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Explorations in secondary mental health care

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Psychopathology in borderline intellectual functioning

Explorations in secondary mental health care

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Voor mijn patiënten

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Chapter 1

General introduction



Borderline intellectual functioning

The term Borderline Intellectual Functioning (BIF) refers to intellectual functioning between normal intellectual functioning and intellectual disability (ID) (see figure 1). ID is defined as a total intelligence quotient (TIQ) of 2 or more standard deviations below the mean on the normal curve of intelligence and BIF as between 1 and 2 standard deviations (SD) below the mean. Roughly this category of BIF corresponds with a TIQ on a standardised intelligence test between 70 and 85. According to the normal IQ distribution as much as 13.59% of the population, i.e. in the Netherlands over 2 million people, fall into this category.

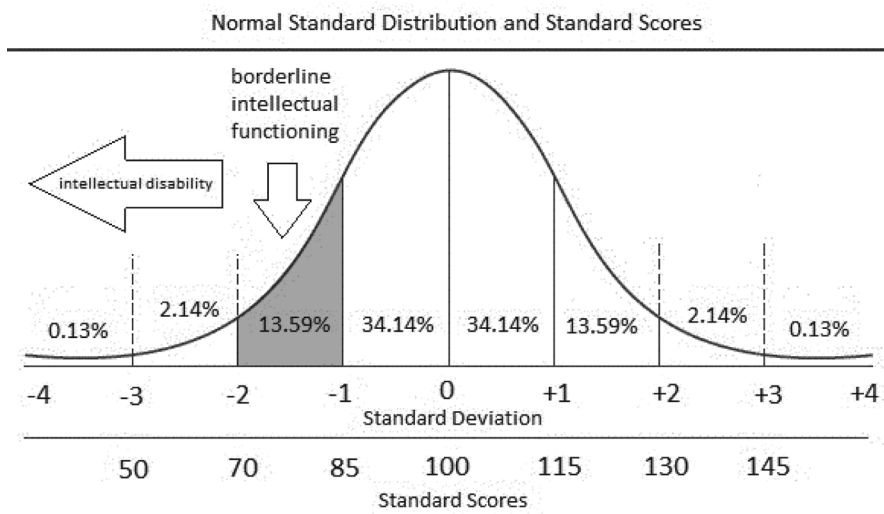


Figure 1. Normal curve of the distribution of intelligence in the general population. The intelligence quotient (IQ) is a score derived from one of the standardized tests designed to assess human intelligence. The median raw score of the normative sample is defined as an IQ of 100. Each standard deviation (SD) up or down equals 15 IQ points. By this definition, approximately two-thirds of the population scores between IQ 85 and IQ 115. BIF is defined as an IQ between 1 and 2 SD below the mean (IQ 70-85) and ID is defined as an IQ of 2 SD or more below the mean (IQ < 70).

In most cases people with BIF live unnoticed in the community. They are not easily recognizable by specific features, personality traits or behavioural phenotypes. People with BIF often try very hard to be 'normal' and are mostly successful in masking their disabilities. On the one hand, this is an advantage as it helps them to maintain themselves in society. On the other hand, they have to always stretch their efforts to the maximum and consequently are more at risk of developing psychiatric disorders than people with higher IQs. Besides, because they are so good in masking their relatively low IQ, they run the risk of being approached as if they have a higher IQ and get explanations about illness and treatment that are too complicated.

In fact, it has been shown that compared to people with higher IQs (TIQ > 85) and possibly also compared to those with lower IQs (TIQ < 70), children and adults with BIF are at increased risk for the development of mental health problems.¹⁻⁵ But, they seem to be less likely to receive treatment³ and if they do get treated, they are more likely to get psychotropic drugs than psychotherapy.³ As a group they are understudied. More knowledge about psychopathology in this group is needed.

It is the aim of this thesis to study the nature and severity of psychiatric symptoms and psychiatric disorders in people with BIF who became so seriously ill that they had to be referred to secondary care units in which BIF is a focus of attention.

BIF as diagnostic category

Borderline Intellectual Functioning (BIF) has always been a difficult concept. It had different names, different boundaries, and travelled through the different versions of the Diagnostic and Statistical Manuals of mental disorders (DSMs) starting as a solid element of - what we now call - intellectual disability (ID) in the DSM I and ending, in DSM-5, as a V-code literally in last place.⁶

In the first two editions of the DSM, BIF was the lightest level of *mental deficiency*; what we now call ID.^{7,8} It was a disorder. Later, in the DSM III, the DSM III-R and the DSM-IV, *mental retardation* was placed as a disorder on axis II, along with the personality disorders⁹⁻¹¹. Meanwhile, BIF was no longer the lightest level of *mental retardation*. This place had been taken over by mild mental retardation (IQ 50-70). BIF had become a so-called V-code (on axis II). This implied that it was no longer considered to be a disorder per se. In the DSM-IV V-codes are defined as *additional conditions that may be a focus of clinical attention*. The description of BIF in the DSM-IV is shown in box 1. In the DSM-5, BIF is also a V-code. The definition of V-codes in the DSM-5 is *other conditions that may be a focus of clinical attention* and BIF is coded under *other circumstances of personal history*.

V62.89 Borderline Intellectual Functioning DSM-IV

This category can be used when the focus of clinical attention is associated with borderline intellectual functioning, that is, an IQ in the 71-84 range. Differential diagnosis between Borderline Intellectual Functioning and Mental Retardation (an IQ of 70 or below) is especially difficult when the coexistence of certain mental disorders (e.g. Schizophrenia) is involved. *Coding note:* This is coded on Axis II.

V62.89 Borderline Intellectual Functioning DSM-5

This category can be used when an individual's borderline intellectual functioning is the focus of clinical attention or has an impact on the individual's treatment or prognosis.

With the criteria for BIF from the DSM-III onwards it is still acknowledged that the presence of this vulnerability may play a role in treatment and it still is possible to

mark it as a focus of clinical attention. However, since BIF is no more listed in the levels of severity of the disorder ID, the classification systems of mental disorders seem to conspire with the people with BIF themselves to keep their psychological problems out of sight. Therefore, it is not surprising that the association of BIF with psychiatric disorders is rarely studied.

Special outpatient clinics for BIF

In the Netherlands, in contrast to most other countries, people with BIF and co-morbid psychiatric disorders are eligible for specialized psychiatric outpatient services for patients with ID. Unfortunately, there they are lumped with patients with a mild intellectual disability (mild ID) in a single group called *Licht Verstandelijk Gehandicapten* (LVG) or – nowadays – *Lichte Verstandelijke Beperking* (LVB).^{12,13} However, as the IQs of all patients in the specialised outpatient clinics of Rivierduinen are assessed it is possible to study patients with BIF apart from those with mild ID.

Rivierduinen, a large regional mental health care provider, has two centres for psychiatry and intellectual disability (CPID): Kristal, centre for psychiatry and intellectual disability, location Leiden and location Gouda. The two CPID offer multidisciplinary integrative diagnostics and treatment for psychiatric patients with an IQ < 85. At the two CPID next to IQ the developmental perspective is always taken into account, including social and emotional development and level of adaptive functioning, in interpreting psychiatric symptoms and classifying psychiatric disorders.¹⁴ During the 10 years of its existence Kristal has built up much clinical experience in the diagnostics and treatment of psychiatric disorders of patients with low IQs. Treatments have been developed and adapted to fit in with the cognitive and social-emotional abilities of patients with low IQs and are described in the care-program 'Psychiatry and Intellectual Disability'.

Routine Outcome Monitoring

Routine Outcome Monitoring (ROM) was developed in 2002 by the Leiden University Medical Centre, the University of Amsterdam and Rivierduinen.^{15,16} Within mental health care, ROM is used to measure treatment outcome, by routinely or periodically measuring the nature and severity of psychiatric symptoms, at baseline and during treatment. Goals of ROM include 1. determining the nature and severity of symptoms at baseline; the moment of first presentation in the clinic 2. establishing the course of symptoms over time and 3. visualizing the effect of treatment. Collected data can be used for scientific research. A very important part of routine outcome monitoring is the fact that the system allows for feedback to treating psychiatrists, psychologist and other health care practitioners.

Patients are informed about possible use of anonymised data from ROM for research purposes. If people object to such use, their data is removed. A comprehensive protocol safeguards anonymity of the patients and ensures proper handling of the data.

The Medical Ethical Committee of the Leiden University Medical Centre (LUMC) approved the regulations and agreed with this policy.¹⁶

At Kristal, Centre for Psychiatry and Intellectual Disability, ROM was introduced starting at the end of 2009. The goals of this ROM especially for patients with low IQs (TIQ < 85), were similar to the original goals. However, the use of assessment instruments in daily clinical practise, especially self-report questionnaires, in psychiatric patients with low IQs was a novelty. This was at least partly due to the lack of adequately translated and tested psychiatric assessment instruments in the Dutch language.¹⁷ There were only a few measures available especially developed for people with intellectual disabilities and little was known about the utility of existing 'regular' assessment measures. We did not find any literature on the use of (self-report) assessment instruments in psychiatric patients with BIF.

Because, in addition to the goals of ROM in general mental health care we wanted to be able to compare patient groups with lower IQs (TIQ < 85) with those of average or above average intelligence we decided to use existing non-altered ROM measures where possible. One of the first goals of this thesis was to test the utility and psychometric properties of one of the primary screeners and general psychopathology outcome measures of ROM in regular mental health care, the Brief Symptom Inventory (BSI).^{18,19}

Some alterations to the ROM process were made. Most importantly an 'assisted completion format' was used. In this format assessment was conducted in a one-to-one setting. Instruction and items of the questionnaires were read in order, either together with the patient or verbatim to the patient. The answer feedback sheet contained both numerical and written representations. Language was adapted when needed, meaning that the same item was repeated in simplified wordings. Previous research showed that assisted completion influenced the patients' ratings of symptoms only modestly and did not affect the psychometric properties.^{20,21}

Aim of the studies and outline of the thesis

The overall aim of the studies described in this thesis was to learn more about the nature and severity of psychiatric symptoms and psychiatric disorders in secondary mental health care outpatients with BIF. In order to do so, we used anonymised diagnostic information recorded in the official registration system of the electronic patient file, we investigated the utility and psychometric properties of the BSI and we then used ROM data from both patients from regular mental health care (RMHC) and patients with BIF and/or mild ID to look at symptom profiles and prognostic factors of treatment.

Chapter 2 describes in detail the history of the concept of BIF throughout previous DSMs and other classifications systems and its place in DSM-5. It provides information about BIF and on the importance of placing the concept of BIF in the right context and in the right place in future DSMs.

In chapter 3 we address the question with which psychiatric disorders people with BIF present themselves in mental health care by reporting the rates of DSM-IV-TR axis I diagnoses of mental health care outpatients with BIF compared to patients from RMHC and patients with mild ID.

In chapter 4 rates of DSM-IV-TR axis II diagnoses were compared in the same way. In chapter 5 we describe the feasibility and psychometric properties of the Brief Symptom Inventory (BSI) as a ROM assessment measure in patients with BIF and mild ID.

Chapter 6 describes BSI symptom profiles of outpatients with BIF and either major depressive disorder or posttraumatic stress disorder, compared to symptom profiles of outpatients from regular mental health care and outpatients with mild ID.

In chapter 7, to learn more about possible prognostic factors in the treatment of psychiatric disorders in BIF, the aim was to explore whether gender, age, level of ID and cluster B personality disorders (PD) were associated with treatment outcome.

Last, in chapter 8 the main results are summarised, results and clinical implications are discussed and recommendations are provided for the improvement of mental health care in patients with BIF and for future research.

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Chapter 2

Where goes borderline intellectual functioning

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Abstract

Borderline intellectual functioning (BIF) is an important and frequently unrecognized co-morbid condition relevant to the diagnosis and treatment of any and all psychiatric disorders. In the *Diagnostic and Statistical Manual of mental disorders* (DSM)–IV-TR, BIF is defined as having an Intelligence Quotient (IQ) in the 71-84 range. In DSM-5 IQ boundaries are no longer part of the classification, leaving the concept of BIF without a clear definition. This modification of the classification of BIF is one of the least highlighted changes in the DSM-5. In this paper we describe the history of the classification of BIF and provide information about BIF and on the importance of placing the concept of BIF in the right context and in the right place in future DSMs and other classification systems like the International Classification of Disease (ICD).

Introduction

One of the least highlighted changes in the DSM-5 is the modification of the classification of Borderline Intellectual Functioning (BIF).¹ Contrary to earlier versions of DSM, Intelligence Quotient (IQ) boundaries are no longer part of the classification, leaving the concept of BIF without a clear definition. IQ scores are, over most of the range, well described by a normal distribution. The term BIF describes the group of people that function on the border between normal intellectual functioning and intellectual disability (ID), between 1 and 2 standard deviations below the mean on the normal curve of the distribution of intelligence, roughly an IQ between 70 and 85. According to the normal curve, as much as 13.6% of the population falls into this category. BIF has always been a difficult concept. It had different names, different boundaries, and travelled through earlier DSMs starting as a solid element of mental deficiency in the DSM I and ending, in DSM-5, as a V-code literally in last place. The classification of BIF in DSM-5 has followed a similar path as in the international classification of disease (ICD).^{2,3,4} And although ICD-11 is not due until 2017, ICD-11 and DSM-5 will likely share the same view.

In DSM-5, similar to the new classification of ID, IQ test scores are removed from the diagnostic description of BIF. This is detrimental to the concept of BIF, since it was the only criterion left. Within the classification of ID, even in DSM-5, the importance of standardized IQ scores is well described. As a V-code BIF ultimately has been defined solely by IQ. By removing the IQ criterion, DSM-5 no longer provides any criteria for what exactly is BIF. ICD-11 will probably do the same or might score out the classification of BIF altogether. This, in spite of the fact that it is critically an important and frequently unrecognized co-morbid condition vastly relevant to the diagnosis and treatment of any and all psychiatric disorders.

In this paper we describe the history of the classification of BIF and provide information about BIF and on the importance of placing the concept of BIF in the right context and in the right place in future DSMs and other classification systems like the ICD.

