THE BURDEN OF DISEASE IN PERSONALITY DISORDERS: DIAGNOSIS-SPECIFIC QUALITY OF LIFE

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A generic quality of life measure was used to investigate the burden of disease in a large sample of patients with personality disorders. The 1,708 subjects included in this study were recruited from six different mental health care institutes in the Netherlands. The burden of disease was measured using the EuroQol EQ-5D. Personality disorders were diagnosed using the Structured Interview for DSM-IV Personality (SIDP-IV). The mean EQ-5D index value was 0.56. Primarily the total number of personality disorder diagnoses rather than the specific type determined the quality of life. Notably borderline personality disorder was not associated with the highest burden. The findings indicate that patients with personality disorders experience a high burden of disease, comparable to that of severe somatic illnesses. The results call into question the primary focus in literature on borderline personality disorder. The current study yields a strong argument in favor of reimbursing (effective) treatments for this patient population.

Personality disorders are known to be associated with significant impairment in social, occupational, and other important areas of functioning. Several studies indicate poorer social and interpersonal functioning, and poorer occupational functioning, satisfaction, and achievement among patients with personality disorders as compared with others (Lim, Sander-son, & Andrews, 2000; Oltmanns, Melley, & Turkheimer, 2002). On measures of global functioning, most studies have shown significant functional impairments for patients with personality disorders (Abrams, Alexopoulos,...
Spielman, Klausner, & Kakuma, 2001; Hueston, Mainous, & Schilling, 1996; Johnson et al., 1996). A study by Skodol and colleagues (2002), for instance, compared the psychosocial functioning in patients with personality disorder (schizotypal, borderline, avoidant, and obsessive-compulsive) with major depressive disorder. They found patients with schizotypal and borderline personality disorder to be more impaired than patients with obsessive-compulsive personality disorder or major depressive disorder. This impairment is remarkable because impairment in major depressive disorder has been found to be comparable to that of chronic medical illnesses such as diabetes and arthritis (Hayes, Wells, Sherbourne, Rogers, & Spritzer, 1995; Wells et al., 1989). A study of outpatients by Nakao, Gunderson, and Phillips (1992), showed that patients with any personality disorder are more functionally impaired (GAF-scores) than those without a personality disorder.

All these investigations studied the “functioning” in personality disorder patients. However, in contemporary research, more and more emphasis is put on the “subjective quality of life” of these patients. This paradigm shift is reinforced by a number of studies showing that it is the patients’ subjective well being, rather than objective medical condition, that determines their treatment-seeking behavior, their compliance and their evaluation of treatment (Hunt, & McKenna, 1993). Furthermore, quality of life has become an important outcome in cost-effectiveness analysis (Drummond, Sculpher, Torrance, O’Brien, & Stoddart, 2005). As a consequence, the interest of psychologists and psychiatrists is no longer limited to symptom-focused outcome assessment, as they have become aware of the importance of quality of life measures in their clinical outcome measures.

In a recent Norwegian study, the quality of life of 72 patients with personality disorders in a psychiatric outpatient clinic was examined (Narud, Mykletun, & Dahl, 2005). The investigators used the multi-dimensional Short Form 36 (SF-36), a standardized generic measure, to assess the quality of life. The main finding of this study was that personality disorder patients treated in a psychiatric outpatient clinic had a significantly lower quality of life, on both the physical and mental SF-36 dimensions, than an age- and gender-adjusted general population sample. Furthermore, in a group of 1651 inpatients with complex personality problems and personality disorders, Soeteman, Timman, Trijsburg, Verheul, and Busschbach (2005) found a severe impairment in quality of life (EuroQol EQ-5D index score of .54). They compared the quality of life in this mental condition with those in severe somatic illnesses such as Parkinson’s disease (EQ-5D index score = .58) and rheumatic disease (EQ-5D index score = .53). Both studies described above have to be considered explorative studies of quality of life in personality disorders. The Norwegian study used a small sample of 72 psychiatric outpatients, and has therefore a limited external validity. Soeteman and colleagues’ sample size was substantial, but no standardized Axis II diagnoses were available; thus the results have limited internal validity.

The aim of this study is to investigate the relation of the burden of dis-
ease in terms of quality of life with the 14 DSM-IV personality disorders using a generic quality of life questionnaire, i.e., the EuroQol EQ-5D. Such a generic instrument can measure the burden of disease regardless of patients’ diagnoses and can therefore be used to compare the burden of disease in patients with personality disorders with patients with other medical conditions, for example severe somatic illnesses. Moreover, the different dimensions of quality of life in the EQ-5D are combined into one weighted score, thereby yielding unambiguous comparisons. Note that in this investigation we assume an inverse relation between quality of life and burden of disease; this assumption is also made in the Global Burden of Disease project of the WHO (Ustun, Ayuso-Mateos, Chatterji, Mathers, & Murray, 2004).

