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ARTICLE in EUROPEAN PSYCHIATRY · OCTOBER 2007

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European Psychiatry 22 (2007) 354-361

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Original article

The cost of borderline personality disorder: Societal cost of illness in BPD-patients

A.D.I. van Asselt^{a,*}, C.D. Dirksen^a, A. Arntz^b, J.L. Severens^{a,c}

^a Department of Clinical Epidemiology and MTA, University Hospital Maastricht, Maastricht, The Netherlands

^b Department of Clinical Psychological Science, Maastricht University, Maastricht, The Netherlands

^c Department of Health Organization, Policy, and Economics (HOPE), Maastricht University, Maastricht, The Netherlands

Received 8 January 2007; received in revised form 3 April 2007; accepted 4 April 2007 Available online 4 June 2007

Abstract

Background. – Borderline personality disorder (BPD) is a highly prevalent, chronic condition. Because of its very problematic nature BPD is expected to be associated with substantial societal costs, although this has never been comprehensively assessed.

Objective. – Estimate the societal cost of BPD in the Netherlands.

Study Design. – We used a prevalence-based bottom-up approach with a sample of 88 BPD patients who enrolled in a multicenter clinical trial comparing two kinds of outpatient psychotherapy. Costs were assessed by means of a structured interview, covering all healthcare costs, medication, informal care, productivity losses, and out-of-pocket expenses. Only BPD-related costs were included. All costs were expressed in Euros for the year 2000. A bootstrap procedure was performed to determine statistical uncertainty.

Patients. - All patients had been diagnosed with BPD using DSM-IV criteria. Mean age was 30.5 years and 92% was female.

Results. – Based on a prevalence of 1.1% and an adult population of 11,990,942, we derived that there were 131,900 BPD patients in the Netherlands. Total bootstrapped yearly cost of illness was $\in 2,222,763,789$ ($\in 1,372,412,403 - \in 3,260,248,300$), only 22% was health-care-related. Costs per patient were $\in 16,852$.

Conclusions. – Although healthcare costs of non-institutionalized Borderline patients might not be disproportionate, total societal costs are substantial.

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Keywords: Borderline personality disorder; Economics and psychiatry; Health economics

1. Introduction

Borderline personality disorder is a chronic condition, which is estimated to be present in 0.5%-2.5% of the general population [1,3,9,20,32,36]. The problematic nature of BPD is characterized by recurring crises, hospitalizations, self-mutilation, suicide attempts, addictions and episodes of depression, anxiety and aggression [1]. Moreover, BPD is very frequently diagnosed in psychiatric inpatients [18,24], substance abusers

[6,21,22,31,40], and convicts in general prisons as well as forensic psychiatric institutions [17,35]. In addition, suicide in BPD-patients is frequent, even after psychiatric treatment. In several studies, the percentage of BPD-patients that eventually commits suicide is found to be between 2% and 17%, depending on the length of the follow-up [23,28,43]. Quality of Life, as studied in two recently performed clinical trials [15,26] is severely impaired in BPD-patients. Utility scores found in these trials, generated by the EuroQol-5D [8], varied around 0.5.

Intuitively, considering all the above factors, one would say that BPD must be associated with substantial tangible and intangible costs. Several studies [4,44] have found that BPD-patients continuously use outpatient treatment and

^{*} Corresponding author. Department of Clinical Epidemiology and Medical Technology Assessment, University Hospital Maastricht, P.O. Box 5800, 6202 AZ Maastricht, The Netherlands. Tel.: +31 43 3875587; fax: +31 43 3874419.

E-mail address: avas@kemta.azm.nl (A.D.I. van Asselt).

take psychotropic medication, thus imposing a significant burden on health care services. Bender et al. [4] also found that BPD-patients, compared to patients with other personality disorders and patients with major depression, used more treatment and medication. A recent paper by Frankenburg and Zanarini [13] showed that patients with active BPD have a higher risk of suffering from chronic physical conditions, making poor health-related lifestyle choices, and using costly forms of medical services than patients with remitted BPD. Smith et al. [34] and Rendu et al. [29] tried to quantify the cost of illness of personality disorders in general. Rendu et al. found that the costs (both healthcare and non-healthcare) for patients with personality disorder were significantly higher than the costs for those without a personality disorder, when the BPD-diagnosis was accompanied by other common mental disorders. BPD in itself was not a significant explanatory factor for higher costs. Although all of the above studies have done some work on exploring the costs of personality disorders in general and BPD in special, a formal cost of illness study using a comprehensive societal perspective for BPD has not yet been performed. The aim of the present study therefore is to estimate the societal cost of illness of BPD in the Netherlands.