History of borderline Intellectual functioning

Before DSM-I, there were different cut offs in IQ-scores used when it comes to - what is now called - Intellectual disability (ID) or intellectual developmental disorder (IDD). Consequently, ID included what we now call BIF as part of ID. In DSM-I, BIF was called mild mental deficiency, listed in the section *Mental Deficiency*.⁵ The classification applied when there was both an IQ of about 1 to 2 standard deviations below the mean – equalling an IQ between 70 and 85 - and functional impairment. DSM-I already made a plea for a classification based on more than a standardized IQ test alone. It states that cultural, physical and emotional determinants, as well as school, vocational and social effectiveness should be taken into consideration.⁵ In DSM-II, BIF was called borderline mental retardation. It had a place in the section

Mental Retardation.⁶ The boundaries of *borderline mental retardation* (IQ 68-83) differed slightly from those of mild mental deficiency in the DSM-I, but the other criteria remained the same. The place of BIF dramatically changes in DSM-III.⁷ In DSM-III, BIF is no longer part of what by then are called intellectual disorders. *Mental retardation* is now covered in the chapter of disorders usually first evident in infancy, childhood or adolescence. BIF is now a V-code 'exiled' to the chapter "V-codes for conditions not attributable to a mental disorder that are the focus of attention or treatment" in the far back of the DSM. The V-code BIF is to be used when the focus of attention or treatment is associated with BIF, i.e. an IQ in the 71-84 range. Where in the classification of mental retardation it is still recognized and described that IQ should not be the only criterion in making a diagnoses of mental retardation or in evaluating its severity, in the V-code BIF, IQ is now the only criterion left.

ICD

In the ICD, borderline intellectual functioning has a similar history being excluded from the section of mental retardation at about the same time.^{2,3} This change obviously caused a significant decrease in the prevalence of ID. In the DSM-III the argument was that the large majority of individuals with borderline intellectual functioning does not have significantly impaired adaptive behavior.⁷ For more than 30 years then, classification of BIF does not change. DSM-III, IV and IV-TR all use the V-code BIF. During the same time in the ICD, BIF got shifted to the residual code R41.8; a rather non-specific code referring to "other and unspecified symptoms and signs involving cognitive functions and awareness".⁴

Now, DSM-5 has further stripped the definition of BIF. The V-code BIF in DSM-5 is listed in *Other Conditions That May Be a Focus of clinical Attention*, under *Other Circumstances of Personal History*. It ceases to provide any description of what BIF entails. The DSM-5 just states that the V-code can be used when an individual's borderline intellectual functioning is the focus of clinical attention or has an impact on the individual's treatment or prognosis.

Vulnerability and mental health

According to DSM and ICD, BIF is not a disorder. But people with BIF, or an IQ between 70 and 85, do comprise a vulnerable group. Genetic liability, biological causes like perinatal difficulties and epigenetic factors such as socioeconomic status and maternal stress all contribute to BIF.⁸ Children with BIF are uniquely at risk for receiving poor parenting.⁹ Mothers of children with BIF were less positive and sensitive; showed less positive engagement even though their children did not exhibit more difficult child behaviour. Given the importance of positive and sensitive parenting for secure attachment and adaptive regulatory capabilities, children with BIF might be at risk at a very early age.⁹ In adult life, contrary to the DSM-III statement, perhaps increasingly so due to the growing complexity of society, many people with BIF do have pro-

blems in adaptive functioning. In fact, they face difficulties across all areas of ordinary life.¹⁰⁻¹⁴ They are at increased risk of experiencing physical problems,¹³ poverty,¹⁵ have more difficulties with activities of daily living,¹¹ have limited social support^{11, 12} and no access to specialised services.¹⁵ They often live problematic lives, functioning under high strain but unnoticed by the rest of society.¹⁵ Many people with BIF do not have psychiatric disorders, but people with BIF are more vulnerable for the development of mental health problems than people of average or above average intelligence and maybe also more vulnerable than people with mild ID.^{11, 15-20} Several studies show increased risk for the development of almost all psychiatric disorders in childhood as well as in adulthood, including substance misuse and personality disorders.^{11, 12, 16, 17, 21, 22} When people with BIF do develop psychiatric disorders, especially when there are additional problems in adaptive functioning, BIF and its impact on the presentation, diagnostics and treatment of these psychiatric disorders should not be overlooked. Because even though BIF is not a disorder and not a disability by itself, when people with BIF develop a psychiatric disorder, BIF is an impediment in diagnostics and treatment.

Unfortunately, despite the fact that BIF is a vulnerability and has impact on co-morbid disorders, people with BIF are almost invisible in research and – when they develop co-morbid psychiatric disorders – are rarely identified as having BIF in mental health care. The DSM-5 classification of BIF as is, is not likely going to improve on this problem.

Why paying serious attention to BIF remains important

As is the case with many psychiatric diagnoses, the classification BIF can have a stigmatizing effect. People with a low IQ often themselves try to prevent their limited intellectual capabilities being exposed by painstakingly trying to behave ‘normally’ and masking their disabilities and special needs. Also, society as a whole, tries to look away from BIF. For example, people with BIF are not entitled to the special support services for intellectually disabled people because their IQs are deemed too high. Unlike other countries, in the Netherlands, individuals with BIF and co-morbid psychiatric disorders are eligible to the same specialised mental health care services as people with ID. In this way special attention to the impact of BIF on co-morbid psychiatric disorders and the special skills training mental health workers need to treat this patient group is adequately guaranteed. It is doubtful whether general mental health care services are able to deliver the same adequate care. It is important to take BIF into account as a complicating factor from the start of diagnostics and treatment and to train mental health workers in this respect.

At this time however, most mental health care professionals are not trained in recognizing BIF and miss the extra skills needed for effectively treating psychiatric disorders in patients with BIF. Right now psychiatric patients with BIF in regular mental health care are more likely to get psychotropic drugs (and more likely antipsychotics and se-

datives than antidepressants) than psychotherapy.^{11,23} Psychiatric treatments in regular mental health care are not adapted to the cognitive limitations of such patients, like deficits in memory function¹⁷ of patients with BIF. Results from daily clinical practise show that many forms of treatment can be adapted to the cognitive abilities of people with BIF but also that neglect of BIF in psychiatric patients leads to longer duration of treatment, more need for crisis intervention^{11,18} and limited or adverse treatment effect.

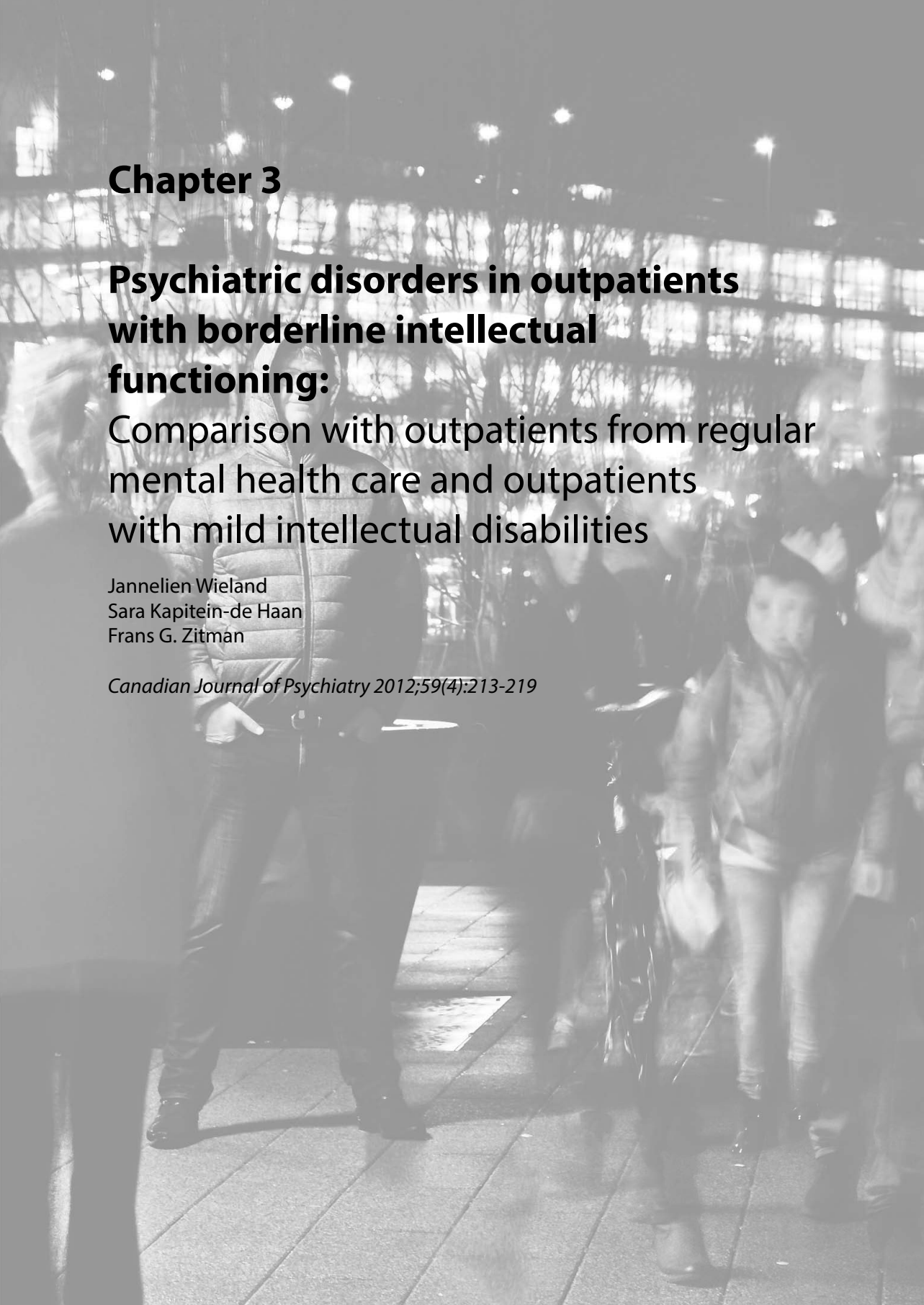
Conclusion

We recommend a renewed regard to the concept of BIF and its place in DSM and other classification systems like ICD. A well-defined classification can improve visibility of patients with BIF in mental health care, bridging the gap between high prevalence and low recognition and acknowledgement. Recognition of patients with BIF and attention to specific mental health care needs is likely to improve the quality mental health care substantially for a group of people that comes last too often. Even in the DSM-5 V-codes.

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Chapter 3

Psychiatric disorders in outpatients with borderline intellectual functioning:

Comparison with outpatients from regular
mental health care and outpatients
with mild intellectual disabilities

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Abstract

Objective In the Netherlands patients with borderline intellectual functioning (BIF) are eligible for specialized mental health care. This offers the unique possibility to examine the mix of psychiatric disorders in patients who, in other countries, are treated in regular outpatient mental health care clinics. Our study sought to examine the rates of all main Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision, axis I psychiatric diagnoses in outpatients with BIF of two specialized regional psychiatric outpatient departments and to compare these with rates of the same disorders in outpatients from regular mental health care (RMHC) and outpatients with mild intellectual disabilities (ID).

Method Our study was a cross-sectional anonymized medical chart review. All participants were patients from the Dutch regional mental health care provider Rivierduinen. Diagnoses of patients with BIF (BIF group; $n = 235$) were compared to diagnoses of patients from RMHC (RMHC group; $n = 1026$) and mild ID patients (mild ID group; $n = 152$).

Results Compared with the RMHC group, psychotic and MDD were less common in the BIF group, while posttraumatic stress disorders and V-codes were more common. Compared with the mild ID group psychotic disorders were significantly less common.

Conclusion Mental health problems in people with BIF may be not well addressed in general psychiatry, or by standard psychiatry for patients with ID. Specific attention to this group in clinical practice and research may be warranted lest they fall between two stools.

Introduction

In the International Classification of Diseases, 10th Revision, there is no specific code for it, but in the DSM-IV-TR, as well as in DSM-5, borderline intellectual functioning (BIF) is a V-code that can be used to signify problems associated with subaverage intellectual performance.¹⁻³ These patients function in between people with average or above average intelligence and people with ID. Adults with BIF are believed to suffer from high rates of psychiatric disorders and rely mostly on outpatient treatment.⁴ In most countries they are not considered part of the ID population and are treated in the same clinics as patients without ID. However, it is unknown to what extent the mix of disorders with which they present themselves in mental health outpatient clinics differs from patients without ID. It is also unknown to what extent this mix of disorders differs from patients with lower intelligence quotients (IQs). Most studies in the general population, as well as in outpatients, did not include people with BIF.⁵⁻⁷ This may be important, as the prevalence of mental health disorders has been reported to vary by the severity of the ID.⁸

Unlike most other countries, in the Netherlands, patients with BIF and comorbid psychiatric disorders are eligible for the same specialist psychiatric services as patients with ID. For instance, the Dutch regional mental health care provider Rivierduinen has over 10 years of experience with two outpatient mental health care centres specialized in psychiatry and ID, mainly for patients with BIF and mild ID, apart from outpatient clinics for people without ID. Well established referral pathways and focus on patients with BIF as a separate group made referral of patients with BIF and psychiatric disorders to specialized mental health care the default procedure. Using data from these two specialized outpatient clinics and from a general outpatient clinic of Rivierduinen operating in the same region, we were able to compare psychiatric morbidity of patients with BIF with outpatients from regular mental health care and outpatients with mild ID.

Methods

Participants

Our study was a cross-sectional anonymized medical chart review. All participants were patients from the Dutch regional mental health care provider Rivierduinen. We compared anonymized data of patients from two regional secondary care adult outpatient departments, specialized in psychiatry and ID (CPID; centres for Psychiatry and Intellectual Disability; BIF and mild ID groups) with anonymized data of patients from a regular secondary care outpatient department (Regular Mental Health Care (RMHC) group). The BIF and mild ID groups came from the complete catchment area of Rivierduinen and the RMHC group came from one particular region within this area (Katwijk, Zuid Holland, the Netherlands). Both groups consisted of outpatients registered on January 1, 2011. All diagnoses were the DSM-IV-TR² axis I

diagnoses as recorded in the official registration system of the electronic patient file. In the BIF and mild ID groups diagnoses were based on the integrative approach of Došen.^{9–11} For people with ID, the integrative diagnosis considers the developmental perspective as the fourth dimension in addition to the biopsychosocial model. In daily clinical practice this means that in order to consider all four dimensions, patients are always assessed multidisciplinary, by at least a certified and experienced psychiatrist, a certified and experienced mental health psychologist and an experienced psychiatric community worker. DSM-IV-TR diagnoses are formulated using the Diagnostic Manual-Intellectual Disability (DM-ID) criteria.¹² The DM-ID offers adaptations of DSM-IV-TR diagnostic criteria and provide guidelines for making accurate psychiatric diagnoses in patients with various levels of ID. In the RMHC group diagnoses were formulated using the DSM-IV -TR.²

Among the 599 registered at the two specialized centres, diagnostic information was available for 576 patients (95.8%). Of these 576 patients, 511 (85.3%) were diagnosed with either BIF or mild ID. A total of 65 patients (11.3%) were excluded from the present study because level of ID was not known at the time (2.3%) or because they had moderate (8.9%) or severe (0.2%) ID. For the RMHC group diagnostic information was available for 1054 of the 1254 registered patients (84.1%). Among these patients, 14 (1.1%) were diagnosed with BIF. These patients were excluded from the current analyses.

