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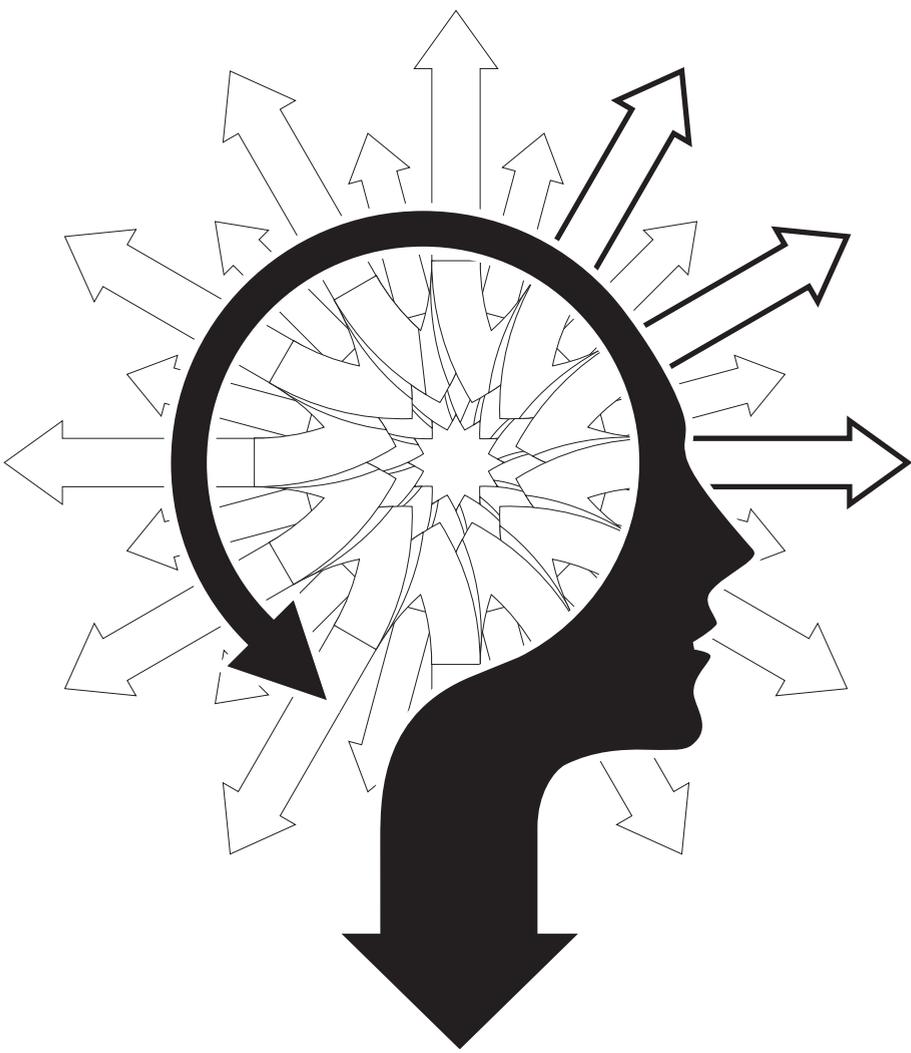
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**The burden of disease among
adolescents with personality
pathology:
quality of life and costs**

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ABSTRACT

In adults, personality disorders are associated with a low quality of life and high societal costs. To explore whether these findings also apply to adolescents, 131 adolescent patients were recruited from a mental health care institute in The Netherlands. Axis I and Axis II disorders were diagnosed using semi-structured interviews. The EuroQol EQ-5D was used to measure quality of life, costs were measured by the Trimbos and Institute for Medical Technology Assessment Questionnaire on Costs Associated with Psychiatric Illness. The mean EQ-5D index value was 0.55. The mean direct medical cost in the year prior to treatment was €14,032 per patient. The co-occurrence of Axis I and Axis II disorders was a significant predictor of a low quality of life. Direct medical costs were higher for the depressive personality disorder. This study shows that the burden of disease among adolescents with personality pathology is high. This high burden provides evidence to suggest that further research and development of (cost-)effective treatment strategies for this population may be worthwhile.