2. Materials and methods

2.1. Design

In performing a COI, there is a choice between a bottom-up and a top-down approach [11]. The first entails that healthcare consumption or cost data of a sample of patients are gathered and extrapolated to the total population. However, extrapolating can be difficult when the sample is not representative for the entire population. Also, not all events which are regarded typical for the cost profile of a specific disease may occur in the sample population and in the sample period. The alternative for a bottom-up approach is a top-down estimation, where total cost per healthcare sector are used as a starting point, and fractions of these costs are assigned to a specific disease according to the prevalence of that specific disease for that specific sector. The top-down method does not suffer from the shortcomings mentioned above. However, the problem with top-down for the Borderline population is that, as we experienced, very little diagnosis-specific information is available for this type of patients. Most registrations can only deliver data for personality disorders in general, but not for each specific personality disorder separately. Because of these difficulties with the top-down data, we decided to choose the bottom-up approach, as this was expected to yield more reliable results.

The population for which COI was calculated was based on prevalence, so the results apply to all prevalent cases for a specific point in time, i.e. the year 2000. Costs of lost productivity were calculated according to the Human Capital approach [19]. The analysis was performed from a societal perspective.

2.2. Study population and data collection

The baseline cost interviews of 88 BPD-patients who enrolled in a Dutch randomized trial were used [15]. This multicenter trial compares two outpatient psychotherapies for BPD patients. All patients had been diagnosed with BPD according to DSM-IV criteria [1], using the Structured Clinical Interview for DSM-IV Personality Disorders, the SCID-II [12,42]. Patients were referred to the trial by therapists at secondary and tertiary community mental health institutes based on a clinical diagnosis of BPD. Age had to be between 18 and 60 at inclusion, and the severity-score according to the Borderline Personality Disorder Severity Index (BPDSI) [2,41] higher than 20. Exclusion criteria were psychotic disorder of some kind, bipolar disorder, depression with psychotic symptoms at early age, organic causes for the problems, antisocial personality disorder, ADHD, mental retardation, or severe addiction needing clinical detoxification. All patients gave written informed consent and the study was approved by the medical ethical committees of the three participating centers.

The face to face cost interview took place before randomization and onset of therapy and covered a period of three months preceding the inclusion. Items in the interview concerned healthcare costs in mental as well as regular health care institutions, productivity costs due to absence of work and disability, informal care by family and friends, and outof-pocket expenses. Informal care is an especially important item in mental health care, since patients can place a large burden on their environment. Informal care means that persons near the patient take care of the patient and possibly take over some domestic tasks. These persons can be family, friends, or neighbours. Informal care might in some cases be paid for, but a key characteristic is that the caregiver would not want to care for someone outside of his social environment for a similar wage [37]. In the interview, the number of hours the patient receives informal care is collected, and then the costs are calculated by multiplying this number by a shadow price [25].

For all items, only BPD-related costs were taken into account. Unit costs per item were derived from Dutch reference prices [25], unless specified otherwise. All costs are expressed in Euros using the 2000 price level, since the majority of the patients enrolled in the trial in that year. On February 1st 2000, 1 Euro was worth 0.97 US Dollars. Volumes obtained from the interview were multiplied with unit costs resulting in mean costs per three months per patient. These costs were then multiplied by four to obtain mean yearly costs per patient. Since inclusion of patients was scattered throughout the year, there is no structural seasonal effect in the three months covered by the baseline interview. Mean yearly costs were multiplied with the prevalence figure for the adult general population in order to estimate the total cost of illness of BPD to society.

There was a number of BPD-related events that, by definition, could not occur in our sample population, because of the fact that the baseline measurement was a retrospective interview. These events were suicide and imprisonment in a forensic psychiatric institution. To be able to take account of these events, we estimated the costs for suicide and forensic psychiatric institutions by means of the top-down approach.

Sensitivity analysis explored the robustness of the results when varying several parameters. A bootstrap resampling procedure was performed to be able to determine statistical uncertainty of the cost estimate [5,10]. Confidence Intervals (CI) were constructed based on bootstrapped 2.5 and 97.5 percentiles.

3. Results

3.1. Study population

Among the 88 patients who completed the baseline cost interview were 81 females (92%) and 7 males (8%). The mean age was 30,5 years (range 20–53). Sixty four of them (73%) were insured by the Dutch national sick fund, thirteen (15%) had private insurance, and of eleven patients (12%) the insurance form was unknown. The mean score on the BPDSI, which has a possible range of 0–90, with higher scores indicating a higher severity, was 33.76 with a standard deviation of 7.97.