Within our organization, patients with average or above average intellectual functioning with pervasive developmental disorders (PDDs) are referred to a special centre for autism spectrum disorders, while patients with a PDD and ID are referred to one of the two CPID. This would lead to a possible referral bias when comparing the rates of autism because patients with PDDs were underrepresented in the RMHC group compared to the BIF and mild ID groups. Therefore, patients with PDDs were excluded from the current analyses. One hundred-and-twenty-four (24.3%) individuals were excluded from the BIF and mild ID groups and another 14 (1.1%) individuals were excluded from the RMHC group because of a diagnosis of PDD.

A total of 235 individuals were diagnosed with BIF and 152 individuals had a mild ID. Thus, the final groups consisted of 235 participants with BIF (BIF group), 1026 participants from regular mental health care (RMHC group) and 152 participants with mild ID (mild ID group).

Measures

Demographic variables and diagnostic categories

The following variables were collected for each patient from the electronic patient file: age, sex, level of ID and DSM-IV-TR axis I diagnoses. All DSM-IV-TR axis I diagnoses recorded in the official registration system of the electronic patient file were registered. For analyses, the DSM-IV-TR diagnoses were categorized as follows: psy-

chotic disorders (subdivided into schizophrenia and psychotic disorder Not Otherwise Specified (NOS)), mood disorders (subdivided into major depressive disorder (MDD), dysthymic disorder, depressive disorder NOS and bipolar disorder), anxiety disorders (subdivided into posttraumatic stress disorder (PTSD), panic disorder, generalized anxiety disorder, social and specific phobia and obsessive compulsive disorders (OCD)), somatoform disorders (subdivided into somatisation disorder, undifferentiated somatoform disorder, conversion disorder, pain disorder and hypochondria) and V-codes. Individuals with attention deficit hyperactivity disorder (ADHD) and impulse control disorders NOS were categorized together as ADHD and impulse control disorders. Alcohol abuse and alcohol dependence were categorized together as alcohol abuse and dependence. Cannabis abuse and cannabis dependence were categorized together as cannabis abuse and dependence. The remaining diagnoses were not analysed because rates were too low or they were absent. These included cognitive disorders, tic disorders, sexual disorders, other substance abuse disorders, eating disorders and sleep disorders.

Intelligence

In the BIF and mild ID groups, level of ID was based on IQ testing, using the Wechsler Adult Intelligence Scale (WAIS-III).^{13–15} Following DSM-IV-TR criteria, participants were divided into two groups: BIF (Total Intelligence Quotient (TIQ) 70–85) and mild ID (TIQ 50–70). There was no IQ testing in the RMHC group.

Statistical analyses

Demographic and clinical variables were compared among the BIF group and the RMHC and mild ID groups using analysis of variance (ANOVA) with host-hoc Bonferroni correction for continuous variables (for example, age) and Chi-square tests for dichotomous and categorical variables (for example, gender and diagnoses). First, all three groups were compared using a Chi-square test. Second, when overall differences were found, a comparison was conducted comparing the BIF group with both the RMHC and mild ID groups. In additional analyses outcomes were corrected for gender and age using binary logistic regression. All analyses were performed using SPSS Statistics version 16.0 (SPSS Inc, Chicago, IL). for Windows. When chi-square conditions were not met, percentages were given but no statistical analyses were performed. A conservative level of significance was set at $p \leq 0.01$.

Results

Demographic characteristics

As shown in Table 1, The RMHC group consisted of 1026 participants. A total of 235 individuals were diagnosed with BIF and 152 individuals had a mild ID. Even though the percentage of females was highest in the BIF group (66.8%), there was no

significant difference among the three groups ($\chi^2 = 5.65$, $df = 2$, $p = 0.06$). There was a significant difference in mean age among the three groups ($p < 0.001$). The mean age was lowest in the BIF group (33.4, $SD = 12.5$) and highest in the RMHC group (44.3, $SD = 16.6$, $p < 0.001$). There was a significant difference in mean age between the BIF and the RMHC group ($p < 0.001$), as shown in table 2. There was no difference in mean age between the BIF and the mild ID group.

Comparison of diagnoses

The mean number of DSM-IV-TR axis I diagnoses did not differ significantly among the three groups. Comparisons of the percentages of diagnostic categories among the three groups are presented in table 1. In table 2, percentages of different disorder-types are presented between the BIF group and the RMHC group on the one hand and the mild ID group on the other hand.

Psychotic disorders

A significant difference was found in the presence of psychotic disorders among the three groups ($\chi^2 = 10.7$, $df = 2$, $p = 0.005$), with the lowest rates (6.8%) in the BIF group (table 1). The rate of schizophrenia was highest in the RMHC group (8.3%) and lowest in the BIF group (1.2%) ($\chi^2 = 15.5$, $p < 0.001$). The rate of psychotic disorders NOS was highest in the mild ID group (8.6%) and lowest in the RMHC group (2.9%) ($\chi^2 = 11.8$, $df = 2$, $p < 0.003$). Table 2 shows that the rate of psychotic disorders was significantly lower in the BIF group compared to both the RMHC (14.7%) and the mild ID (15.1%) groups ($\chi^2 = 7.1$, $df = 1$, $p = 0.008$).

Mood disorders

There was a significant difference among the three groups in the overall presence of mood disorders ($\chi^2 = 40.6$, $df = 2$, $p < 0.001$) (table 1). This was also true for depressive disorder ($\chi^2 = 23.7$, $df = 2$, $p < 0.001$). The highest rates of overall mood disorders (36.2%) and MDD (21.2%) were in the RMHC group. The rate of bipolar disorder was also highest in the RMHC group (6.7%). The overall presence of mood disorders and the rate of depressive disorder did not differ between the BIF (17.4%) and mild ID (20.4%) groups (table 2). Most groups of mood disorders however, were too small to conduct statistical tests.

Anxiety disorders (including PTSD)

The rate of all anxiety disorders taken together differed significantly among the three groups ($\chi^2 = 14.3$, $df = 2$, $p = 0.001$) (table 1). This difference was mainly due to the higher rate of PTSD in the BIF (19.6%) and mild ID groups (19.7%) compared to the RMHC (10.4%) group ($\chi^2 = 21.1$, $df = 2$, $p < 0.001$). The rates of panic disorder, generalized anxiety disorder, social phobia, specific phobia, OCD and anxiety disorder NOS did not differ much among the groups. Most groups of specific anxiety disorder

ders were too small to conduct statistical tests. There was no significant difference in the overall rate of anxiety disorders, or in the rate of PTSD between the BIF and the mild ID groups (table 2).

Somatoform disorders

There was no significant difference among the three groups in the overall presence of somatoform disorders (table 1). The different categories of somatoform disorders were too small to conduct statistical tests.

Table 1. Demographic characteristics and statistical comparisons of the percentages of DSM-IV-TR axis I diagnoses between the RMHC, BIF and mild ID Groups.

	RMHC (=1026)	BIF (n=235)	Mild ID (n=152)	p-value
Demographic characteristics				
Gender, n females (%)	603 (58.8%)	157 (66.8%)	96 (63.2%)	0.06
Age, mean (SD)	44.3 (16.6)	33.4 (12.5)	37.2 (13.6)	< 0.001
Age, range	15.8 - 95.4	16.3-78.2	16.8-70.6	
DSM-IV-TR axis I diagnoses, mean (SD)	1.46 (0.7)	1.49 (0.7)	1.38 (0.6)	0.30
DSM-IV-TR axis I diagnoses				
<i>Psychotic disorders</i>	151 (14.7%)	16 (6.8%)	23 (15.1%)	0.005
Schizophrenia	85 (8.3%)	3 (1.2%)	8 (5.3%)	< 0.001
Psychotic disorder NOS	30 (2.9%)	10 (4.3%)	13 (8.6%)	0.003
<i>Mood disorders</i>	371 (36.2%)	41 (17.4%)	31 (20.4%)	< 0.001
Depressive disorder	217 (21.2%)	21 (8.9%)	18 (11.8%)	< 0.001
Dysthymic disorder	37 (3.6%)	6 (2.6%)	4 (2.6%)	–
Bipolar disorder	69 (6.7%)	4 (1.6%)	5 (3.3%)	–
Mood disorder NOS	6 (0.6%)	7 (3.0%)	4 (2.6%)	–
<i>Anxiety disorders</i>	237 (23.1%)	81 (34.5%)	45 (29.6%)	0.001
PTSD	107 (10.4%)	46 (19.6%)	30 (19.7%)	< 0.001
Panic disorder	57 (5.6%)	10 (4.3%)	4 (2.6%)	0.26
Generalized anxiety disorder	14 (1.4%)	3 (1.3%)	1 (0.7%)	–
Social phobia	16 (1.6%)	5 (2.1%)	2 (1.3%)	–
Specific phobia	6 (0.6%)	5 (2.1%)	1 (0.7%)	–



Continuation of table 1.

Obsessive compulsive disorder	17 (1.7%)	7 (3.0%)	3 (2.0%)	–
Anxiety disorder NOS	58 (5.7%)	13 (5.5%)	6 (3.9%)	0.69
<i>Somatoform disorder</i>	26 (2.5%)	3 (1.3%)	5 (3.3%)	0.39
Somatisation disorder	2 (0.2%)	0 (0%)	0 (0%)	–
Undifferentiated Somatoform disorder	10 (1.0%)	2 (0.9%)	2 (1.3%)	–
Conversion disorder	4 (0.4%)	0 (0%)	3 (2.0%)	–
Pain disorder	4 (0.4%)	1 (0.4%)	0 (0%)	–
Hypochondria	8 (0.7%)	0 (0%)	0 (0%)	–
<i>ADHD or Impulse control disorder</i>	135 (13.2%)	31 (13.2%)	10 (6.6%)	0.67
<i>Alcohol abuses or dependence</i>	68 (6.6%)	11 (4.7%)	5 (3.3%)	0.18
<i>Cannabis abuse or dependence</i>	22 (2.1%)	12 (5.1%)	2 (1.3%)	0.02
<i>V-codes</i>	97 (9.5%)	53 (22.6%)	20 (13.2%)	< 0.001

All p-values based on Chi-square testing with 2 df, - conditions for chi-square test are not met. SD= Standard Deviation, BIF= Borderline Intellectual Functioning, ID= Intellectual Disability, RMHC= Regular Mental Health Care, NOS= Not Otherwise Specified, PTSD= Posttraumatic Stress Disorder, ADHD= Attention Deficit Hyperactive Disorder

Substance abuse/dependence

There was no difference in the presence of alcohol and or cannabis abuse/dependence among the three groups (table 1).

ADHD/ Impulse-control disorders

There was no significant difference in the percentage of diagnosed ADHD/impulse-control disorders among the three groups (table 1).

V-codes

There was a significant difference in the percentage of diagnosed V-codes among the three groups ($\chi^2 = 31.2$, $df = 2$, $p < 0.001$)(table 1). The percentage of V-codes was over twice as high in the BIF group (22.5%) compared to the RMHC group (9.5%)($\chi^2 = 31.2$, $df = 2$, $p < 0.001$)(table 2).

Table 2. Demographic characteristics and statistical comparisons of the percentages of DSM-IV-TR axis I diagnoses between the BIF group and the RMHC and mild ID group.

	BIF (n=235)	RMHC (n=1026)	p-value *	Mild ID (n=152)	p-value **
Demographic characteristics					
Gender, n females (%)	157 (66.8%)	603 (58.8%)	0.02	96 (63.2%)	0.46
Age, mean (SD)	33.4 (12.5)	44.3 (16.6)	<0.001	37.2 (13.6)	0.06
DSM-IV-TR axis I diagnoses					
<i>Psychotic disorders</i>	16 (6.8%)	151 (14.7%)	0.001	23 (15.1%)	0.008
Schizophrenia	3 (1.2%)	85 (8.3%)	–	8 (5.3%)	–
Psychotic disorder NOS	10 (4.3%)	30 (2.9%)	0.29	13 (8.6%)	0.08
<i>Mood disorders</i>	41 (17.4%)	371 (36.2%)	<0.001	31 (20.4%)	0.47
Depressive disorder	21 (8.9%)	217 (21.2%)	<0.001	18 (11.8%)	0.35
<i>Anxiety disorders</i>	81 (34.5%)	237 (23.1%)	<0.001	45 (29.6%)	0.32
PTSD	46 (19.6%)	107 (10.4%)	<0.001	30 (19.7%)	0.97
<i>V-codes</i>	54 (22.6%)	97 (9.5%)	<0.001	20 (13.2%)	0.02

All p-values based on Chi-square testing with 1 df, • p-value of statistical comparisons between the borderline ID and the RMHC groups, ** p-value of statistical comparisons between the borderline ID and the mild ID groups. SD= standard deviation, –= Conditions for chi-square test are not met, BIF= Borderline Intellectual Functioning, ID= Intellectual Disability, RMHC= Regular Mental Health Care, NOS= Not Otherwise Specified, PTSD= Posttraumatic Stress Disorder

Discussion

In the Netherlands, patients with BIF are eligible to specialized outpatient mental health care, offering the opportunity to examine psychiatric co-morbidity in a group of people intellectually functioning in between people with and without an ID and often going unnoticed in most countries. In the current study, the rates of DSM-IV-TR axis I psychiatric disorders were compared among patients with BIF (BIF group), outpatients from regular mental health care (RMHC group) and outpatients with mild ID (mild ID group). To our knowledge there are no previous studies specifically focused on the rate of psychiatric disorders of patients with BIF in outpatient mental health care. Most striking differences, compared to the RMHC group, were the high rate of PTSD and V-codes in the BIF group and the low rates of psychotic disorders and MDD. Also compared to the mild ID group, psychotic disorders were significantly less common in the BIF group.

