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BRIEF RESEARCH REPORT

Morbidity and Health-Care Use in People with Intellectual Disabilities in General Practice: First Results of a Survey in the Netherlands

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ABSTRACT

Reported here are the preliminary results of the second Dutch National Survey of General Practice in which data were collected on all contacts with general practitioners (GPs) during a 12-month period to determine characteristics of patients with intellectual disabilities (ID). Sociodemographic characteristics differed significantly between people with ID and controls, indicating significant differences in morbidity between the two groups (people with ID were found to have more psychological problems, more digestive problems, more ear problems, more neurological problems, and more general and unspecified problems).

INTRODUCTION

Over the past few years residential facilities for people with intellectual disabilities (ID) in the Netherlands have closed down, and people with ID have moved into small-scale housing in the community and enrolled with general medical practices in their neighborhood. Previous research has shown that people with ID have twice as many health problems as persons in the general population; comorbidity is more frequent and patterns differ from the general population (van Schrojenstein Lantman-de Valk et al., 2000).

The consultation rate, the nature of health problems, and the interventions performed by their general practitioner (GP) are generally unknown. The Second Dutch National Survey of General Practice (National Survey) offered an opportunity to explore these questions. Our study questions were:

- How many contacts do people with ID have with their GP?
- Which health problems do they present?
- How do these results differ from the general population?

METHOD AND STUDY DESIGN

The National Survey collected data on all contacts with a GP during a 12-month period (in 2001) from a representative sample of 104 general medical practices (195 GPs). Data were collected on 385,461 listed patients, 1.6 million contacts, and 950,000 episodes of care (Westert et al., 2004).

Sociodemographic data were collected by using a survey questionnaire sent to all 385,461 patients (response rate was 76%).

A nested case-control study was performed. Patients with ID were identified in three ways, the first, through a specially developed software package, which searched patient records on keywords referring to ID. In each case, the GP had to decide whether or not this person had ID. Second, the GPs were asked to review all patients who had an International Classification on Primary Care (ICPC) code P85 ("mental retardation") in their records and to decide if the patients indeed had an ID. Third, checklists were sent to participating practices to identify people with ID in their patient records. These checklists were based on the American Association on Mental Retardation (AAMR) definition of intellectual disability (Luckasson et al., 2002). Double counts were excluded based on each patient's unique identification number. For each person with ID, five matched controls were randomly selected (where possible) with the same age and sex from the same practice. We used data on morbidity and data on contacts as recorded in the practice computers. Morbidity was coded using the ICPC (Lamberts & Wood, 1987). Contacts for the same health problem were clustered into episodes of care. Contacts included home visits, office consultations, consultations by telephone, and administrative contacts.

Morbidity was analyzed on ICPC chapter level. Differences between groups regarding demographic data, morbidity, and consultation frequency were checked by bivariate statistical analysis using a chi-square test or an unpaired *t*-test.

RESULTS

Eight hundred and sixty-eight patients with ID were identified in 71 practices and 4305 age, sex, and practice-matched controls selected. Sociodemographic characteristics differed significantly between people with ID and controls (see Table 1). Characteristic differences were found in the percentages of persons in out-ofhome residential living (21% vs. 1%), the percentages of people without any school training (37% vs. 17%), the percentages of people who had a paid job (17% vs. 32%), and the percentages of people who were unable to work (21% vs. 2%). In both groups, about a third of the information requested was unavailable. Significant differences in morbidity were found between the two groups, for example, people with ID had more psychological problems (21% vs. 8%), more digestive problems (19% vs. 12%), more ear problems (15% vs. 8%), more neurological problems (15% vs. 5%), and more general and unspecified problems (21% vs. 10%). Also, data on the nature of the health problems lacked more often in people with ID (22% vs. 11%). Differences were significant with $P < 0.01$ (chi-square). People with ID had 1.5 times more contacts with their GP and had more episodes of care than the controls (see Table 2).

[TABLE 1]

[TABLE 2]

COMMENTS

These preliminary analyses indicate that people with ID have more contacts with their GP and that they have more episodes of care. Striking differences were found in psychological problems, in general, and in unspecified problems. A lack of school training and higher unemployment rates among people with ID appear to reflect a higher risk for health threats (Kramers, 2003). That data on the type of presenting health problems were lacking in people with ID may reflect communication problems. These problems may be exhibited both by people with ID with limited or absent verbal capacities (who cannot express their health concerns), and by GPs who received little or no training in communicating with this group of patients and most often unfamiliar with the atypical comorbidity patterns of people with ID.

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TABLES

TABLE 1
Comparative demographic data (by percent) on people in the Netherlands with intellectual disabilities (ID) and controls from general population

	People with ID (%, $n = 868$)	Controls (%, $n = 4305$)
Marital status[a]		
Unmarried	59	38
Married	6	31
Divorced	2	2
Widow/Widower	1	2
Unknown	33	28
Living situation[a]		
Alone	8	6
With others	56	64
Unknown	36	31
Residential living[a]		
Yes	21	1
No	46	70
Unknown	33	29
Education[a]		
No school training	37	17
Primary school	21	12
Secondary and higher school	10	44
Unknown	34	26
Employment[a]		
School training	18	25
Paid job	17	32
Looking for a job	2	1
Housewife/houseman	2	8
Unable to work	21	2
Retired	4	5
Unknown	36	29

[a]Chi-square: all differences between the two groups: $P < 0.01$

TABLE 2
Episodes of care and contacts with primary care within the registration year for people with intellectual disabilities (ID) and controls

	People with ID ($n = 868$)	Controls ($n = 4305$)
Number of episodes[a]		
Mean (SD)	3.7 (3.8)	2.2 (2.7)
Range	0–30	0–25
Total number of contacts[a]		
Mean (SD)	5.4 (6.3)	3.2 (4.4)
Range	0–41	0–53

[a]Unpaired t-test: $P < 0.0001$

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