**METHOD**

**PARTICIPANTS**

Participants were recruited from a consecutive series of admissions to six mental health care institutes in the Netherlands offering outpatient, day hospital, and/or inpatient psychotherapy for adult patients with personality pathology and/or personality disorders. As part of the standard admission procedure, all applicants performed a routinely distributed assessment battery including self-report questionnaires in order to measure psychopathology, personality, functional impairments, and treatment history, and a semi-structured interview for diagnosing personality disorders. When the administration of the questionnaires forms part of the routinely administered clinical intake procedure and does not involve additional risks or load, informed consent is not mandatory under Dutch law. For this reason, informed consent was only asked if the patient participated in any further follow-up investigations.

From March 2003 to March 2006, 2,540 individuals have been registered as admissions to the six mental health care institutes. Of these patients, 462 (18.2%) did not start and 272 (10.7%) did not complete the formal admission procedure. Of the remaining 1,806 patients, 46 were excluded due to clear signs of unreliable data in the interview and/or questionnaires (2.3%) or due to serious intellectual impairment (0.3%). The EQ-5D was missing or incomplete for 52 patients, leaving 1,708 patients for the current study sample, i.e., 94.6% of those who completed the formal assessment procedure.

Of these patients, 35.4% were male. The mean age was 33.7 years (SD 9.9, range 18–67). Of these, 65.6% were unmarried, 22.0% married, and 12.4% were divorced or widowed. No differences with respect to gender, age, and educational level were found between those admissions that were included as compared to those who were excluded from the sample.

**MEASURES**

The quality of life was measured using the EuroQol EQ-5D (Brooks, Rabin, & de Charro, 2003). The descriptive system of the EQ-5D records quality
of life in 5 dimensions: mobility (walking about), self-care (washing and dressing oneself), usual activities (e.g., work, study, housework, family, or leisure activities), pain/discomfort and anxiety/depression. Each dimension is divided into 3 response levels: no problems, some or moderate problems, and extreme problems or unable to. The combination of scores define a total of 243 different possible health states and each of these are weighted to arrive at a single index score between −0.33 (worst imaginable health state) and 1.00 (best imaginable health state). The Dutch norm scores were used for calculating the mean EQ-5D index values (Lamers, Stalmeier, McDonnell, Krabbe, & Busschbach, 2005).

Personality disorders were measured using the Dutch version of the Structured Interview for DSM-IV Personality (SIDP-IV; Pfohl, Blum, & Zimmerman, 1995; translated by De Jong, Derks, Van Oel, & Rinne, 1996). This instrument includes the 11 formal DSM-IV-TR Axis II diagnoses (e.g., schizoid personality disorder) including personality disorder mixed, the two DSM-IV-TR appendix diagnoses (depressive and negativistic personality disorder), and—in addition—the DSM-III-R self-defeating personality disorder. Interviewers were master-level psychologists, who were trained thoroughly by one of the authors (RV), and who received monthly booster sessions to avoid drift from the interviewer guidelines. Inter-rater reliability was computed in 30 videotaped interviews rated by three observer-raters. Percentage agreement ranged from 84% (avoidant PD) to 100% (schizoid; median 95%). Intraclass correlation coefficients (ICC) for the sum of DSM-IV personality disorder traits present (i.e., scores “2” or “3”) ranged from 0.60 (schizotypal) through 0.92 (antisocial; median 0.74).

STATISTICAL ANALYSES

A multiple regression main effect analysis was conducted, measuring the independent contribution of the different diagnoses on quality of life. The majority of patients (54.9%) received at least two personality disorder diagnoses. That is the reason an additional regression was performed to account for possible interactions between diagnoses. Because the number of possible interactions between 14 independent variables becomes intractable, the interaction term is represented by a count of the diagnoses given. Age, gender, and education (socioeconomic status) variables are associated with quality of life and were therefore entered into the multiple regression models (Brooks et al., 2003).