INTRODUCTION

Personality disorders are among the most prevalent mental disorders in the adult population (Torgersen, Kringlen, & Cramer, 2001). Moreover, they are associated with a low quality of life (Soeteman, Verheul, & Busschbach, 2008) and high societal costs (Soeteman, Hakkaart-van Roijen, Verheul, & Busschbach, 2008). This evidence is increasingly being used to inform policy debates about the necessity and reimbursement of treatment strategies for the adult population with personality disorders. Little is known about personality disorders in adolescents. One reason for this is the relative lack of data on adolescent personality pathology. Moreover, clinicians seem to have ambiguous feelings about diagnosing personality disorders in this population (Allertz & van der Voorst, 2007). Recent studies suggest however, that personality disorders can indeed be classified in adolescents, and that the prevalence in both the general population (Johnson, et al., 2000) and patient populations (Feenstra, Busschbach, Verheul, & Hutsebaut, 2011; Grilo, et al., 1998; Westen, Shedler, Durrett, Glass, & Martens, 2003) is comparable to that in adults. The main focus of quality of life research among adolescents has been on physical disorders. One of the studies that considered mental disorders found that adolescents with a mental disorder have poorer quality of life than those without, and even lower quality of life than adolescents with physical disorders (Bastiaansen, Koot, Bongers, Varni, & Verhulst, 2004). Studies investigating the costs of child and adolescent mental health problems in general, in for instance the United States and the Netherlands, showed that the economic burden is substantial (Hilderink & Van 't Land, 2009; Lynch & Clarke, 2006). However, no studies have investigated the quality of life and economic burden among adolescents with personality disorders, and the impact of co-morbidity of Axis I disorders and medical disorders on the burden is also unknown. Health care interventions for both mental and physical disorders have a competing interest in the limited resources available. In the priority-setting process for reimbursement, the burden of disease of the patient population is one of the issues considered (Stolk, Pickee, Ament, & Busschbach, 2005). Therefore, it is important to provide evidence about the burden of disease using generic measures such as quality of life and costs which allows for comparison among different mental and physical disorders. The aim of this study is to investigate the burden of disease among treatment-seeking adolescents with personality pathology in terms of quality of life and costs, and to explore the impact of co-morbid Axis I disorders and medical disorders on these outcomes.

METHODS

Participants

From June 2006 to January 2009, 133 adolescents were consecutively admitted to the inpatient unit of the Center for Psychotherapy DeViersprong, a mental health care institute in the Netherlands offering specialized outpatient, day hospital, and inpatient psychotherapy for adolescent and adult patients with personality disorders. Inclusion criteria for this study and admission to the inpatient unit were the presence of severe, chronic and multiple complaints, leading to clinically significant distress and impaired social and school functioning, and for which previous outpatient treatment has not resulted in significant improvement of functioning. The exclusion criteria for this study and admission were psychotic disorders (e.g., schizophrenia), organic cerebral impairment, and mental retardation. Two patients did not complete the assessment battery as part of the formal admission procedure, leaving 131 patients for the current sample. Of these patients, 111 were female (85%). The mean age was 16.6 (SD = 1.28, range 14-19). In the inpatient treatment program, patients are offered psychotherapy combined with psychosocial nursing and non-verbal therapies over a period of 12 months. Patients reside in the treatment center five days per week and attend school for approximately four hours per day at the property of the treatment center.

Measures

Quality of life was measured using the EuroQol EQ-5D (Brooks, Rabin, & de Charro, 2003). The EQ-5D measures quality of life in five dimensions, including mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The dimensions are divided into three response levels: no problems, some or moderate problems, and extreme problems or unable to. The combination of scores are weighted to arrive at a single index score between -0.33 (worst imaginable health state) and 1.00 (best imaginable health state). Dutch norm scores were used to calculate the mean EQ-5D index values (Lamers, Stalmeier, McDonnell, Krabbe, & Busschbach, 2005).