The rate of psychotic disorders was lower in the BIF group than in both the RMHC and the mild ID groups. Considering the association found in earlier studies between lower IQ scores and an increased risk for schizophrenia^{16–18} this is a notable finding. It is unlikely that BIF is associated with less chance of becoming psychotic. Based on our experience we can say that psychotic patients with BIF are frequently referred from our outpatient department to teams specialized in the treatment of psychoses, like early detection and Intervention teams and functional assertive community treatment,¹⁹ more so than psychotic patients with mild ID who do not seem able to profit from the above-mentioned approaches. More research is needed to explore this further.

The low rates of mood disorders in patients with BIF compared to the RMCH group is also notable. It is contrary to what may be expected from literature. Hurley et al.⁵ found high rates of mood disorders. We do not think it to be very probable that a BIF predisposes to less mood disorders than a more severe ID. This is in line with the absence of differences in our sample between BIF and mild disorders in this respect. We do not think that our therapists missed these diagnoses either. However, depressed patients may have been referred less often to our department as a lower mood is less easily recognized and labelled as a possible disorder by significant others.^{20,21} Compared to the RMHC group PTSD was almost twice as common in the BIF group and rates did not differ between patients with BIF and patients with mild ID. We know that patients with ID are more likely to experience traumatic events.^{22–24} They are also more vulnerable to the disruptive effects of trauma, and thus to PTSD.¹² Thus far PTSD in patients with BIF is underexposed in the literature. Our data warrant more attention to this subject.

Another result that merits discussion was the high rate of V-codes in the BIF group compared to both the RMHC and the mild ID groups. In the DSM-IV-TR, V-codes are used to indicate “other conditions that may be a focus of clinical attention”. V-codes include, for instance, codes for relational problems, occupational problems and phase of life problems. In general, V-codes are used to capture clinically significant distress or problems functioning in daily life.² At the least, the high rates of V-codes in the BIF group suggest that these patients present with complex problems: ID, psychiatric disorders and clinically significant distress or problems functioning in daily life as signified by these V-codes. The alternative explanation might be that this specialized clinic is more likely to record these additional diagnoses. More research is needed to explore this further.

The present study has several strengths. First, this study examines a large sample BIF outpatients which is a population not considered part of the ID population in most countries. They are thought to be especially vulnerable for developing psychiatric disorders and less likely to receive adequate treatment.⁴ Second, in the BIF and mild ID-patients the level of ID was always recently established and based on the standardized WAIS-III, which ensured that the labels of BIF and mild ID were carefully

applied. Third, a broad range of DMS-IV-TR diagnoses was included. Fourth, these diagnoses were the diagnoses as recorded in the official registration system of the electronic patient file, applied after a careful diagnostic process. Fifth, the fact that the findings are based on large samples from a naturalistic outpatient setting makes them generalizable to the clinical field of interest.

The results should also be interpreted in the light of some limitations. First, issues of referral most likely introduced some bias. The BIF group consisted of significantly more females than the RMHC group. In addition, the mean age in the BIF and mild ID groups was lower than in the RMHC group. Using binary logistic regression to correct for gender and age did not alter the outcomes (data not shown). Post hoc analyses showed that the difference in gender was accounted for by the high rate of female PTSD patients with BIF or mild ID. When PTSD patients were excluded, there was no longer a difference in male-to-female ratio (data not shown). The mean age was lowest in the patients with BIF. This could mean that individuals with BIF develop psychiatric symptoms at a younger age. It could also mean that older individuals with BIF are less likely to be referred to specialized services. In both the BIF and mild ID groups there were many patients diagnosed with an autism spectrum disorder because of a special referral policy. They were excluded from analysis, which means that part of the initial sample was not included. However, most patients diagnosed with an autism spectrum disorder did not report other psychiatric disorders and only made up a minor part of the rates of psychiatric disorders in the ID groups, so the extent of the introduced bias probably is small. A second limitation is that results apply only to outpatients and cannot be generalized to more severely ill in-patients. Third, There was no IQ testing in the RMHC group. Fourth, demographic information was limited and information on treatment was not available. And fifth, co morbidity of axis II disorders was not accounted for. Future research could investigate the rates and co morbidity of axis I and II disorders in patients with a BIF.

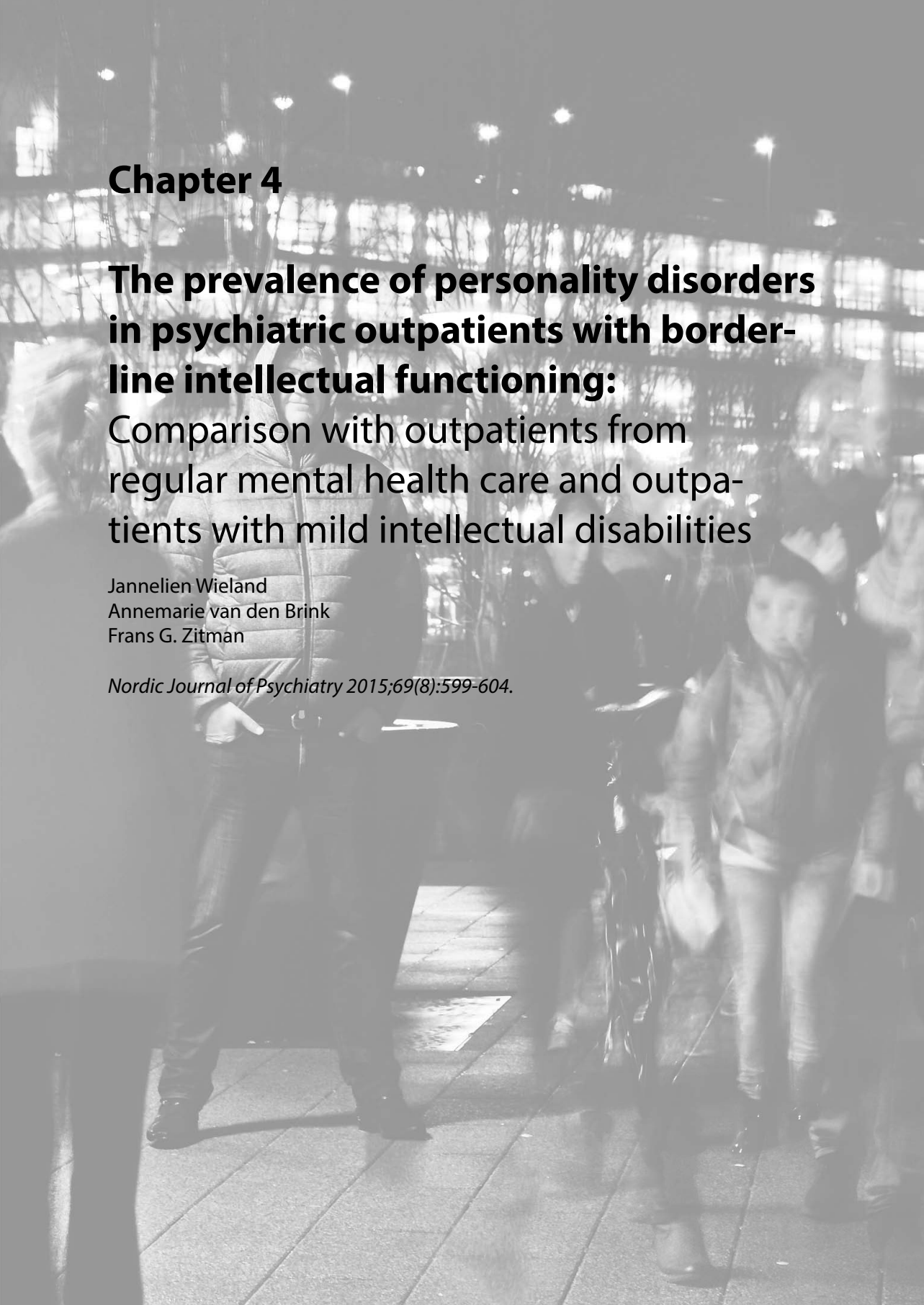
Conclusion

In conclusion, results indicate that individuals with BIF are most commonly diagnosed with PTSD and V-codes. Compared to patients from regular mental health care they are younger, less likely to be diagnosed with psychotic and mood disorders and more likely with anxiety disorders, more specifically PTSD. Compared to their peers with mild ID referred to the same service, they are less likely to be diagnosed with psychotic disorders. Perhaps, the results remind us that this in many countries invisible group in the middle may not be well addressed by general psychiatry, or by ID psychiatry. Specific attention may be warranted in clinical practice as well as in research lest they fall between two stools.

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Chapter 4

The prevalence of personality disorders in psychiatric outpatients with borderline intellectual functioning:

Comparison with outpatients from regular mental health care and outpatients with mild intellectual disabilities

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Abstract

Background There is little research on the subject of personality disorder (PD) in individuals with borderline intellectual functioning (BIF). Unlike in most countries, in the Netherlands, patients with BIF are eligible for specialized mental health care. This offers the unique possibility to examine the rates of PD in patients, who in other countries are treated relatively invisible in regular mental health care.

Aim To compare, in a naturalistic setting, the frequency PD diagnoses in outpatients with BIF to outpatients from regular mental health care and outpatients with mild ID.

Methods We compared the rates of all DSM-IV-TR axis II PD in outpatients with BIF (BIF group; $n = 235$) with rates of the same disorders in outpatients from regular mental health care (RMHC group; $n = 1026$) and outpatients with mild intellectual disability (ID) (mild ID group; $n = 152$) in a naturalistic cross-sectional anonymized medical chart review.

Results Over half of the patients with BIF (52.8%) were diagnosed with a PD, compared to one in five in the RMHC group (19.3%) and one in three of the mild ID group (33.6%). All PD diagnoses, except for cluster A PD and histrionic PD, were most frequently diagnosed in the BIF group. The majority of PD patients had one or more comorbid axis I disorder.

Conclusion There is a high frequency of PD diagnoses in BIF outpatients in daily clinical practice. In anticipation of further scientific research, results suggest that PD should not be overlooked in patients with BIF.

Background

Borderline intellectual functioning (BIF) is a complex clinical entity, which has barely been studied.¹ It is defined as a total intellectual quotient (TIQ) between 1 and 2 standard deviations below average (TIQ 70-85), but has no clear diagnostic code in either DSM-IV-TR, DSM-5 or ICD-10.¹⁻⁵ According to the normal IQ distribution 13.6% of the population has an IQ between 70 and 85; according to available studies the percentage lies between 12 and 18%.^{6,7} In most countries people with BIF live unnoticed in the community. Because they are not considered part of the intellectual disability (ID) population (TIQ < 70), they are not eligible for specialist ID services. If they develop psychiatric disorders, they depend largely on regular mental health care, where they represent a relatively invisible patient group. In the Netherlands patients with BIF are focused on as a separate group and they are eligible to the same specialised mental health care services as patients with ID. Because of well-established referral pathways, referral of patients with BIF and psychiatric disorders to specialized mental health care has become the default procedure. This offers the unique opportunity to examine, in a naturalistic setting, the psychiatric co-morbidity of this otherwise largely hidden population. We previously showed that the rates of axis I psychiatric disorders of patients with BIF differ from both patients from regular mental health care (RMHC) and patients with mild intellectual disabilities (ID).² In this paper we discuss whether this also holds true for axis II personality disorders (PD).

Hassiotis et al.⁸ -using data from a UK-wide cross-sectional survey of 8450 people - showed 37.4% of people screened as having borderline intelligence, were diagnosed as having a PD using the structured clinical interview for DSM-IV axis II PD (SCID-II). In comparison, in the normal intellectual functioning group this was 27%. We are not aware of published studies on PD specifically focusing on patients with BIF in mental health care, nor do we know of any studies comparing rates of PD among patients with either normal intelligence, BIF or mild ID.

Aim

The Dutch regional mental health care provider Rivierduinen has over 10 years experience with 2 outpatient mental health care centres specialized in psychiatry and ID (CPID; Centres for Psychiatry and Intellectual Disability), mainly for patients with BIF and mild ID, apart from outpatient clinics for people without ID. Using data from these two CPID and from a general outpatient clinic of Rivierduinen operating in the same region, the aim of the present study was to compare, in a naturalistic setting, the frequency of PD diagnoses in patients with BIF to outpatients from regular mental health care and outpatients with mild ID. In this study we focus on official DSM-IV-TR diagnoses because treatment plans and therefore extent, nature and content of treatment are based on these diagnoses.

Materials and methods

Participants

Our study was a naturalistic anonymized cross-sectional medical chart review. All diagnoses were the official DSM-IV-TR axis II diagnoses as registered in the electronic patient file. Treatment plans are based on these diagnoses and therefore are highly relevant. All participants were patients from the Dutch regional mental health care provider Rivierduinen. We compared data of patients from two CPID, regional secondary care adult outpatient departments (Kristal Centre for Psychiatry and ID in the Leiden and Gouda locations; BIF and mild ID groups) with anonymized data of patients from a regular secondary care outpatient department (RMHC group). The BIF and mild ID groups came from complete catchment area of Rivierduinen and the RMHC group came from one particular region within this area (Katwijk, Zuid Holland, the Netherlands). Both groups consisted of outpatients registered on January 1, 2011.

In the RMHC group diagnoses were formulated using the DSM-IV-TR. In the BIF and mild ID groups DSM-IV-TR diagnoses were formulated using the DM-ID.⁹

Where necessary the DM-ID offers supplements and adaptations for DSM-IV-TR diagnostic criteria and provides guidelines for making accurate psychiatric diagnoses in patients with various levels of ID. For people with mild ID the DM-ID offers some special diagnostic considerations. Primary consideration is the developmental delay. Another consideration is to always take into account the context. The DM-ID strongly recommends greater use of behavioural observation and informant information in making a diagnosis of PD. The DM-ID offers specific adaptations for diagnosing PD mainly for the age criterion. Because of the developmental delay in ID the DM-ID states that a diagnosis of PD should only be considered provisionally before the individual is 21 years old. For individuals with BIF, diagnoses were formulated using the DSM-IV-TR but keeping in mind the same considerations concerning the developmental perspective and context as for patients with mild ID.

For inclusion and exclusion, see figures 1 and 2. Within our organization, patients with average or above average intellectual functioning with Pervasive Developmental Disorder (PDD) are referred to a special centre for autism spectrum disorders, while patients with a PDD and ID are referred to Kristal, Centre for Psychiatry and ID. Because patients with PDD were underrepresented in the RMHC group, leading to a possible bias when comparing the rates of PD, patients with PDD were excluded from our analyses. In the excluded PDD group there were only 12 patients with a comorbid PD. The vast majority of these patients (75%) had a PD Not Otherwise Specified (NOS). The final groups consisted of 235 patients with BIF (BIF group), 1026 patients from RMHC (RMHC group), and 152 patients with mild ID (mild ID group).