RESULTS

In Table 1, the rank ordering of the quality of life figures is displayed for the 14 specific DSM-IV personality disorders. Because patients can have more than one personality disorder, the sum of the number of patients in
### TABLE 1. EuroQol EQ-5D Index Scores (Mean and Standard Deviation) for the 14 DSM-IV Personality Disorders

<table>
<thead>
<tr>
<th>Personality disorder</th>
<th>N</th>
<th>%</th>
<th>EQ-5D</th>
<th>SD</th>
<th>β^1</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personality disorder mixed</td>
<td>255</td>
<td>14.9</td>
<td>.62</td>
<td>.27</td>
<td>-0.05</td>
<td>0.05</td>
</tr>
<tr>
<td>Schizotypal</td>
<td>15</td>
<td>0.9</td>
<td>.56</td>
<td>.30</td>
<td>0.02</td>
<td>0.49</td>
</tr>
<tr>
<td>Avoidant</td>
<td>487</td>
<td>28.5</td>
<td>.54</td>
<td>.26</td>
<td>-0.04</td>
<td>0.16</td>
</tr>
<tr>
<td>Obsessive-compulsive</td>
<td>356</td>
<td>20.8</td>
<td>.53</td>
<td>.27</td>
<td>-0.06</td>
<td>0.02</td>
</tr>
<tr>
<td>Borderline</td>
<td>356</td>
<td>20.8</td>
<td>.52</td>
<td>.28</td>
<td>-0.07</td>
<td>0.01</td>
</tr>
<tr>
<td>Antisocial</td>
<td>36</td>
<td>2.1</td>
<td>.52</td>
<td>.30</td>
<td>-0.03</td>
<td>0.26</td>
</tr>
<tr>
<td>Dependent</td>
<td>179</td>
<td>10.5</td>
<td>.52</td>
<td>.27</td>
<td>-0.03</td>
<td>0.22</td>
</tr>
<tr>
<td>Paranoid</td>
<td>102</td>
<td>6.0</td>
<td>.51</td>
<td>.28</td>
<td>0.00</td>
<td>0.92</td>
</tr>
<tr>
<td>Narcissistic</td>
<td>99</td>
<td>5.8</td>
<td>.51</td>
<td>.30</td>
<td>-0.08</td>
<td>0.00</td>
</tr>
<tr>
<td>Schizoid</td>
<td>18</td>
<td>1.1</td>
<td>.51</td>
<td>.28</td>
<td>-0.03</td>
<td>0.21</td>
</tr>
<tr>
<td>Depressive</td>
<td>546</td>
<td>32.0</td>
<td>.50</td>
<td>.27</td>
<td>-0.17</td>
<td>0.00</td>
</tr>
<tr>
<td>Histrionic</td>
<td>49</td>
<td>2.9</td>
<td>.50</td>
<td>.26</td>
<td>-0.01</td>
<td>0.83</td>
</tr>
<tr>
<td>Self-defeating</td>
<td>116</td>
<td>6.8</td>
<td>.48</td>
<td>.28</td>
<td>-0.03</td>
<td>0.22</td>
</tr>
<tr>
<td>Negativistic</td>
<td>61</td>
<td>3.6</td>
<td>.42</td>
<td>.28</td>
<td>-0.06</td>
<td>0.01</td>
</tr>
<tr>
<td>N with at least one personality disorder</td>
<td>1396</td>
<td>81.7</td>
<td>.56</td>
<td>.27</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N without personality disorder</td>
<td>312</td>
<td>18.3</td>
<td>.67</td>
<td>.25</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1Linear regression analysis: dependent variable quality of life; independent variables categorical diagnoses: having or not having that particular personality disorder

The mean EQ-5D index value for the personality disordered group as a whole was .56 (SD = .27), representing a severe burden of disease. Note that the mean EQ-5D index scores for almost all of the specific diagnostic groups (except for PD mixed and schizotypal personality disorder) in Table 1 appear to be lower than the mean EQ-5D index score for the total group of patients with at least one disorder (.56). This is possible because patients with a large number of diagnoses, and concordantly a low quality of life (see also Table 2), are represented in an equally large number of diagnostic groups. As a consequence of their poor quality of life, they “lower” the mean EQ-5D index scores of all of these groups.

In the present sample, depressive (32.0%), avoidant (28.5%), obsessive-compulsive (20.8%), and borderline personality disorder (20.8%) were the most frequently diagnosed disorders. Schizotypal (0.9%) and schizoid personality disorder (1.1%) were the least frequently diagnosed disorders. In about one-fifth of the total group of patients no personality disorder could be diagnosed.

When studying the main effects of the specific personality disorders in a linear regression analysis, six out of 14 appeared significant (p < 0.05), indicating that having or not having that specific disorder has a significant effect on the quality of life in this sample. These six disorders are borderline, narcissistic, obsessive-compulsive, depressive, negativistic personality disorder, and personality disorder mixed.