The Trimbos and Institute for Medical Technology Assessment (iMTA) Questionnaire on Costs Associated with Psychiatric Illness (TiC-P) was used to collect data on direct medical costs i.e., costs due to health care consumption (Hakkaart-van Roijen, Van Straten, Donker, & Tiemens, 2002). The first part of

the TiC-P consists of questions on: (1) the number of visits to e.g., a general practitioner, psychiatrist, medical specialist, physiotherapist, and alternative health practitioner; (2) the day care/hospital lengths of stay; and (3) the use of medication in the four weeks prior to filling out the questionnaire. Bottom-up methodology was used to calculate the total direct medical costs; that is, the total number of medical visits was multiplied by the 2003 unit prices of the corresponding health care services (Oostenbrink, Bouwmans, Koopmanschap, & Rutten, 2004; The Health Care Insurance Board (CVZ), 2005). The reference unit prices of health care services of 2003 were adjusted to prices in 2005 by using the consumer price index (Statistics Netherlands, 2007). The mean direct costs per four weeks were multiplied by 13 to calculate the annual costs. Additionally, the TiC-P includes a list of 28 chronic medical disorders, e.g., rheumatic disease, diabetes, asthma, migraine, cancer, and burnout/ severe tension. The adolescents were requested to indicate which of the chronic medical disorders they had experienced in the past year.

The Anxiety Disorders Interview Schedule for DSM-IV Child Version – Child interview (Adis-C) (Siebelink & Treffers, 2001; Silverman & Albano, 1996) was used to diagnose anxiety disorders and mood disorders. In addition, the Structured Clinical Interview for DSM-IV Axis I disorders (SCID I) (First, Spitzer, Gibbon, & Williams, 1997; Groenestijn, Akkerhuis, Kupka, Schneider, & Nolen, 1999) was used to diagnose substance use disorders, somatoform disorders, and eating disorders.

The Structured Clinical Interview for DSM-IV Axis II Personality disorders (SCID II) (First, Spitzer, Gibbon, Williams, & Benjamin, 1996; Weertman, Arntz, & Kerkhofs, 2000) was used for diagnosing Axis II personality disorders. Criteria were scored if they were pathologic, pervasive, and persistent and if they were present for at least one year, consistent with the DSM-IV-TR general diagnostic criteria for the presence of a personality disorder (American Psychiatric Association, 2000). Because DSM-IV-TR does not allow for antisocial personality disorder to be diagnosed in adolescents younger than 18, this section was omitted from the interview.

Timing of measures

The Structured Clinical Interview for DSM-IV Axis I and II Personality disorders and the Anxiety Disorders Interview Schedule for DSM-IV Child Version were

administered to the adolescents as part of the formal admission procedure. Both the EQ-5D and the TiC-P were administered in the first week of their stay at the inpatient unit.

Statistical analysis

Multiple regression main effect analyses were conducted in order to explore the impact of personality pathology and co-morbid Axis I disorders on the quality of life and cost outcomes. Age and gender are associated with quality of life and costs and were therefore entered in the multiple regression models (Brooks, et al., 2003). Chronic medical disorders are expected to induce high costs due to elevated use of both mental and somatic health care services. Therefore, an additional regression analysis was performed to explore the impact of chronic medical disorders on the health care consumption of adolescents. To investigate the relation between severity of personality pathology and quality of life, we observed the trend in EQ-5D scores with an increasing number of personality disorder traits.

RESULTS

Participants

In the sample of 131 treatment-seeking patients, 62 adolescents (47.3%) were diagnosed with a DSM-IV personality disorder diagnosis. Borderline personality disorder was most frequently diagnosed (25.2%), followed by avoidant personality disorder (16.0%), personality disorder not otherwise specified (PD NOS; 5.3%), depressive personality disorder (3.8%), and obsessive-compulsive personality disorder (3.8%). Paranoid, schizoid, schizotypal, narcissistic, histrionic, dependent, and passive-aggressive personality disorders were not diagnosed in this population of adolescents. The majority of the adolescents with a diagnosis of personality disorder had a co-occurring Axis I disorder (N = 52; 83.9%). Dysthymic disorder was most frequently diagnosed (26.7%), followed by social phobia (24.4%), and major depressive disorder (12.2%).

Quality of life

The mean EQ-5D index score among the total group of adolescents was 0.55 (SD = 0.27). Table 1 shows the EQ-5D values for the different personality disorder diagnoses, suggesting depressive personality disorder to be the most severely impaired disorder with an EQ-5D index score of 0.34. The results of the linear regression analysis (see Table 1) show however that no specific personality disorder diagnosis significantly predicted an impaired quality of life in this sample of adolescents ($p < 0.05$); only gender ($p = 0.031$) had a significant impact on quality of life, with girls having a lower quality of life than boys.