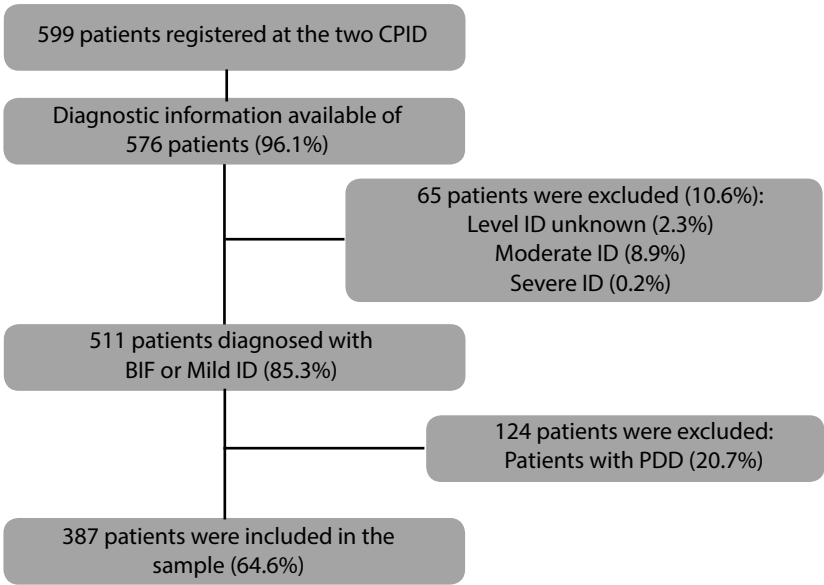


Figure 1. Inclusion flowchart CPID.

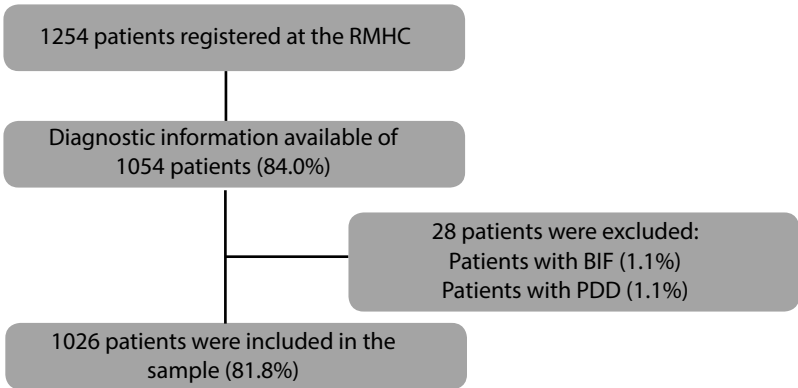


Figure 2. Inclusion flowchart RMHC.

Measures

Demographic variables and diagnostic categories

The following variables were collected for each patient from the electronic patient file: age, sex, level of ID, and DSM-IV-TR axis II diagnoses. DSM-IV-TR axis I and II diagnoses recorded in the official registration system of the electronic patient file were recorded. For analyses, the DSM-IV-TR diagnoses were categorized as follows: Cluster A PD (the “odd, eccentric” cluster, subdivided into paranoid, schizoid and schizotypal PD), Cluster B PD (the “dramatic, emotional erratic” cluster, subdivided into antisocial, borderline, histrionic and narcissistic PD), cluster C PD (the “anxious, fearful” cluster, subdivided into avoidant, dependent and obsessive–compulsive PD) and PD not otherwise specified (NOS).

Intelligence

In the BIF and mild ID groups, level of ID was based on IQ testing, using the WAIS-III,^{10–12} in combination with multidisciplinary assessment of present adaptive functioning. Patients were divided into 2 groups according to DSM-IV-TR criteria based on TIQ and adaptive functioning: BIF (TIQ 70–85) and mild ID (TIQ 50–70). There was no IQ testing in the RMHC group.

Statistical analyses

Demographic and clinical variables were compared among the BIF group and the RMHC and mild ID groups, using analysis of variance (ANOVA) for age and a Chi-square test for gender. All axis II were expressed in number and percentage. Differences in axis II were compared using binary logistic regression. Odds ratios (OR) were calculated adjusted for sex and age. Within the BIF group we used a Chi-square and T-tests to analyse the association between gender and age and PD. All analyses were performed using SPSS version 19.0 (SPSS Inc, Chicago, IL).

Table 1. Demographic characteristics among the BIF, RMHC and mild ID groups.

	BIF (n= 235)	RMHC (n=1026)	Mild ID (n=152)	p-value
Gender				
Male (%)	78 (33.2)	423 (41.2)	56 (36.8)	0.06
Female (%)	157 (66.8)	603 (58.8)	96 (63.2)	
Age (SD)	33.4 (12.5)	44.3 (16.6)	37.2 (13.6)	<0.001

Results

As shown in table 1. the RMHC group consisted of 1026 participants. A total of 235 individuals was diagnosed with borderline intellectual functioning and 152 individuals were diagnosed with mild ID. The percentage of females differed from 66.8% in the BIF group, 63.2% in the mild ID group and 58.8% in the RMHC group ($\chi^2 = 5.65$, $p = 0.06$). Age difference was significant among the three groups with the mean age in the BIF group being 33.4, in the mild ID group 37.2 and in the RMHC group 44.3 ($p < 0.001$). Because of the differences among the groups in gender and age, ORs are adjusted for gender and age. Details of the results are presented in Table 2. Summarized, 52% ($n = 124$) of the patients with BIF were diagnosed with a PD. PD NOS was the most frequently diagnosed PD (28.1%) in BIF followed by borderline PD (15.3%). Patients with BIF were more likely to be diagnosed with a PD than both the RMHC group (OR = 4.3, 95% CI 3.2-5.9) and the mild ID group (OR = 2.2, 95% CI 1.5-3.4). Compared to the RMHC group all rates of PD diagnoses, except for cluster A PD, were increased in the BIF group. This increase was significant for cluster B PD (OR = 2.44, 95% CI 1.56-3.81), especially borderline PD (OR = 2.3, 95% CI 1.43-3.73), cluster C PD (OR = 2.45, 95% CI 1.34-4.49) and PD NOS (OR = 3.6, 95% CI 2.45-5.21). Compared to the mild ID group, rates of all PD diagnoses except for cluster A PD and histrionic PD were increased in the BIF group. This increase was significant for cluster C PD (OR = 3.54, 95% CI 1.2-10.7).

The vast majority of PD patients had one or more comorbid axis I disorder. There was no significant difference in rates of comorbid axis I disorders in the BIF group compared to RMHC (OR = 0.52, CI 0.23-1.15) or compared to the mild ID group (OR = 1.34 CI 0.57-3.16). Most prevalent axis I disorders in all three groups were Mood, Anxiety and Somatoform (MAS) disorders.

Within the BIF group, there was no association found between gender and PD ($\chi^2 = 2.92$, $p = 0.09$) or between age and PD ($p = 0.49$, 95% CI -4.4 – 2.1).

Table 2. Comparison of the rates of personality disorders (PD) among the borderline intellectual functioning (BIF), regular mental health care (RMHC) and mild intellectual disability (Mild ID) groups using logistic regression corrected for sex and age.

Personality Disorder	BIF (n=235)	RMHC (n=1026)	Adjusted OR* compared to RMHC	95% CI	Mild ID (n=152)	Adjusted OR* compared to mild ID	95% CI
PD, all (%)	124 (52.8)	198 (19.3)	4.3	3.2-5.9**	51 (33.6)	2.2	1.5-3.4**
Cluster A (%)	0 (0)	2 (0.2)	-	-	0 (0)	-	-
Paranoid PD	0 (0)	2 (0.2)	-	-	0 (0)	-	-
Schizoid PD	0 (0)	0 (0)	-	-	0 (0)	-	-
Schizotypal PD	0 (0)	0 (0)	-	-	0 (0)	-	-
Cluster B (%)	41 (17.4)	63 (6.1)	2.44	1.56-3.81**	14 (9.2)	1.86	0.96-3.6
Antisocial PD	4 (1.7)	5 (0.5)	3.97	0.97-16.2	0 (0.0)	-	-
Borderline PD	36 (15.3)	53 (5.2)	2.3	1.43-3.73**	12 (7.9)	1.9	0.92-3.8
Histrionic PD	0 (0)	2 (0.2)	-	-	1 (0.7)	-	-
Narcissistic PD	3 (1.3)	3 (0.3)	5.79	1.04-32.3**	1 (0.7)	-	-
Cluster C (%)	19 (8.1)	38 (3.7)	2.45	1.34-4.49**	4 (2.6)	3.54	1.2-10.7**
Avoidant PD	6 (2.6)	21 (2.0)	1.09	0.42-2.83	2 (2.0)	1.3	0.32-5.38
Dependent PD	11 (4.7)	13 (1.3)	4.78	1.96-11.65**	1 (0.7)	7.96	1.0-62.9**
OC PD	3 (1.3)	5 (0.5)	3.33	0.71-15.58	0 (0)	-	-
PD NOS (%)	66 (28.1)	101 (9.8)	3.6	2.48-5.21**	33 (21.7)	1.5	0.92-2.4
Comorbid Axis I in patients with PD	BIF (n=124)	RMHC (n=198)	Adjusted OR* compared to RMHC	95% CI	Mild ID (n=51)	Adjusted OR* compared to mild ID	95% CI
Comorbid Axis I, all (%)	105 (84.7)	186 (93.9)	0.52	0.23-1.15	41 (80.4)	1.34	0.57-3.16

CI= Confidence Interval, BIF= borderline intellectual functioning, PD= Personality Disorder, ID= Intellectual Disability, NOS= Not Otherwise Specified

* Odds Ratios adjusted for sex and age, ** Value 1 not in confidence interval, -Number too small for analyses

Conclusion

The important finding of this study is the high frequency of PD diagnoses in BIF patients in daily clinical practice. Axis I and II DSM-IV-TR diagnoses of 235 outpatients with BIF were compared with 1026 outpatients from regular mental health care and 152 mild ID outpatients. We found that over half of the patients with BIF (52.8%) were diagnosed with a PD, compared to one in five in the RMHC group (19.3%) and one in three of the mild ID group (33.6%). All PD diagnoses, except for cluster A PD and histrionic PD, were most frequently diagnosed in the BIF group. PD NOS and borderline PD were the most frequently diagnosed PD in borderline intellectual functioning. The vast majority of PD patients in all three groups had one or more comorbid axis I disorder. MAS disorders were the most prevalent axis I disorders in all three groups. Within the BIF group no association was found between gender and age and PD.

Even though there is growing evidence that low IQ is associated with increased risk of and severity of mental disorders including PD,^{8,13–16} our evidence based knowledge concerning PD in BIF is rudimentary. Up until now, in most countries BIF is scarcely even recognized in outpatients in mental health care. This, in spite of the fact that evidence increasingly shows that many people with BIF face major difficulties across their life courses including several risk factors for the development of mental health problems.^{7,17} People with BIF are more likely to experience childhood trauma, have more psychosocial problems and are less likely to have adequate support systems,^{2,7,18–20} all risk factors for the development of a PD.

Having a PD with concurrent BIF is likely to influence treatment and prognosis. At this time, in most places, adults with BIF and concurrent mental health problems are less likely to receive treatment of any kind.⁸ If they do receive treatment they are more likely to receive psychopharmacological treatment and less likely to receive counseling or psychological interventions.⁸ This is in contrast with all the evidence based treatments available for patients with PD and average intelligence, like Dialectical Behaviour Therapy (DBT)^{21–23} and Mentalisation Based Therapy (MBT).^{24–26} It is also in contrast with the growing evidence on treatments for patients with PD and ID, like DBT.^{27,28}

There are several strengths in the present study. First, this study examines a large sample of patients with borderline intellectual functioning, which is a hidden population in mental health care in most countries. Second, the label of BIF was always carefully applied and recently established, based on formal IQ testing using the standardized Wechsler Adult Intelligence Scale (WAIS-III). This holds also true for the label of mild ID. Third, PD diagnoses were the diagnoses as recorded in the official registration system of the electronic patient file, making this study a reflection of actual daily clinical practice. Patients with BIF and mild ID were assessed multidisciplinary, according to a strict protocol based and PD diagnoses were made following DM-ID guide-

lines.⁹ Fourth, the fact that the findings are based on large samples from a naturalistic outpatient setting makes them generalizable to the clinical field of interest.