Table 2 shows that the quality of life is inversely associated with the number of personality disorders diagnosed. As could be predicted from the
TABLE 2. EuroQol EQ-5D Index Scores (Mean and Standard Deviation) for Increasing Number of Personality Disorder Diagnoses

<table>
<thead>
<tr>
<th>Number of PDs</th>
<th>N</th>
<th>%</th>
<th>EQ-5D index score</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>No PD</td>
<td>312</td>
<td>18.3</td>
<td>.67</td>
<td>.25</td>
</tr>
<tr>
<td>One PD</td>
<td>458</td>
<td>26.8</td>
<td>.62</td>
<td>.27</td>
</tr>
<tr>
<td>Two PDs</td>
<td>365</td>
<td>21.4</td>
<td>.58</td>
<td>.26</td>
</tr>
<tr>
<td>Three PDs</td>
<td>279</td>
<td>16.3</td>
<td>.55</td>
<td>.27</td>
</tr>
<tr>
<td>Four PDs</td>
<td>168</td>
<td>9.8</td>
<td>.48</td>
<td>.28</td>
</tr>
<tr>
<td>Five PDs</td>
<td>76</td>
<td>4.4</td>
<td>.50</td>
<td>.26</td>
</tr>
<tr>
<td>Six PDs</td>
<td>26</td>
<td>1.5</td>
<td>.42</td>
<td>.28</td>
</tr>
<tr>
<td>Seven or more</td>
<td>24</td>
<td>1.4</td>
<td>.32</td>
<td>.23</td>
</tr>
</tbody>
</table>

lower means for specific diagnoses compared to the overall mean in Table 1, the number of personality disorders has a large effect on quality of life \( (p = 0.000) \). When controlling for the number of disorders in the regression analysis, only depressive personality disorder maintains a unique statistically significant effect on quality of life \( (p = 0.03) \).

DISCUSSION

Personality disorders are associated with a severe impairment in quality of life. The overall EQ-5D index value of .56 suggests that the quality of life experienced by patients with personality disorders can be compared to the quality of life in, for instance, rheumatic disease, lung cancer, or Parkinson’s disease with EQ-5D index scores of .53, .58, and .58, respectively (Siderowf, Ravina, & Glick, 2002; Trippoli, Vaiani, Lucioni, & Messori, 2001; Wolfe & Hawley, 1997). The burden of having a personality disorder seems even higher than in patients with type II diabetes (EQ-5D score of .69), schizophrenia outpatients treated with neuroleptics (.73), and HIV infected patients (.77; Dernovsek, Prevolnik Rupel, Rebolj, & Tavcar, 2001; Koopmanschap, 2002; Stavem, Frøland, & Hellum, 2005). The burden is only found to be higher in major depressive disorder (.33) and patients with renal failure on haemodialysis (.44; Lee, Morgan, Conway, & Currie, 2005; Sapin, Fantino, Nowicki, & Kind, 2004). It can be concluded that patients who are in search for treatment for their personality disorders experience a high burden of disease, as compared to other populations with severe somatic illnesses.

Borderline, narcissistic, obsessive-compulsive, depressive, negativistic personality disorder and personality disorder mixed appear to have a significant effect on the quality of life. However, when the total number of personality disorders diagnosed is taken into account and included in the analysis, the latter appears the most important predictor of quality of life, leaving only the depressive personality disorder with an additional effect. These findings seem to imply that in patients with borderline, narcissistic, obsessive-compulsive, negativistic personality disorder, and personality disorder mixed the comorbidity of other Axis II disorders rather than the specific diagnosis caused the quality of life to be more impaired. This con-
clusion is in line with the results of a study by Jackson and Burgess (2004), in which no significant differences could be found on the SF-12 Mental Summary Scale between eight ICD-10 personality disorders in an Australian community sample of 10,641 participants. Consistently, the authors mentioned that the addition of other comorbid personality disorders to the specific personality disorders led to sizeable increases in the odds ratios for all personality disorder types on the disability measures. Similar results were found by Nakao et al. (1992), who showed a strong positive relationship between the total number of Axis II criteria met and the severity of the functional impairment as measured with the Global Assessment of Functioning Scale (GAF score). Jackson and Burgess (2000) also found an increasing disability according to the SF-12 Mental Summary Subscale with an increasing number of personality disorders. The only exception seems the study by Narud et al. (2005) who found no worsening of quality of life as measured with the SF-36, with increasing number of personality disorders. They attributed this to a small sample size.