3.2. Prevalence

For the base-case analysis, in accordance with a German prevalence study [20], the prevalence of BPD in the Dutch general population aged 20 and over was estimated at 1.1% (0.9% for men and 1.3% for women). Maier et al. find a prevalence that is somewhere in between the range of 0.5%-2.5% we already mentioned before [1,3,9,20,32,36]. Also, Germany is a neighboring country and BPD prevalence in Germany might be similar to BPD prevalence in the Netherlands, although this is merely an assumption. Other prevalence figures will be considered in the sensitivity analyses. In 2000, the Dutch adult population consisted of 11,990,942 residents [7]. When applying the prevalence rate of 1.1% to this population, it can be derived that in the Netherlands 131,900 adults suffered from BPD in 2000.

3.3. Costs of BPD

Table 1 shows the unit costs, quantities of the units per patient and total costs for all BPD-patients as well as the bootstrapped mean and costs with a confidence interval based on percentiles. The mean bootstrapped costs and confidence intervals are visually represented in Fig. 1. For a number of cost items, details are explained below.

3.3.1. Out-of-pocket costs

Out-of-pocket costs for BPD patients mainly arise as a consequence of their lifestyle. Of the patients included in the trial, almost 60% reported to have costs associated with their BPDproblems. The majority of these patients (63%) mentioned excessive smoking, shopping and (binge) eating and extremely high phone bills as the main cost drivers. Also mentioned sometimes were, for instance, costs of bandaging self-inflicted wounds and excessive buying of presents for others. Total out-of-pocket costs were on average ≤ 1395 per patient. In addition to this, we measured costs of medication which was not prescribed, and therefore paid by the patient. These costs were ≤ 28 per patient. Total bootstrapped out-of-pocket costs amounted to $\leq 189,144,600$ (CI $\leq 123,722,200 - \leq 262,744,800$).

3.3.2. Forensic psychiatric institutions (top-down)

In forensic psychiatry, the majority of patients suffers from a personality disorder. Within this group, the prevalence of antisocial and borderline personality disorder is by far the largest [9]. Of the 657 inpatients at the end of 1997, 34 (5.18%) had a primary diagnosis BPD [14]. Total costs of Forensic Psychiatric institutions in the Netherlands in 2000 were \in 78,297,000 which implies total BPD costs of \in 4,051,900 top-down.

3.3.3. Productivity costs due to morbidity

Patients reported to have been absent from their job for 218 h per year. When valued against actual wages, mean productivity costs due to absence from work for the trial sample were \in 1320 per patient per year, implying total costs to be \in 174,108,000. With respect to disability, almost 32% [28] of the patients was fully disabled due to BPD. Furthermore, 8 patients (9%) were partially disabled with a mean of 64% disablement, varying from 35% to 95%. This implies a total of 46,996 fully disabled and 6065 partially disabled individuals due to BPD for the Netherlands. The average gross yearly income in the Netherlands in 2000 was \in 31,000 for men and \in 16,200 for women [7]. Using these wages resulted in total bootstrapped productivity costs of \in 888,214,600 (CI \in 649,211,800– \in 1,138,692,700) due to disability.

3.3.4. Productivity costs due to mortality (top-down)

In national registrations, no figures concerning BPD-suicides were available. However, the suicide rate in BPDpatients has been found to be considerable. Paris et al. [27] for instance, report a chance of 10.3% over a 27-year follow-up. Based on this publication, the instantaneous suicide risk was calculated at 0.49% per year, which means 646 BPD-related suicides in the Netherlands each year. However, taking into account that 40.90% of these patients were already disabled and therefore not productive, as we have calculated in the preceding section, this leaves 382 suicides which lead to actual production losses. Next, production losses were assessed by assigning the expected net value of production, corrected for age and sex, to these suicides, according to the Human Capital method. Average production in the Netherlands [7] was used for these calculations. Total top-down production losses due to premature mortality were €87,520,492.