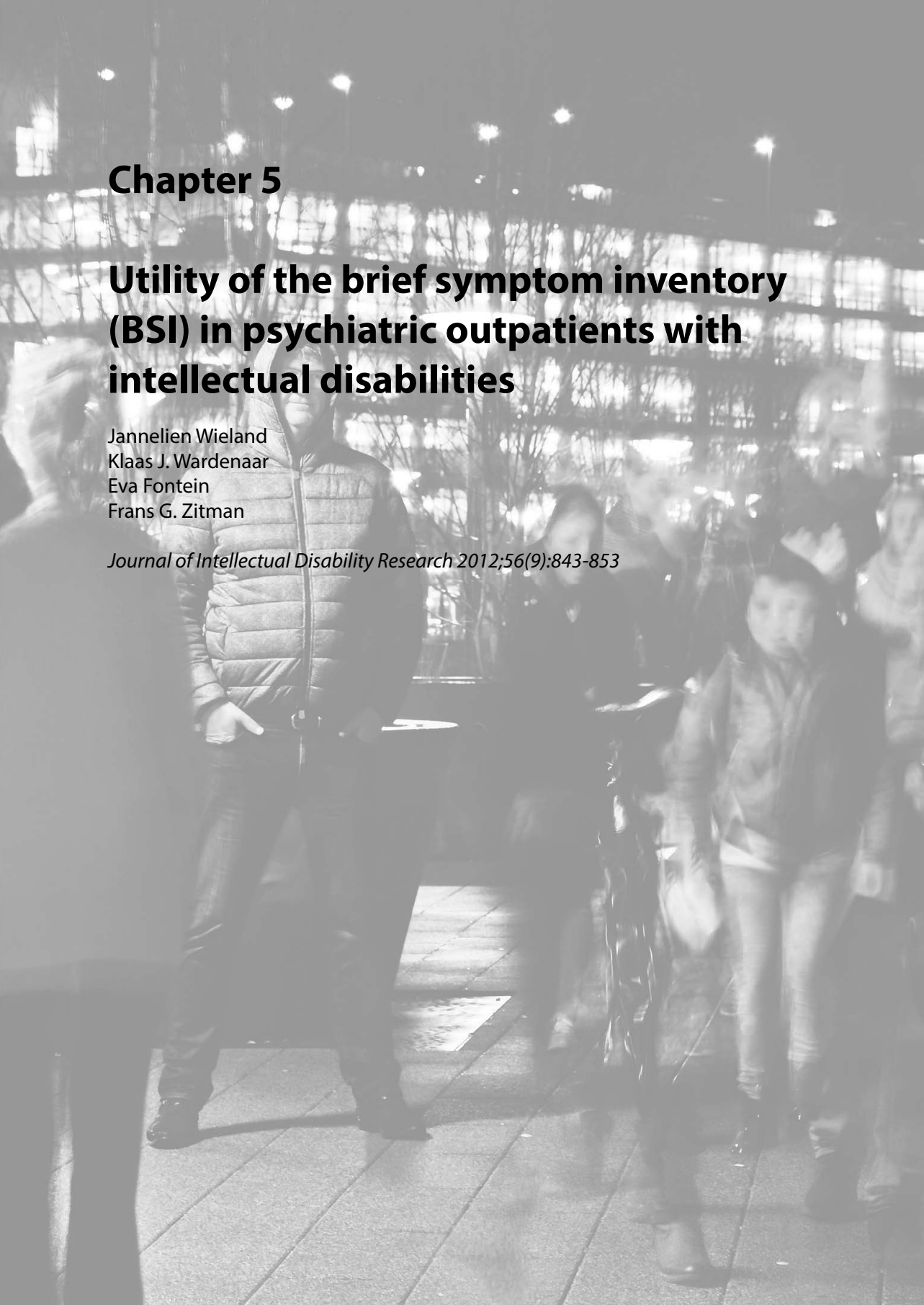
However, the results should also be interpreted in the light of some limitations. First, issues of referral may have introduced bias. Even though referral pathways are well established, not all patients with BIF receive specialised outpatient psychiatric treatment. There might be individuals with unidentified BIF in regular psychiatric services. Second, in both the BIF and mild ID groups there were many patients diagnosed with PDD because of a special referral policy. They were excluded from analysis, which means that part of the initial sample was not included. However, most patients diagnosed with PDD were not diagnosed with any co-morbid PD, so the extent of the introduced bias probably is small. A third limitation is that results apply only to outpatients and cannot be generalized to more severely ill in-patients. Fourth, there was no IQ testing in the RMHC group. Fifth, demographic information was limited and information on treatment was not available.

In conclusion, there is a high frequency of PD diagnoses in BIF outpatients in daily clinical practice. In anticipation of further scientific research, results suggest that PD should not be overlooked in patients with BIF.

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Chapter 5

Utility of the brief symptom inventory (BSI) in psychiatric outpatients with intellectual disabilities

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Abstract

Background Diagnostics and care for people with intellectual disabilities and psychiatric disorders need to be improved. This can be done by using assessment instruments to routinely measure the nature and severity of psychiatric symptoms. Up until now, in the Netherlands, assessment measures are seldom used in the psychiatric care for this population.

The objective of the present paper is to evaluate the use of the BSI, a widely used standardised questionnaire in general psychiatry, in a well-defined sample of people with borderline intellectual functioning (BIF) or mild intellectual disabilities (ID) diagnosed with one or more psychiatric disorders.

Method A total of 224 psychiatric outpatients with either BIF or mild ID participated in this study. All participants were new patients of the two Centres for Psychiatry and Intellectual Disability (CPID) of Rivierduinen, a large regional mental health care provider in the Netherlands, in the period between April 1 2008 and October 1 2009. All participants were assessed by a multidisciplinary team. DSM-IV-TR criteria were applied. The mean total intelligence coefficient (TIQ) was measured with the Wechsler Adult Intelligence Scale (WAIS-III). The BSI was administered in an assisted fashion. Psychometric properties of the BSI were investigated. Bivariate correlations between the subscales were computed to assess differentiation between the scales and mean subscale scores were compared between different DSM-IV-TR subgroups to investigate the discriminant abilities of the scales. A confirmatory factor analysis was conducted.

Results The results suggest that the BSI is practically useful. Internal consistencies ranged from 0.70 – 0.96 and thus are considered good to adequate. Subscale inter-correlations showed there is a degree of differentiation between the subscales. Discriminant validity was shown for the subscales *Depression*, *Anxiety* and *Phobic anxiety*. Confirmatory factor analysis showed that the underlying structure of the BSI could be described by the same 9-factor model as reported in previous studies.

Conclusions As a result of the psychometric properties illustrated, this study supports the use of the BSI as a screener for psychopathology and a general outcome measure in people with intellectual disabilities.

Introduction

It is commonly known by now that people with intellectual disabilities (ID) experience the full range of psychiatric disorders. And even though prevalence rates vary, in most studies, they turn out much higher than in the general population.^{1–8} In contrast, psychiatric diagnoses are often missed and little is known about the effectiveness of treatment of psychiatric disorders in this population.^{4,7,9} Therefore diagnostics and care for people with ID and psychiatric disorders need to be improved. This can be done by using assessment instruments to routinely measure the nature and severity of psychiatric symptoms.

In the Netherlands, assessment measures are seldom used in the psychiatric care for this population. This is at least in part due to the lack of adequately translated and tested assessment instruments in the Dutch language.

In the Dutch language there are only a few measures available specially developed for people with ID and little is known about the utility of existing ‘regular’ assessment measures. This is especially true for self-report measures.

Using self-report measures may present challenges due to language and memory problems, a reduced ability to conceptualize and express emotions, as well as due to social desirability.^{7,10}

However, people with borderline intellectual functioning (BIF) or mild ID are generally quite capable of reporting about their own behaviours and feelings.^{11–15}

If self-report measures are used, they are usually developed or modified for people with ID, but with little attention paid to psychometric properties and comparability with existing psychiatric ratings.¹⁶

One could argue, as did Kellett et al.,¹⁷ that it is ethically and theoretically more appropriate to explore the application of existing non-altered assessment measures before modifying existing, or developing new instruments.

Examples of existing self-report measures from general psychiatry already researched for their use in people with ID are the Beck Depression Inventory and the Zung Self-Rating Depression Scale,¹⁸ the Beck Anxiety Inventory,¹⁹ the Zung Self-Rating Anxiety Scale,¹² and the Hospital Anxiety and Depression Scale.²⁰ Although more research is needed, all authors stress the applicability and potential utility of these instruments in people with ID.

Kellett et al.^{21,22} evaluated the use of the Brief Symptom Inventory (BSI), a widely used assessment measure in the general psychiatry, in people with ID in the United Kingdom. Their first study consisted of 200 mild ID participants from three distinct groups: a clinical, a community and a forensic group. The second study consisted of 335 participants, all diagnosed with mild ID, but with no reference of psychopathology.

Kellett et al.^{21,22} found that people with ID respond to most questions of the BSI in a similar way as do people without ID and that internal consistency of the different subscales was satisfactory. Moreover they concluded, in their first study, that the BSI

could effectively discriminate between the different groups. They concluded that the BSI can be employed as an assessment instrument and as a treatment outcome measure in people with ID.

The objective of the present paper was to further extend the research on the utility of the BSI in a well-defined sample of people with BIF or mild ID. In view of the findings of Kellett et al.^{21,22} it is reasonable to hypothesize that the BSI has adequate psychometric properties and can be used in this population.

Method

Participants

A total of 224 people participated in the study. All participants were new patients of one of the two Centres for Psychiatry and Intellectual Disability (CPID) of Rivierduinen, a large regional mental health care provider in the Netherlands, between April 1 2008 and October 1 2009. All participants were assessed by a multidisciplinary team, including a certified psychiatrist, and were classified according to the criteria of the Diagnostic and Statistical Manual of mental disorders (DSM-IV-TR) with either BIF or mild ID. In addition, 92.9% were classified with one or more DSM-IV-TR psychiatric disorders. Intelligence could be assessed in 205 (91.5 %) participants. The mean total intelligence coefficient (TIQ), measured with the Wechsler Adult Intelligence Scale (WAIS-III), was 71 (SD=8.1; range 50-87). 44.6% of participants were diagnosed with a mild ID; 53.9% with BIF. Two people had a TIQ of respectively 86 and 87. TIQ could not be obtained for 19 participants, either because no IQ-test was administered (13 cases) or because the discrepancy between verbal and performal IQ was too large to make a reliable statement about the total IQ score (6 cases).

Instrument

The Brief Symptom Inventory (BSI)²³ is essentially the brief form of the SCL-90-R, a self-report inventory that has been developed and used in a wide variety of settings and applications.^{24,25} It is a self-report (or interview administered) symptom scale consisting of 53 items, covering nine symptom dimensions: *Somatisation* (SOM), *Obsession-Compulsion* (O-C), *Interpersonal Sensitivity* (I-S), *Depression* (DEP), *Anxiety* (ANX), *Hostility* (HOS), *Phobic anxiety* (PHOB), *Paranoid ideation* (PAR) and *Psychoticism* (PSY). Each item is ranked on a 5-point Likert scale ranging from 0 (not at all) to 4 (extremely). Rankings characterize the intensity of distress during the past seven days. Next to scores on all of the nine symptom dimensions, 3 global indices of severity of psychopathology can be calculated: The average score on all 53 items together, the number of items with non-zero responses (or: the number of symptoms experienced by the respondent) and the severity of the existing symptoms (or: the total score divided by the number of symptoms experienced by the respondent).²⁶

Several studies have shown the BSI to have adequate internal consistency in the general population. Cronbach's alphas of the original American version of the BSI range from 0.71 (PSY) to 0.85 (DEP), with 4 out of 9 scales having an alpha over 0.80.^{27,28} Also the BSI had adequate construct validity: a 9-factor structure.^{27,29}

In Kellett's study²¹ of ID patient population, the Cronbach's alphas for all participants (all three groups included) ranged from 0.63 (PSY) to 0.78 (O-C). Using normal varimax rotation Kellett et al.²² derived 8 interpretable factors. However they also found a marked degree of overlap with the existing BSI factor structure.

De Beurs & Zitman³⁰ translated the BSI in Dutch. They did a large-scale evaluation of the BSI and found that the reliability of the different subscales of the Dutch version of the BSI was good and that the convergent and divergent validity was adequate. The Dutch translation of the BSI showed Cronbach's alphas of 0.71 (PSY) to 0.87 (DEP and ANX), with 8 out of 9 scales having an alpha over 0.80, and the same 9-factor structure. De Beurs & Zitman³⁰ concluded that the BSI is an excellent screener for psychopathology and a good general outcome measure.

Procedure

The BSI was administered in an assisted fashion, much like the "assisted completion format" for the SCL-90 as described by Kellett et al.^{17,21} They concluded that the assisted completion format was shown not to influence respondents' ratings of symptoms excessively and did not affect the psychometric properties of the test.^{17,21}

Our assisted administration consisted of the following: The assessment was conducted in a one-to-one setting. Both the instruction and the items of the BSI were read in order. The items were either read together with the respondent or verbatim to the respondent. The answer feedback sheet contained both numerical and grammatical representations. Language was adapted when needed, meaning that the same item was repeated in simplified wordings. Using this format, administration time was between 10 and 30 minutes, on average 20 minutes.

A list of difficult items was kept for part of the sample ($n = 43$). A question was considered difficult when either the respondent indicated not understanding the question completely, or when the administrator noted that the question was not understood properly. The latter was confirmed by asking the respondent to rephrase the question in his or her own words. Afterwards items were explained as needed.

Statistical analyses

To investigate the utility of the BSI in our patient group, for each item, the number of times an item needed explaining was counted to identify difficult items. To investigate the role of intelligence for ease of administration, a regression analysis was conducted with the number of items that needed explaining as dependent variable and TIQ as independent variable. For each item the distribution of responses on the

Likert-scale was inspected to identify possible response tendencies. Several additional analyses were conducted to investigate the psychometric characteristics. First, internal consistency coefficients (Cronbach's alphas) were computed for the total scale and the subscales. Second, bivariate correlations between the subscales were computed to assess differentiation between the scales. Third, mean subscale scores were compared between different DSM-IV-TR subgroups to investigate the discriminant abilities of the scales. Fourth, confirmatory factor analysis (CFA) was conducted to investigate whether the previously identified 9-factor structure²³ fit to our data. Because the items were categorical and non-normal, robust maximum likelihood fit-estimations³¹ were used, based on a polychoric correlation matrix³². Model-fit was investigated with fit-in-indices instead of a traditional χ^2 -test, because the latter is oversensitive to minor deviations from perfect model-fit for complex model.³³ The used fit robust indices were: the normed fit index (NFI), the comparative fit index (CFI) and the root mean square error of approximation (RMSEA). An NFI and CFI of at least 0.90 indicate adequate fit (≥ 0.95 indicates good fit) and an RMSEA smaller than 0.06 indicates good fit. Analyses were conducted with the SPSS version 16.0 (SPSS Inc, Chicago, IL) and EQS 6.1 (Multivariate Software inc., Encino, California, USA) software packages.

Ethical Considerations and privacy issues

Within the regional mental health care organisation Rivierduinen, it is part of the general policy to monitor treatment outcome using a method called ROM (Routine Outcome Monitoring).³⁴ The two CPID of Rivierduinen have their own form of ROM, using instruments especially developed for people with ID and instruments from regular psychiatry such as the BSI. People are informed at the beginning of the assessment that if data from these instruments is used for research purposes, this is done in anonymous form. If people object to such use, their data is removed. A comprehensive protocol safeguards anonymity of the patients and ensures proper handling of the data. This protocol is available for patients on request. The Medical Ethical Committee of the Leiden University Medical Centre (LUMC) approved the regulations and agreed with this policy.³⁴

Results

Descriptive and diagnostic information

Both the descriptive and diagnostic information about the study group are shown in Table 1. There were 136 (60.7%) women and the mean age was 32.2 (Standard Deviation (SD)= 12.1; range 16-71). The TIQ had a mean of 71.3 (SD= 8.3) and ranged from 50 to 87. The large majority (92.3%) of the group had a broad variety of DSM-IV-TR diagnoses. Most prevalent were anxiety disorders, which were present in 17.9% of the patients and pervasive developmental disorders (PDD) (17.9%), followed by posttraumatic stress disorders (PTSD) (12.9%), ADHD or ADD and disruptive beha-

viour disorders (9.8%) and mood disorders (9.4%). A DSM-IV-TR personality disorder (PD) was diagnosed in a total 25.4% of all patients. Of those patients diagnosed with a PD, almost half (47%) was also diagnosed with an axis I disorder. Not taking into account classifications for BIF and ID, 24.6% of participants had two psychiatric diagnoses and 6.7% had three or more psychiatric diagnoses.