Table 1. EuroQol EQ-5D Index Scores for DSM-IV Axis II personality disorders (n = 131)

	N	%	EQ-5D	SD	Analysis	
					β	p
Age					-.030	.739
Gender					.198	.031
Borderline PD	33	25.2	.49	.28	-.074	.417
Avoidant PD	21	16.0	.49	.27	-.084	.350
Obsessive-compulsive PD	5	3.8	.50	.33	-.022	.799
Depressive PD	5	3.8	.34	.20	-.107	.235
Personality disorder NOS	7	5.3	.70	.23	.106	.230
Any PD	62	47.3	.51	.28		
No PD	69	52.7	.59	.26		

Footnote: The sum of the number of patients in the different diagnostic groups is higher than the total number of patients because patients can have more than one personality disorder.

The mean EQ-5D values for the different Axis I disorder diagnoses are presented in Table 2. When Axis I disorders were included in the regression analysis, gender ($p = 0.031$), dysthymic disorder ($p = 0.049$), and personality disorder not otherwise specified ($p = 0.043$) appeared to be significant predictors of quality of life (see Table 2). Girls and adolescents with dysthymic disorder experienced a significantly lower quality of life within the current sample, whereas adolescents with PD NOS experienced a higher quality of life.

Table 2. EuroQol EQ-5D Index Scores for DSM-IV Axis I and Axis II disorders (n = 131)

	N	%	EQ-5D	SD	Analysis	
					β	p
Age					-.026	.793
Gender					.212	.031
Anxiety disorders						
Social phobia	32	24.4	.47	.31	-.158	.221
Specific phobia	7	5.3	.57	.36	.082	.401
Panic disorder	2	1.5	.55	.42	.003	.972
Agoraphobia	2	1.5	.71	.08	-.044	.726
Generalized anxiety disorder	11	8.4	.35	.33	-.160	.122
Obsessive compulsive disorder	8	6.1	.57	.27	-.003	.972
Posttraumatic stress disorder	13	9.9	.47	.27	-.025	.787
Mood disorders						
Dysthymic disorder	35	26.7	.45	.26	-.194	.049
Major depressive disorder	16	12.2	.55	.23	-.054	.592
Substance use disorders						
Alcohol abuse	3	2.3	.61	.31	.050	.572
Alcohol dependence	1	0.8	.77	-	.155	.237
Substance abuse	1	0.8	.81	-	.052	.571
Substance dependence	6	4.6	.47	.26	-.123	.204
Eating disorders						
Anorexia nervosa	9	6.9	.57	.26	.062	.498
Bulimia nervosa	2	1.5	.61	.33	.022	.805
Eating disorder not otherwise specified	12	9.2	.56	.26	.029	.758
Somatoform disorders						
Conversion disorder	1	0.8	.81	-	.061	.488
Hypochondriasis	1	0.8	.25	-	-.110	.205
Other disorders						
Enuresis	1	0.8	.25	-	-.060	.495
Personality disorders						
Borderline PD	33	25.2	.49	.28	-.092	.342
Avoidant PD	21	16.0	.49	.27	.010	.934
Obsessive-compulsive PD	5	3.8	.50	.33	-.005	.961
Depressive PD	5	3.8	.34	.20	-.062	.539
Personality disorder NOS	7	5.3	.70	.23	.190	.043
Total group	131	100.0	.55	.27		

Footnote: The sum of the number of patients in the different diagnostic groups is higher than the total number of patients because patients can have more than one disorder.

Finally, a third regression model investigated the predictive value of having no disorder, only having an Axis I disorder, only having an Axis II disorder or having both an Axis I and Axis II disorder on quality of life. The analysis showed that, besides gender ($p = 0.021$), having both an Axis I and an Axis II disorder ($p = 0.019$) was a significant predictor of an impaired quality of life, with the results shown in Table 3.