3.4. Total costs

Total bootstrapped cost of illness was €2,222,763,789 (CI €1,372,412,403–€3,260,248,300). This total COI includes

Table 1	
Unit costs, quantities and costs of BPD-patients in the Netherland	ls

Cost item	Unit price	Mean quantity	Total costs BPD	Bootstrapped mean quantity	Total costs BPD bootstrapped mean	Total costs BPD bootstrapped	Total costs BPD bootstrapped	
				(2.5–97.5 percentile)		2.5 percentile	97.5 percentile	
Healthcare costs								
Psychiatric hospital								
 Inpatient days 	€183	5.68	€137,102,136	5.68 (0.05-14.68)	€137,102,136	€1,206,885	€354,341,436	
- Day care	€81	7.09	€75,748,851	7.17 (1.00-15.73)	€76,603,563	€10,683,900	€168,057,747	
 Outpatient treatment 	€46	8.92	€54,121,208	8.98 (4.97-13.66)	€54,485,252	€30,154,978	€82,880,684	
General/university hospital								
- Inpatient days	€256	0.32	€10,805,248	0.33 (0.00-0.91)	€11,142,912	€0	€30,727,424	
- Day care	€81	3.18	€33,974,802	3.17 (0.00-7.55)	€33,867,963	€0	€80,663,445	
 Outpatient treatment 	€46	0.5	€3,033,700	0.48 (0.00-1.36)	€2,912,352	€0	€8,251,664	
Commun. healthcare centre	€105	7.36	€101,932,320	7.37 (4.54-10.32)	€102,070,815	€62,876,730	€142,926,840	
Addiction clinic treatment	€57	0.18	€1,353,294	0.18 (0.00-0.50)	€1,353,294	€0	€3,759,150	
General practitioner	€17	5.18	€11,615,114	5.20 (3.16-7.86)	€11,659,960	€7,085,668	€17,624,478	
Medication ^a	Various	NA	€44,318,400	NA	€44,054,600	€33,106,900	€57,244,600	
Alternative therapies ^a	Various	3.5	€8,837,300	NA	€8,441,600	€2,242,300	€17,542,700	
Total healthcare			€482,842,373	NA	€482,086,294	€304,327,397	€723,834,475	
Non-healthcare costs								
Out-of-pocket costs ^a	NA	NA	€187,693,700	NA	€189,144,600	€123,722,200	€262,744,800	
Forensic psychiatric inst. ^b	NA	NA	€4,051,900	NA	NA	NA	NA	
Informal care	€8.15	370	€397,744,450	370 (250-504)	€397,744,450	€268,746,250	€541,792,440	
Productivity costs								
- Due to absence of work ^a	Actual wage	NA	€174,108,000	NA	€172,393,300	€91,802,400	€261,425,800	
 Due to disability^a 	Standard wage	NA	€892,435,400	NA	€888,214,600	€649,211,800	€1,138,692,700	
- Due to suicide ^b	Standard wage	NA	€87,520,492	NA	NA	NA	NA	
Overall total ^c	-		€2,226,396,315		€2,222,763,789	€1,372,412,403	€3,260,248,300	

^a No bootstrapped volumes available, only directly bootstrapped costs.
 ^b Top-down items: no bootstraps available.
 ^c Keeping top-down items constant.



Fig. 1. Mean bootstrapped costs and 2.5 and 97.5 percentiles in million Euros for BPD-patients in the Netherlands. *Top-down items have no error bars because there is no bootstrap available.

the top-down estimates for forensic psychiatric institutions and lost productivity due to suicide. When we leave these two items out, the total bottom up COI amounts to $\in 2,131,191,397$, which is 4% less. The larger part of total COI was not healthcare-related. Total bootstrapped healthcare costs were $\in 482,086,294$ (CI $\in 304,327,297 - \notin 723,$ 834,475), representing 21.69% of total COI and 0.63% of total Dutch health care expenditure in 2000, respectively. When translating the total cost of illness to a 'yearly cost per inhabitant' figure, this cost is $\notin 140$. These numbers were calculated using the entire population, including children. The costs per case, which are the costs per BPD-patient in the Netherlands per year, are $\notin 16,852$.

3.5. Sensitivity analysis

The parameters used in the present study were, at least to some extent, subject to uncertainty. To test the robustness of the results to changes in prevalence and unit prices, a univariate sensitivity analysis was performed. Ranges for unit prices were obtained by roughly dividing and multiplying the basecase unit price by two. The results of the sensitivity analysis for the mean total COI are shown in Table 2.

Most striking is the fact that unit prices are not of much influence on the outcome, except for the unit price of informal care. The prevalence of BPD in the general population is the most important factor, as was to be expected, since this parameter has an impact on all cost items. The second most important factor is the disability rate. Varying the out-of-pocket costs has a moderate influence on total costs, but one should bear in mind that, because of the subjective nature of this cost category, the results of the sensitivity analysis for the out-of-pocket costs are highly relevant.

