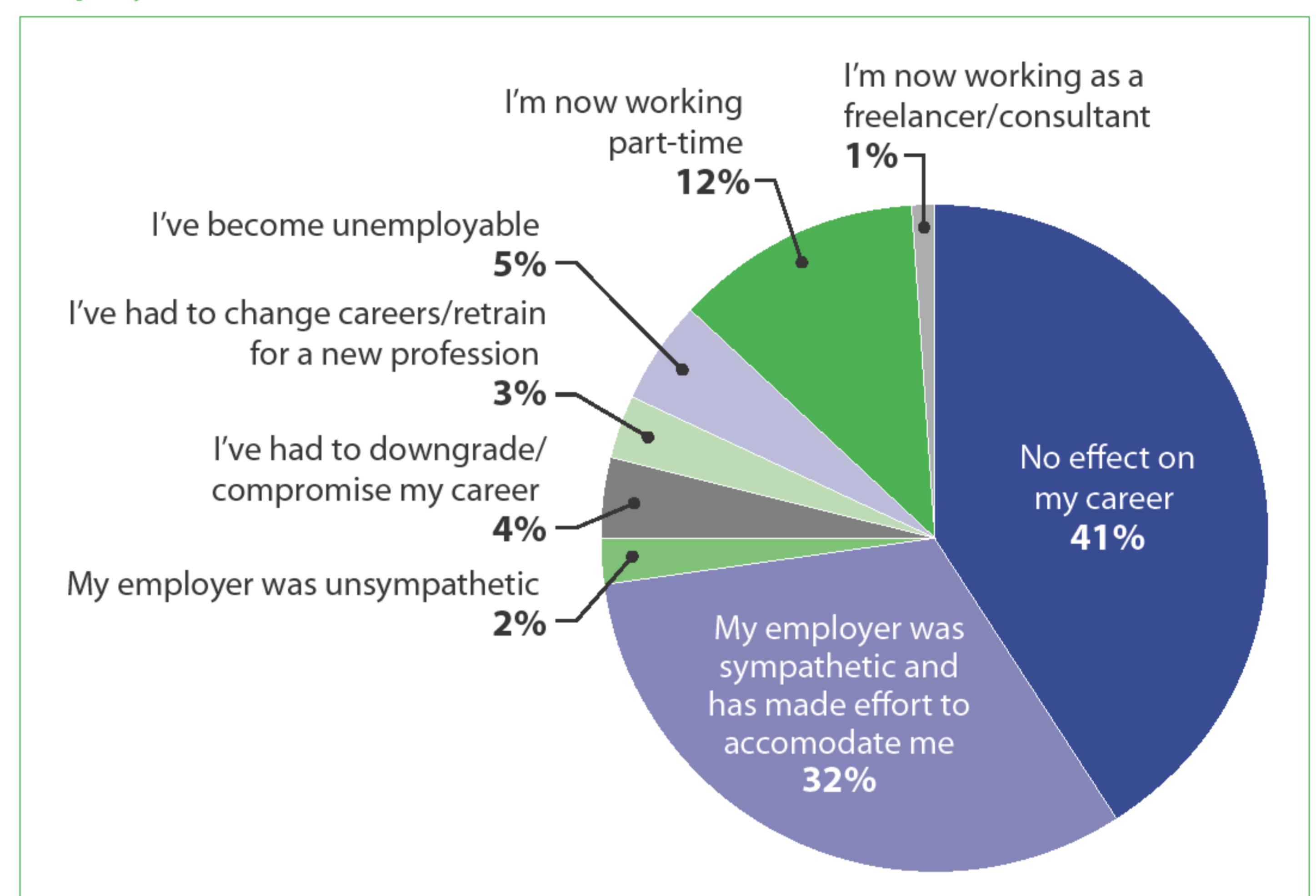


Figure 2. Effect on respondents' careers of disclosure of disease status to employer.



Sick leave had been taken by 81% of employed respondents, ranging from 1–70 days in the last 12 months. The overall average number of sick days taken for ADPKD-related issues was 4.8 days over 12 months across all stages, which rose to 7.6 days in a subset group of patients with CKD stages 3–5. In this subset, average values were high in Italy (19 days, N=20) and low in Spain (0.2 days, N=20), but in all other countries there was little variation from the average.

The majority of self-employed patients were in CKD stages 1–3 and had made no alterations to their business to accommodate their condition; in later CKD stages (4–5) 51% of patients had to make changes to their working life, mostly by reducing working hours.

Conclusions

The diagnosis of ADPKD appears to carry a stigma in the workplace, leading almost a fifth of employees to withhold their condition. It might be thought that the potential effects on insurance cover would be a barrier to disclosure in countries with social health insurance systems, but the reaction of German employers was more helpful than reported in some other countries. As the effect of ADPKD on health is unlikely to vary between countries, the frequency of sick leave may be affected by the degree of support offered by employers.

It is possible that some of the 15% of patients who had not informed employers of their disease status until CKD stage 3 or later did so because they were diagnosed late. Only 70% of respondents had been diagnosed between ages 25–40, and older patients may have been in later stages of CKD.