Table 1. Demographic and psychopathology information in a sample of psychiatric outpatients with BIF or mild ID (n= 224).

Descriptive information	
Female (%)	136 (60.7%)
Male (%)	88 (39.3%)
Mean age (SD)	32.2 (12.1)
Age range	16-71
Mean TIQ (SD)	71.3 (8.3)
TIQ range	50-87
Axis I diagnoses (DSM-IV-TR)	
Pervasive developmental disorders	40 (17.9%)
Mood disorders	21 (9.4%)
Anxiety disorders	40 (17.9%)
Somatoform disorders	7 (3.1%)
Posttraumatic stress disorder	29 (12.9%)
ADHD, ADD and disruptive behaviour disorder	22 (9.8%)
Psychotic disorders	9 (4.0%)
Addictive disorders	15 (6.7%)
Adjustment disorders	17 (7.6%)
Other*	61 (29.0%)
Personality Disorders (DSM-IV-TR)	
Borderline	15 (6.7%)
Other**	10 (4.4%)
Not Otherwise Specified	33 (14.7%)
No DSM-IV-TR diagnosis	17 (7.6%)

TIQ= total intelligence quotient, ADHD= Attention-Deficit Hyperactivity-Disorder, ADD= Attention Deficit Disorder, *mainly DSM-IV-TR V-codes, **This group includes mostly cluster C, dependent and avoidant personality disorders

Practical utility

A list of difficult questions was kept for part of the sample (n= 43). The mean number of questions that needed explaining was 3.9 (SD= 3.6). Only 14.0% of participants needed 6 or more questions explained to them. And 51.2% of participants needed explaining of only 3 questions or less. Also, 16 (30.0%) of the 53 BSI items were

understood by all participants. Only 4 items needed explaining in more than a third of cases. Those items were The idea that someone else can control your thoughts (item 3), Feeling blocked in getting things done (item 15), Your mind going black (items 32) and Never feeling close to another person (item 44). A regression analysis showed that there was an association between the number of explained items and TIQ (regression coefficient (b)= -0.19; $p= 0.007$). These results indicate that TIQ plays a role in the number of items needing explanation: with an increase of roughly 5 points in TIQ, the number of explained items decreases with $(0.19 \times 5 \approx) 1$.

Internal consistency

The internal consistency of the BSI was calculated using Cronbach's coefficient alpha. The number of items and internal consistencies of the different BSI subscales are given in Table 2. Alpha coefficients of the different subscales ranged from 0.70 to 0.86 and alpha was 0.96 for the BSI-total. For 5 subscales, coefficient alpha exceeded 0.80, which indicates good internal consistency. The other 4 subscales all had alpha coefficients exceeding 0.70, which is considered adequate.

Table 2. Description of the Brief Symptom Inventory (sub)scales and their Cronbach's alpha coefficients in a sample of psychiatric outpatients with BIF or mild ID ($n= 224$).

BSI scale	Description	Included item numbers	Cronbach's α
SOM	<i>Somatic complaints</i>	2, 7, 23, 29, 30, 33, 37	0.83
O-C	<i>Obsession-compulsion</i>	5, 15, 26, 27, 32, 36	0.81
I-S	<i>Interpersonal Sensitivity</i>	20, 21, 22, 42	0.80
DEP	<i>Depression</i>	9, 16, 17, 18, 35, 50	0.86
ANX	<i>Anxiety</i>	1, 12, 19, 38, 45, 49	0.82
HOS	<i>Hostility</i>	6, 13, 40, 41, 46	0.78
PHOB	<i>Phobic anxiety</i>	8, 28, 31, 43, 47	0.78
PAR	<i>Paranoid ideation</i>	4, 10, 24, 48, 51	0.77
PSY	<i>Psychoticism</i>	3, 14, 34, 44, 53	0.70
BSI Total	<i>Brief Symptom Inventory Total score</i>	1-53	0.96

All alpha coefficients that indicate good internal consistency are printed in bold font; all alpha coefficients that indicate adequate internal consistency are printed in italic font

Subscale intercorrelations

To investigate the relationships between the different BSI subscales, bivariate correlations were computed. The correlation coefficients are shown in Table 3 and ranged from 0.39 to 0.79, which indicates that there are different inter-scale relations. For instance, the DEP subscale showed substantial correlations with the PSY scale ($r= 0.79$) and the I-S scale ($r= 0.70$) and somewhat lower correlations with the HOS scale

($r = 0.45$), the SOM scale ($r = 0.54$) and the ANX scale ($r = 0.64$). In addition, the ANX scale showed its most substantial correlation with the PHOB scale ($r = 0.73$). The SOM scale showed its strongest correlation with the ANX scale ($r = 0.62$). These results indicate that there is a degree of differentiation between these subscales, based on their content.

Table 3. Inter-correlations of the Brief Symptom Inventory (sub)scales in a sample of psychiatric outpatients with BIF or mild ID ($n=223$).

BSI scale	SOM	O-C	I-S	DEP	ANX	HOS	PHOB	PAR	PSY
SOM	<u>0.83</u>	-	-	-	-	-	-	-	-
O-C	0.56	<u>0.81</u>	-	-	-	-	-	-	-
I-S	0.48	0.69	<u>0.80</u>	-	-	-	-	-	-
DEP	0.54	0.67	0.70	<u>0.86</u>	-	-	-	-	-
ANX	0.62	0.68	0.66	0.64	<u>0.82</u>	-	-	-	-
HOS	0.39	0.45	0.51	0.45	0.54	<u>0.78</u>	-	-	-
PHOB	0.58	0.62	0.71	0.61	0.73	0.42	<u>0.78</u>	-	-
PAR	0.56	0.67	0.66	0.67	0.60	0.58	0.58	<u>0.77</u>	-
PSY	0.52	0.67	0.71	0.79	0.66	0.37	0.71	0.65	<u>0.70</u>

The coefficients are Pearson bivariate correlation coefficients; underlined numbers correspond to the Cronbach's alpha coefficients of the subscales

Discriminant validity

To investigate discriminant validity, mean subscale scores and BSI Total were compared between groups with- and without a DSM-IV-TR disorder and between groups with different DSM-IV-TR diagnoses. The mean BSI Total scores are shown in Figure 1. Subjects with DSM-IV-TR axis-I (Mean BSI Total score = 1.10) disorders had higher total scores than subjects without a diagnosis (Mean BSI Total Score = 0.72; $p = 0.03$). Patients diagnosed with a PD or both an axis-I and a PD (Mean BSI Total score = 1.51) scored much higher than patients with only axis-I disorders ($p = 0.001$). Interestingly, patients diagnosed with an autism spectrum disorder scored lower (mean BSI Total score = 0.78) than other patients ($p < 0.001$) and had a mean score that was similar to subjects without a DSM-IV-TR disorder. At the subscale level, patients with a DSM-IV-TR diagnosis had significantly higher scores on all of the subscales than subjects without a diagnosis, except for phobic anxiety ($p = 0.13$). When patients with PDD were left out of the analyses, the differences between subjects with and without a DSM-IV-TR diagnosis on each of the BSI-subscales all became significant. To investigate the discriminative validity of some of the subscales, mean scores were compared between patients with a mood, anxiety or somatoform disorder. Patients with a major depressive disorder (MDD) scored significantly higher on the DEP sub-

scale (mean 1.79) than patients with other disorders (mean 1.21; $p = 0.02$); see Figure 2. Patients diagnosed with an anxiety disorder scored significantly higher on the ANX subscale and on the PHOB subscale (mean ANX 1.71; mean PHOB 1.28) than patients with other disorders (mean ANX 1.19; mean PHOB 0.87; respectively: $p = 0.005$ and $p = 0.035$); see Figure 3. Patients with a somatoform disorder scored higher on the SOM subscale (mean 1.24) than patients with other disorders (mean 0.89); see Figure 4. However, this difference was not statistically significant ($p = 0.43$), likely due to the small group-size ($n = 7$). Taken together, these results indicate that the DEP, ANX, PHOB and maybe SOM subscales have the ability to discriminate between different DSM-IV-TR diagnoses.

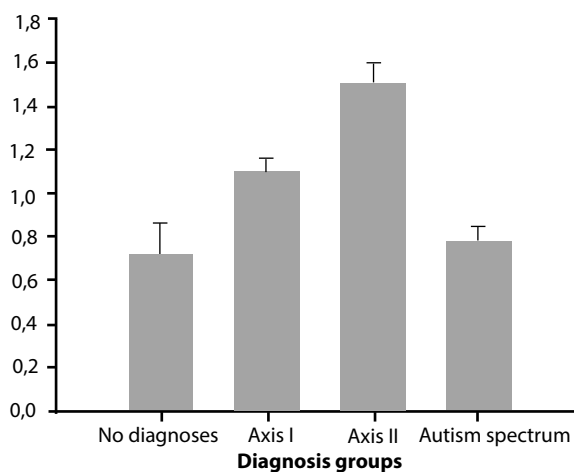


Figure 1. Mean total Brief Symptom Inventory scores for subjects without a psychiatric diagnosis ($n=17$), patients with an axis I diagnosis ($n=150$), patients with an axis II diagnosis ($n=59$) and patients with an autism spectrum diagnosis ($n=40$). Error bars indicate standard errors.

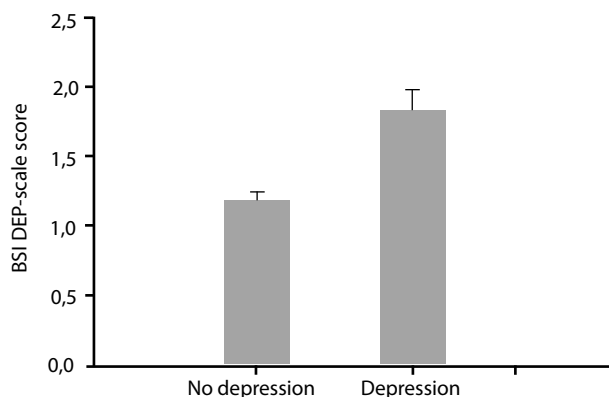


Figure 2. Mean scores on the Brief Symptom Inventory DEP-subscale for subjects with and without a current depression diagnosis. Error bars indicate standard errors.

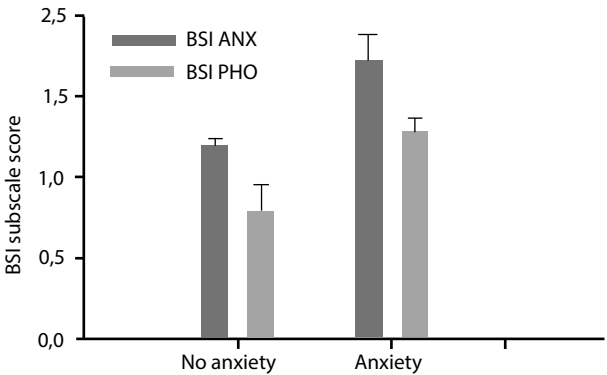


Figure 3. Mean subscale scores on the ANX and PHO subscales of the Brief Symptom Inventory for subjects with and without an anxiety disorder. Error bars indicate standard errors.

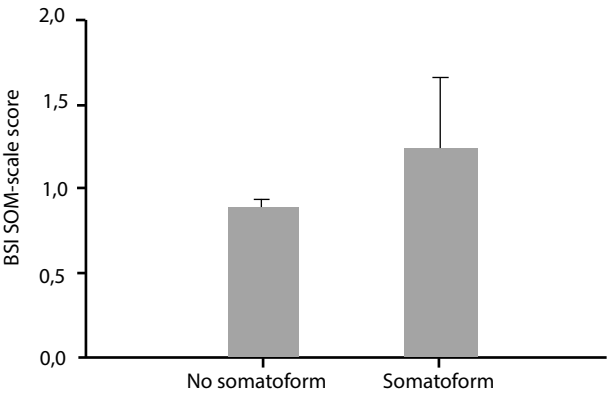


Figure 4. Mean scores on the Brief Symptom Inventory SOM scale for subjects with or without a current somatoform disorder. Error bars indicate standard errors.

Facture structure

To investigate whether the 9-factor structure of the original BSI also fit to the BSI-data from the current ID group, a CFA was conducted. The NFI was 0.94, the CFI was 0.98 and the RMSEA was 0.048 (90% CI 0.043-0.053), which all indicated the model to fit well to the data. These results indicate that the underlying structure of the BSI in the current study can be described by the same 9-factor model, as reported in previous studies.

Discussion

The present study investigated the practical utility and different psychometric aspects of the BSI when applied in people with BIF or mild ID. The results suggest that the BSI is practically useful and has adequate internal consistency and validity. These results have several interesting implications.

Our study especially demonstrated the practical utility of the BSI. Even though Deroogatis²⁷ didn't intend the BSI to be used in people with ID, using the BSI in people with below average intelligence turned out to be not as difficult as previously thought. Most questions of the BSI were easily understood by most participants. On average only 4 questions needed explaining. This is about 7.5% of the total of 53 questions. There was a relation between TIQ and the number of questions participants found difficult. With a decrease of roughly 5 points in TIQ, one more item of the BSI needed explaining.

Concerning the psychometric properties, it can be reported that internal consistencies across the different subscales were good to adequate. The Cronbach's alphas obtained (0.70-0.86) were quite similar to the Cronbach's alphas of the original published norms (0.71-0.85)²⁶ and the study by De Beurs & Zitman³⁰ in a large Dutch non-disabled sample (0.71-0.87) and not very dissimilar from the alphas in the study of Kellett et al.²¹ (0.63-0.78).

Construct and discriminant validity was comparable to those in other non-disabled as well disabled populations.^{21,30} The factor structure of the BSI indicated that the underlying structure of the BSI in the current study can be described by the same 9-factor model, as reported in previous studies.^{23,30} And even though Kellett et al.²², using normal varimax rotation, derived only 8 interpretable factors, they did find a marked degree of overlap with the existing BSI factor structure.