The 1,708 participants included in this study were recruited from six different mental health care institutes in the Netherlands specialized in the psychotherapeutic treatment of personality problems and disorders. The large number of patients and the different settings can be considered one of the strengths of this study, as these enhance the external validity of the results. On the other hand, we only sampled patients that were referred to some sort of psychotherapy; therefore the results may not be generalized to all prevalent cases in the community. However, this cannot be considered legitimate criticism taken into account the aim of the study. The ultimate purpose of our study is providing an argument for reimbursing, in other words providing an answer to the question if an expensive treatment for this population of patients, based on the necessity of treatment (i.e., burden of disease), is justified. Only personality disordered patients who actually search for, or are referred to, some sort of treatment will claim money for that treatment, which is paid for by society.

Another limitation of our study is that no standardized diagnoses of comorbid Axis I psychiatric disorders were available. Note, however, that this limitation does not jeopardize the main finding of our study, namely that patients who seek treatment for their personality disorders experience a high burden of disease. In this stage of their disorder, when patients are admitted to a mental health care facility, it is difficult to find patients with “only” Axis II problems. Isolating the effects of the Axis I disorders would be the same as considering the burden of disease of diabetics without the foot ulcers or the quality of life of schizophrenic patients without the symptoms caused by neglect. Moreover, it has been shown that Axis I and Axis II disorders are independently related to disease-specific burden of disease parameters (Jackson & Burgess, 2000, 2002; Skodol et al., 2002; Verheul et al., 2000). The independent contribution of Axis I and Axis II pathology to the burden of disease should be addressed in future research.

The use of generic quality of life measures in mental health research has been criticized (Chisholm, Healey, & Knapp, 1997). According to Chisholm
and colleagues, one of the concerns is that the domains of particular importance in the measurement of quality of life in people with mental health problems are not represented properly in the prominent generic quality of life measures employing domains of physical mobility, pain, and disability. They argue that this can lead to an undervaluation of the burden of disease in the mentally ill. Another concern is that mental disorders are perceived as more heterogeneous in the course, content, and consequences over time than somatic disorders, which causes the quality of life in mental disorders to have a limited predictability and stability.

However, this study provides evidence that these concerns are not justified for the patient population subject to our investigation. A substantial burden of disease was found by using the generic EuroQol EQ-5D, which at least indicates that an important part of the problems in this particular patient group are well captured in the 5 domains of the EQ-5D. Moreover, a similar high burden of disease (EuroQol EQ-5D index score of .54) was found in an earlier study of Soeteman et al. (2005) among a large group of patients with similar problems, which indicates the robustness of the present findings. Additionally, the reliability and validity of quality of life measures have been established in other mental illnesses, such as schizophrenia (Pukrop et al., 2003). The present demonstration of the use of the EQ-5D in personality disorders should encourage its use in research, which should help positive funding decisions since it is easier to make comparative decisions across disease types using generic quality of life measures such as the EQ-5D.

When examining the ranking of the burden of disease in the 14 specific DSM-IV personality disorders in Table 1, it becomes clear that a high burden is not necessarily associated with receiving more attention in clinical research. Blashfield and Intoccia (2000) have shown that the only personality disorder whose literature was clearly alive and growing was that of the borderline personality disorder; a disorder that is positioned in the upper regions of the ranking of quality of life. On the other hand personality disorders that are associated with a higher burden, according to our ranking, have either very small literatures (e.g., dependent, narcissistic, paranoid, passive-aggressive) or literatures with flat or negative growth rates (e.g., dependent, histrionic, paranoid, passive-aggressive, schizoid). One explanation is that the disorders that cause the greatest societal burden (e.g., antisocial) or the greatest burden to clinicians (e.g., borderline) have traditionally attracted most scientific attention. Our findings suggest that an emphasis on burden from a patient perspective would have lead to completely different choices.

In health care, cost-effectiveness analyses are a well-established decision tool in reimbursement policy. However, a growing body of evidence suggests that cost-effectiveness alone is not sufficient for rational decision making in this regard. It is found that burden of disease interacts with cost-effectiveness considerations: the higher the burden of disease, the more willing society is to accept a poor cost-effectiveness (Pronk, & Bonsel, 2004; Stolk, Brouwer, & Busschbach, 2002). For instance, the cost-effec-
tiveness of Viagra is very favorable, but its funding remains in dispute. On the other hand, lung-transplantation is known for its unfavorable cost-effectiveness, yet the reimbursement is not a matter of debate. It thus seems that the burden of the patients (or how pitiful their situation seems) also plays a key role in the discussion which treatments to fund. More and more existing treatments, which have long been reimbursed without providing any evidence for their cost-effectiveness such as, for instance, psychotherapy, are recently required to demonstrate their efficiency in order to free budget for the treatments, which have already shown to be cost-effective. The current study, showing a high burden of disease in patients with personality disorders, yields a strong argument in favor of reimbursing (effective) treatments for this patient population.

REFERENCES