Table 3. EuroQol EQ-5D Index Scores ($n = 131$)

	N	%	EQ-5D	SD	Analysis	
					β	p
Age					-.062	.484
Gender					.205	.021
Only an Axis I diagnosis	46	35.1	.55	.26	-.194	.104
Only an Axis II diagnosis	10	7.6	.61	.30	-.020	.843
Both an Axis I and an Axis II diagnosis	52	39.7	.49	.28	-.289	.019

Table 4 shows that the quality of life is inversely associated with the severity of personality pathology, as measured by the total number of personality disorder traits.

Table 4. EuroQol EQ-5D index scores by the total number of personality disorder traits ($n = 131$)

	Number of traits	N	%	EQ-5D	SD
Category 1	0-4	42	32.1	.59	.28
Category 2	5-9	63	48.1	.55	.26
Category 3	10-14	22	16.8	.51	.30
Category 4	15 +	4	3.1	.44	.24

Direct medical costs

The mean direct medical cost in the year prior to treatment of adolescents with personality pathology was €14,032 per year per patient (range €0 to €160,186).

Table 5 shows the mean direct medical costs per year differentiated by type of medical service among the total group of adolescents. The total mean direct medical cost of €14,032 per patient was mainly composed of costs due to inpatient health care (57.1%) and outpatient mental health care (15.4%).

In a linear regression analysis including the specific personality disorder diagnoses, only depressive personality disorder ($p = .024$) was associated with increased direct medical costs. When Axis I disorders were included in the regression

analysis, no specific Axis I or Axis II disorder appeared to have a unique effect on the direct medical costs. The third regression model, exploring the influence of having no disorder, only an Axis I disorder, only having an Axis II disorder or having both, showed that none of these categories appeared to be a significant predictor of increased direct medical costs.

When studying the main effects of the chronic medical disorders in a multiple regression analysis, none of the disorders appeared significant, indicating that none of the medical conditions had a significant effect on the direct medical costs in this sample.

Table 5. Mean direct medical costs per year of adolescents with personality pathology (n = 131)

Type of service	Cost (2005 prices) €	Percentage of total direct medical costs	Subjects using the service %
General practitioner	184.33	1.31	37.4
Company doctor	6.36	0.05	1.5
Physiotherapist	124.11	0.88	10.7
Alternative health practitioner	51.81	0.37	6.1
Domestic help	0.00	0	0
Self-help group	114.32	0.81	5.3
Social worker	353.52	2.52	15.3
Substance abuse outpatient care	0.00	0	0
Outpatient mental health care	2,159.48	15.4	29.0
Psychiatric practice	893.05	6.36	22.9
Outpatient clinic	363.23	2.59	8.4
Day hospital care	1,317.50	9.39	11.5
Inpatient health care	8,005.47	57.05	16.8
Medical specialist	72.66	0.52	8.4
Medication	386.54	2.75	62.6
Total	14,032.38	100.0	

DISCUSSION

This study shows that treatment-seeking adolescents with personality pathology experience a high burden of disease, reflected by a low quality of life and high health care costs. The quality of life in this population (EQ-5D index score of 0.55) is comparable to that found in the adult population with personality disorders