4. Discussion

The goal of the present study was to assess the burden of BPD on Dutch society. Total bootstrapped costs for BPD were $\in 2.222.763.789$. Less than a quarter of these costs arose in the healthcare sector. Direct medical costs represent 0.63% of total Dutch health care expenditure in 2000. Given the fact that the prevalence of BPD is estimated to be more than 1% of the general population, it seems that BPD-patients use up a less than proportionate share of the healthcare budget, although it should be taken into account that institutionalized patients are not part of our sample. On the other hand, non-healthcare costs form a large part (more than 77%) of total COI. This is not surprising, regarding the large impact of BPD on the personal and professional life of the patient, which is typical for psychiatric disorders, and BPD in particular. It is difficult to say whether or not these nonhealthcare costs are high or not, since very little research has been done in this field. However, it is plausible that for chronic somatic diseases of patients in the same age category, the ratio of healthcare costs to non-healthcare costs is much higher.

The patient sample used here may not be representative of the entire BPD-population. There are several reasons to assume that this leads the cost of illness to be an overestimation. First, patients included in the sample are treatment seekers, which means that they experience symptoms which are serious enough to seek help, and therefore these patients probably generate more costs than the non-treatment seekers. In the same manner, it is plausible that costs mount up to the point of start of treatment because of these serious symptoms, and therefore the three months previous to this point might not be representative for the whole year preceding. Second, to be included in the trial, a patient had to score over 20 on the

Table 2			
Outcome	univariate	sensitivity	analysis

Parameter	Range			Outcome cost of illness			
	Base-case	Low	High	Low		High	
				COI	Δ %	COI	Δ %
BPD prevalence	1%	0.5%	2.0%	€1,011,998,325	-54.55	€4,047,993,300	81.82
Rate of disability	33%	10%	50%	€1,512,823,493	-27.94	€2,868,135,763	20.65
Suicide rate	0.49%	0.1%	0.8%	€2,156,737,148	-3.13	€2,281,766,422	2.49
% Discounting ^a	5%	0%	8%	€2,281,024,832	2.45	€2,208,452,337	-0.81
Out of pocket costs	€ 187,693,700	↓ 50%	↑ 50%	€2,038,834,515	-8.42	€2,414,090,015	8.43
Unit price of:							
Psychiatric hospital							
Inpatient day	183	92	366	€2,158,219,843	-3.06	€2,363,498,451	6.16
Day care	81	41	162	€2,188,989,475	-1.68	€2,302,145,166	3.40
Outpatient treatment	46	23	92	€2,199,335,711	-1.22	€2,280,517,523	2.43
Non-psychiatric hospital							
Inpatient day	256	128	512	€2,220,993,691	-0.24	€2,237,201,563	0.49
Day care	81	41	162	€2,209,618,635	-0.75	€2,260,371,117	1.53
Outpatient treatment	46	23	92	€2,224,879,465	-0.07	€2,229,430,015	0.14
Community health center	105	53	219	€2,175,915,547	-2.27	€2,328,328,635	4.58
Ambul. addiction treatment	57	29	114	€2,225,731,539	-0.03	€2,227,749,609	0.06
GP visit	17	9	34	€2,220,930,379	-0.25	€2,230,495,767	0.18
1 h of informal care	8.15	4	16	€1,023,863,865	-9.10	€2,609,499,865	17.21

^a For calculating costs of lost productivity due to suicide.

BPDSI, which also implies the presence of considerable symptoms and, consequently, costs.

However, there are also reasons to assume the contrary. Due to the exclusion criteria used in the trial, the bottom-up sample does not contain psychotic patients, patients with bipolar disorder, patients with serious addictions needing inpatient detoxification (like heroin), mentally retarded and forensic patients, or clinical inpatients. Also, the most severe BPD cases might be so demoralized that they do not apply for treatment. These groups of patients represent the most problematic individuals within the BPD-population, and the fact that they are not in the bottom-up sample could lead to underestimation of true costs.

The researchers of the clinical paper found that patients who declined to take part in the study had the same baseline characteristics as patients who participated (J. Giesen-Bloo, personal communication, March 20th 2007). This speaks for a representative sample, but one should bear in mind that the patients who declined to participate did already pass the criteria for in- and exclusion and were therefore a sub-sample of the population.

Summing up these factors, it is difficult to say whether the population in the trial is more or less costly than the average BPD-patient.