(EQ-5D index score of 0.56) (Soeteman, Verheul, et al., 2008), and to the quality of life found in adolescents with major depressive disorder (EQ-5D index score of 0.50) (Byford, Barrett, Roberts, Wilkinson, et al., 2007). For adolescents, the direct medical costs in the year prior to treatment (€14,032 per patient) were substantially higher than the costs found in the adult population with personality disorders (€7,398 per patient) (Soeteman, Hakkaart-van Roijen, et al., 2008). The economic burden of adolescents with personality pathology is also considerably higher than the burden in other child or adolescent conditions, such as patients with conduct disorder (Harrington, et al., 2000; Romeo, Knapp, & Scott, 2006), depressive disorder (Byford, Barrett, Roberts, Wilkinson, et al., 2007), or ADHD (Swensen, et al., 2003), but lower than for adolescents with anorexia nervosa (Byford, Barrett, Roberts, Clark, et al., 2007), adolescents admitted to an inpatient treatment (Green, et al., 2007), or young offenders (Barrett, Byford, Chitsabesan, & Kenning, 2006). The most relevant cost drivers in our study were inpatient health care (57.1%) and outpatient mental health care (15.4%). This conclusion holds even after controlling for chronic medical disorders. Our findings also reveal that, while personality pathology with co-morbid Axis I disorders is a significant predictor of an impaired quality of life in this patient group, co-morbidity of Axis I alone is not associated with increased costs. That is an interesting finding considering the fact that treatment-seeking adolescents with complex personality pathology commonly present themselves at the treatment centres with co-occurring Axis I disorders. These treatment-seeking adolescents represent a group with a severely impaired quality of life. Moreover, literature indicates that it is the patients' subjective well being, rather than objective medical condition, that determines their treatment-seeking behaviour, their compliance, and their evaluation of treatment (Hunt & McKenna, 1993). Whereas in adults some personality disorder diagnoses clearly predicted an impaired quality of life (borderline, narcissistic, obsessive-compulsive, depressive, negativistic personality disorder and personality disorder not otherwise specified) or increased societal costs (borderline and obsessive-compulsive personality disorders), among adolescents the increased burden of disease was hardly attributable to any specific personality disorder diagnosis. This is consistent with literature suggesting that the criteria of different personality disorders overlap more broadly in adolescents than in adults (Bondurant, Greenfield, & Man Tse, 2004). Although Soeteman's sample consists of adult patients with personality disorders that were registered as admissions to outpatient, day hospital or inpatient psychotherapy, the patients

in both samples i.e., adolescents and adults, experience equal burden of disease. Therefore, the difference in direct medical costs between both studies can not be explained by a difference in the quality of life or disease burden. The recall period for the use of medical services was 4 weeks. The annualization of these costs is based on the assumption that these 4 weeks are representative for the rest of the year. In order to test this assumption, in an adult sample of patients with personality disorders at the same institute (N = 922), an additional form was administered on which patients had to indicate the amount of outpatient, day hospital, or inpatient treatment they had received in the year prior to filling out the form. The utilization of these services was then compared against the TiC-P, with a recall period of 4 weeks. The results indicated that on a population level there was no significant difference between the costs as measured with a recall period of a year compared to a recall period of 4 weeks. Concordantly, there is no reason to believe that the costs calculated in the present study were an over/underestimation, but on the contrary are a realistic representation of the actual costs generated by this population in the year prior to treatment.

The major strength of this study is the use of generic measures to assess the burden of disease, allowing us to compare the burden in this patient population with the burden among patients with other physical and mental disorders. Moreover, the burden of disease can be used in further cost-effectiveness studies to assess the societal willingness-to-pay for a gain in health benefit (e.g., quality-adjusted life year: QALY). This study has also several limitations. First, despite evidence that school absenteeism, violence and criminal behavior in adolescents with complex personality pathology is prevalent, these costs were not included in the present study. This limitation leads to an underestimation of cost calculations. Indeed, this sample of adolescents indicated school problems in the year prior to treatment, including absence from school (27.1%) and reduced efficiency at school or difficulties with school performance (43.6%). Literature indicates that chronic absence from school in the early years can be linked to a number of negative outcomes later in life, including substance abuse, delinquency and dropping out of school (Schweinhart, et al., 2005). School absenteeism also has a far-reaching impact on a child's academic progress and thus economic development. That means that our cost calculations are conservative estimates, which further support the notion that personality pathology in adolescents is associated with enormous costs. Future research should include these cost parameters. Another

limitation of our study is that we used data from a treatment-seeking patient population, and in particular those who seek specialized psychotherapy for personality problems that were severe enough to be admitted to an inpatient unit. Therefore, the applicability of the results to non-treatment seekers, forensic care, patients who admit with a primary Axis I diagnosis, or patients attending outpatient services has yet to be established. Finally, research has shown that mental health care problems among adolescents also have an economic impact on families and affect the quality of life of both siblings and parents (Romeo, Byford, & Knapp, 2005). The impact of adolescent personality pathology on the families was not explored in this study. This narrow conceptualisation of quality of life and costs leads to an underestimation of the total burden of personality pathology in adolescents on society.

Despite these limitations, our findings suggest that the burden of disease among treatment-seeking adolescents with complex personality pathology is high, comparable to the burden found in the adult population with personality disorders. This high burden provides evidence to suggest that further research and development of (cost-)effective treatment strategies for this population may be worthwhile in order to provide relief for the patients as well as society.

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