To solve the problem of the representativeness of the trial population, a top-down COI study could be performed. For many diseases, this is very well possible. However, national registrations do not always have diagnosis-specific data, and especially for mental diseases it is very difficult to assign costs. For instance, there are no national databases which contain the number of contacts at the general practice, prescribed medication, or absenteeism at work specified down to the diagnosis level.

For psychiatric illnesses, there is another problem involved with performing a top-down COI calculation. For defining the disease, the standard practice in COI studies is to include only the primary diagnosis to avoid overlap [30]. However, in the case of psychiatric illnesses, the registered primary diagnosis may not always be accurate. When patients present themselves with somatic problems outside the mental healthcare setting, BPD will generally not be identified as the underlying problem. It is very likely that BPD-patients are large consumers of care at General Practitioners, Emergency Rooms, outpatient clinics and general hospitals. However, this type of care is not traceable in the registrations, since BPD will not be registered as the primary diagnosis in these cases.

In addition, a top-down study is not suitable for a disease for which for instance burden to the family, lost productivity in non-paid activities, out-of-pocket costs, alternative therapies, or non-prescribed drugs are the main cost drivers. For the BPD-population this is exactly the case, which means that in a top-down COI design, all these costs could, if at all, only be captured with great difficulty.

The arguments summed up above lead us to believe that a top-down COI calculation will probably result in a COI estimate which is much less accurate than the bottom-up calculation performed in the present study.

Apart from the choice for bottom-up or top-down, we defined a prevalence based approach. In contrast, an incidence approach would have resulted in a figure which informs about lifetime costs of a patients that can be avoided when one case of BPD is prevented. Our prevalence based-approach informs about the cost related to the disease of a patient that can be avoided each year when one case of BPD is cured. Since prevention of BPD is very difficult, and incident cases are not easily traced, the prevalence approach is therefore more useful for current decision making.

A drawback of the instrument we used for assessing the costs, i.e. the cost-interview, is that it entirely relies on the patient's memory and also on the patient's judgment of what costs are BPD-related and what costs are not. Although a 3month recall period is generally thought of as acceptable [33,38], we realize that the BPD-population may be different in that respect. However, validating the information by, for instance checking hospital or insurance records, turned out to be very difficult. The reasons for this are partly in the registration system in the Netherlands, which does not account for mental health care consumption on an individual basis, and partly in the fact that patients could have gone everywhere for their care, and we could not possibly check every health care facility in the country. The difficulties with obtaining data from healthcare providers and insurers have been described in the literature [16,39], and are even more serious here, because it concerns a patient group which is difficult to diagnose and very hard to follow through the system. Moreover, costs made directly by the patient, such as out-of-pocket costs, alcohol and drug use, and over the counter medication cannot be validated by definition. In brief, in our case, it is virtually impossible to obtain complete and reliable data from anywhere else than the patient.

As an alternative for our calculations, choosing the Friction Cost method [45] to value productivity costs would mean leaving out productivity costs due to disability completely. This will therefore lead to a lower estimate of the total COI. However, disabled persons are a cost to society, and in case a certain illness indicates a high risk of becoming disabled, then this increased risk should be expressed in the societal cost of illness. Thus, since rather a large portion of BPD-patients are partly or fully disabled, the currently used human capital approach seems more comprehensive.

4.1. Recommendations and final remarks

In order to overcome problems with respect to representativeness of the sample in a bottom-up design, we recommend to assess prevalence and COI in a combined design. First, prevalence is assessed in an open population. Subsequently, those subjects diagnosed with BPD should be followed for a predefined period of time in order to determine true COI. For psychiatric illnesses, it is not recommendable to perform a top-down COI calculation because of problems of under-registration, difficulty with calculating certain cost categories and inaccurate primary diagnoses.

The present study is the first to investigate the true societal costs of BPD, and leads to the conclusion that, although healthcare costs of non-institutionalized Borderline patients might not be disproportionate, total societal costs, especially the burden to family and friends and lost productivity, are substantial.

Note added in proof

[45] Koopmanschap MA, Rutten FF, van Ineveld BM, et al. The friction cost method for measuring indirect costs of disease. J Health Econ 1995;14(2):171–89.

Acknowledgements

The authors would like to thank Martin Knapp for his very useful comments to an earlier version of the present paper.

The present study was supported by grant no. OG 97-002 from the fund for evaluative research in medicine of the Dutch Healthcare Insurance Board. Publication of the study results was not in any way contingent on the sponsor's approval or censorship of the manuscript.

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