Kellett et al.²¹ already demonstrated that the BSI could reliably discriminate between a clinical, a community and a forensic group. In terms of clinical utility and discriminant validity, the present study also demonstrated that patients diagnosed with a psychiatric disorder had a significantly higher BSI Total score compared to those without a psychiatric diagnosis. Patients had significantly higher scores on all of the subscales except Phobic anxiety. The BSI could reliably distinguish between patients with either a MDD or other disorder, using the scores on the Depression subscale. The same holds true for people with an anxiety disorder, using the scores on the Anxiety and Phobic anxiety subscales. For the Somatisation subscale there was a tendency, however statistically insignificant, to distinguish between people diagnosed with a somatoform disorder and those diagnosed with other psychiatric disorders. Important to note is the fact that people with PDD scored significantly lower than other patients on all subscales of the BSI and comparable to people without a psychiatric diagnosis. This is likely because the problems generally experienced by people with PDD (qualitative impairment in social interaction and communication and restricted repetitive and stereotyped patterns of behaviour, interests and activities) are not reflected in the different

items of the BSI. Therefore the BSI might not be of use in people with PDD. Another finding was that patients diagnosed with a (co-morbid) PD, scored above average on all the subscales of the BSI. This difference was significant for 7 out of 9 of the BSI subscales including the BSI Total. One could hypothesize, that patients with (co-morbid) PD score above average compared to patients with only axis I disorders because they experience a lot of emotional dysregulation and interpersonal problems, and will recognize themselves in many items of the BSI. This of course applies mostly to patients with cluster B personality traits, which was the cluster of personality traits mostly seen in our sample. We found a prevalence rate of PD of 25.4%. This may seem high, but it is in accordance with findings in other studies. Corbett³⁵ found a prevalence of PD of 25.4% in a sample of 402 participants. Eaton & Menolascino³⁶ found a prevalence rate of 27.1% in a community-based sample of 115 people. And in a population of 100 individuals, with mild or moderate ID, Reid & Ballinger³⁷ found a prevalence rate of 22%. Khan et al.³⁸ even reported a warranted personality diagnosis in 31% of their community sample.

On a more general note it should be said that in the Dutch version of the BSI the dimension of *Obsession-Compulsion* (O-C) was translated in *Problems in Cognitive Functioning*, because next to obsessive-compulsive symptoms, this dimension also measures – for instance – concentration loss.³⁰ This re-titling was also proposed by Kellett et al.²², who argued that the scale's item constructions appeared to reflect traditional cognitive difficulties reported by people with ID, rather than obsessive-compulsive symptomatology. Limitations of the present study include the fact that the results from the present outpatient population cannot without further research be generalised to an inpatient population. Also there is a lack of data comparing the assisted completion format with the self-report format. But, not only would this comparison be hard to make, the assisted completion format did not harm the psychometric integrity and was shown by Kellett et al.^{17,21} not to influence respondents' ratings of symptoms excessively. Evidently more research is needed concerning reliability (e.g. test-retest reliability) and convergent and divergent validity of the BSI in intellectually disabled populations. In conclusion, as a result of the psychometric properties illustrated, this study supports the use of the BSI as a screener for psychopathology and a general outcome measure in people with BIF or ID.

Because of the nature of this study, we are hopeful that results will also apply to other intellectually disabled psychiatric outpatient populations. One advantage of the BSI is that it can be used in many patients across a wide range of symptoms and diagnoses.^{e.g.21,30,39–41} Another advantage is that it can be applied across different therapeutic interventions (e.g. pharmacotherapy, cognitive behavioural therapy).^{42–44}

A more general implication of the present study should be that other self-report measures developed for the general psychiatric population might also be of use with patients with BIF or ID. Even though this should not be done without special attention for the psychometric properties in this population, using assessment measures

from general psychiatry could greatly increase the number of available assessment instruments for these patient populations. This in turn will allow for routinely measuring the nature and severity of psychiatric symptoms or Routine Outcome Monitoring (ROM) in this population.

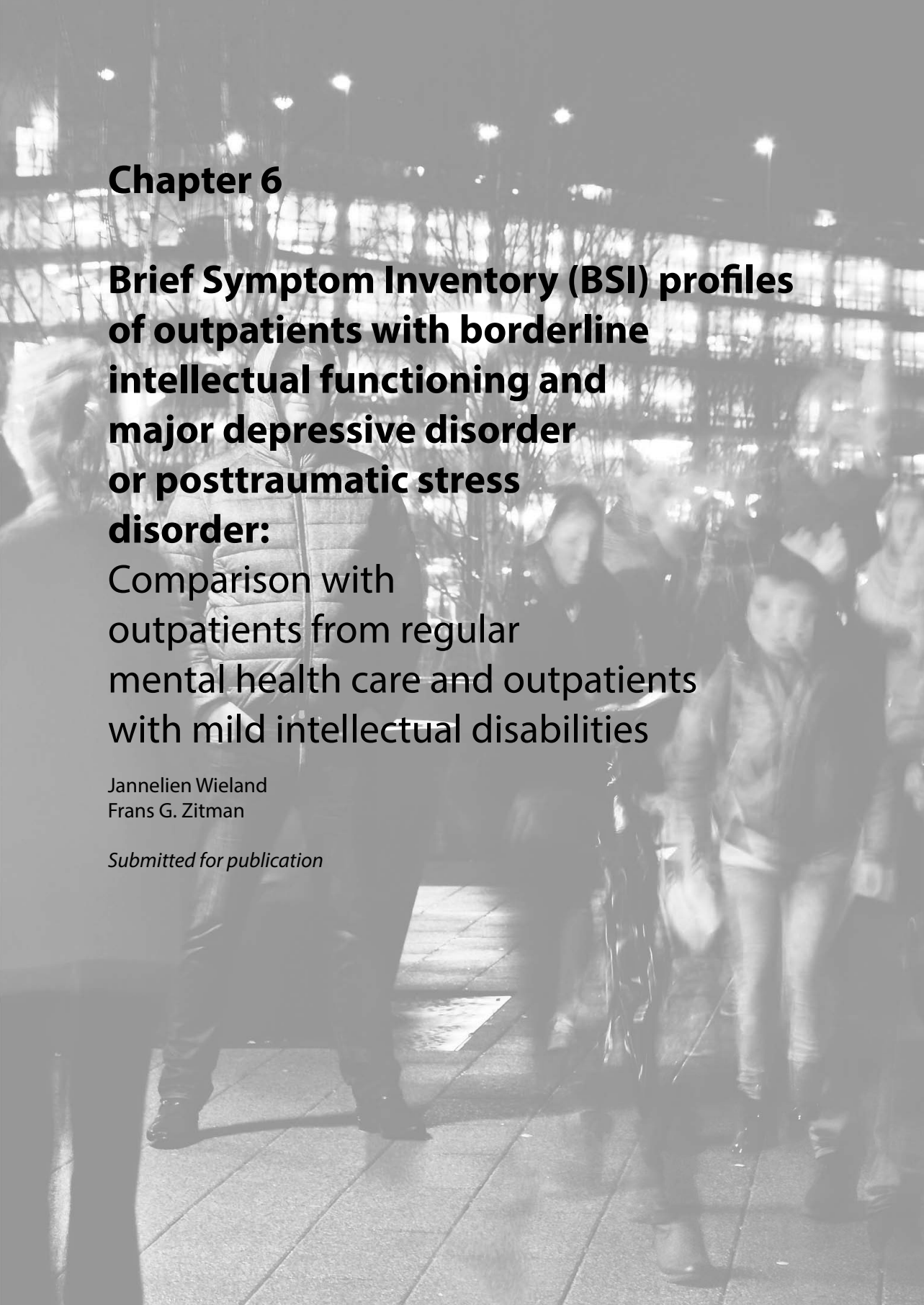
ROM is a method for the systematic use of assessment instruments for collecting information about patients.⁴⁵ In the Netherlands ROM is used in a growing number of mental health care organisations. First, in addition to the clinical interview, to establish the nature and severity of symptoms at baseline or first presentation. This is important for making the right treatment decisions. Second ROM is used to establish the course of symptoms over time, visualizing the effect of the treatment, both on an individual level as well as on group level (for instance all people being treated in a certain way or all people suffering from the same mental illness). An important part of routine outcome monitoring is the fact that the system allows for feedback to treating psychiatrists, psychologist and other health care practitioners, allowing them to talk about the effect of the treatment with their patients and thus use the results therapeutically.⁴⁵ Using ROM in people with BIF and ID will improve psychiatric diagnostics and care and using instruments like the BSI will make ROM possible in this population.

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Chapter 6

Brief Symptom Inventory (BSI) profiles of outpatients with borderline intellectual functioning and major depressive disorder or posttraumatic stress disorder:

Comparison with outpatients from regular mental health care and outpatients with mild intellectual disabilities

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Submitted for publication

Abstract

Introduction In most countries, people with borderline intellectual functioning (BIF) are not considered a separate group in mental health care. There is little to no research on the impact of BIF on the presentation, nature and severity of mental health problems. The aim of the present exploratory study was to compare, in a naturalistic setting of patients referred to secondary care, symptom profiles of patients with BIF diagnosed with either major depressive disorder (MDD) or posttraumatic stress disorder (PTSD) to patients from regular mental health care (RMHC) and patients with mild ID diagnosed with the same disorders.

Methods We used a cohort of adolescent and adult outpatients (aged 16 to 88) with or without BIF diagnosed with a primary diagnosis MDD or PTSD. Primary outcome was the nature and severity of psychopathological symptoms assessed at baseline using the Brief Symptom Inventory. All outcomes were adjusted for gender and age.

Results Results showed that BIF patients with a primary diagnosis MDD reported less severe symptoms on *BSI Total* and the subscales *Depression*, *Obsession-Compulsion* and *Psychoticism* than patients from Regular Mental Health Care (RMHC). There were no statistically significant differences in reported symptom severity on *BSI Total* and the different BSI subscales between BIF patients with PTSD and either patients from RMHC or patients with mild ID. Patients mild ID, did report significantly less severe symptoms on the subscale *Depression* and on the subscale *Psychoticism* than patients from RMHC.

Discussion Since there were no other published studies into symptom profiles of patients with BIF compared to either patients with higher or lower levels of cognitive functioning, the study was mainly exploratory in nature, providing direction for future research. Results indicate that symptom profiles did not widely differ, but that there might be some characteristics unique to patients BIF separating them as a group from both patients from RMHC and patients with mild ID.

Introduction

Borderline intellectual functioning (BIF) refers to the category of intelligence on the normal curve of 1 to 2 standard deviations below the mean, roughly an IQ between 70 and 85. People with BIF function in between people with normal cognitive development ($IQ > 85$) and people with an intellectual disability ($IQ < 70$). According to the normal curve of intelligence as much as 13.6% of the population fall into this category. People with BIF represent a large minority in society and in mental health care. BIF in itself is not considered a disorder, nor a disability. Rather BIF is a vulnerability. People with BIF are more vulnerable for the development of mental health problems like anxiety and depression, than people of average or above average intelligence.¹⁻³ There is little to no research however on the impact of BIF on the presentation, nature and severity of mental health problems and it is unclear to what extent general guidelines are applicable to patients with BIF.

In most countries, people with BIF are not in sight as a separate group in mental health care. BIF is often not noticed and most often not a focus of attention. Psychiatric patients with BIF are diagnosed and treated in the same setting as patients with average or above average cognitive abilities. In theory they are treated according to the same guidelines. Research shows however, that psychiatric patients with BIF are more likely to be treated with psychotropic drugs than psychotherapy.²

In the Netherlands, in contrast to most other countries, people with BIF are eligible to the same specialised mental health care services as patients with intellectual disabilities (ID; $IQ < 70$). This offers the unique opportunity to examine, in a naturalistic setting, the nature and severity of psychiatric symptoms in an otherwise largely hidden population.

There are no published studies examining the differences in the nature and severity of symptoms reported in mental health care by people with BIF as compared to the nature and severity of symptoms reported by people with average or above average intelligence or people with ID. One of the reasons is the supposed lack of questionnaires useful in both patients with higher and lower IQs.

Meanwhile, several studies have emphasised the importance of self-report questionnaires in patients with low IQs, especially for the assessment of more internalising psychiatric symptoms.⁴⁻⁷ Using self-report questionnaires is important, because when it comes to mood and anxiety disorders like major depressive disorder (MDD) and posttraumatic stress disorder (PTSD), it has been suggested that these disorders might present atypically in people with ID.⁷⁻¹⁰ It is unknown to what extent differences in presentation also occur in patients with BIF.

The Brief Symptom Inventory (BSI) is a self-report screener for psychopathology and a general outcome measure.^{11,12} Several studies have examined its use in people with lower IQs, including BIF and mild ID ($IQ 50-70$), and found good to adequate psychometric properties.¹³⁻¹⁵ It is one of the few self-report questionnaires that can be used both in patients with higher and lower IQs.^{15,16}

The aim of the present exploratory study was to compare, in a naturalistic outpatient setting, BSI symptom profiles of patients with BIF diagnosed with two prevalent internalising disorders, MDD or PTSD, to patients from regular mental health care (RMHC) and patients with mild ID diagnosed with the same disorders. Differences and similarities in symptom profiles could improve our understanding of the presentation of MDD and PTSD in BIF, provide clues for improving diagnostics or treatment and further direction of research.

Methods

Patients

We used a sample of adolescent and adult outpatients (aged 16 to 88) with or without BIF referred to either one of the centres for RMHC or one of the two CPID between 2007 and 2012. The cohort consisted of patients with a primary diagnosis MDD or PTSD, who were included in ROM with at least a baseline BSI. Diagnoses were the official diagnoses listed in the electronic patient file and classified following the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM-IV-TR). For patients with mild ID, DSM-IV-TR diagnoses were formulated using the Diagnostic Manual-Intellectual Disability (DM-ID).¹⁹ The DM-ID provides guidelines for making accurate psychiatric diagnoses in patients with various levels of ID and if necessary offers adaptations of DSM-IV-TR diagnostic criteria. For the diagnoses MDD and PTSD in mild ID, the DM-ID offers no adaptations; thus the criteria from DSM-IV-TR and DM-ID completely correspond.

In the two CPID, level of intellectual functioning was based on routine IQ testing, using the Dutch version of the Wechsler Adult Intelligence Scale III (WAIS-III-NL).²⁰⁻²² Using the TIQ of the WAIS-III-NL, following the DSM-IV-TR criteria, participants were either classified as BIF or mild ID and divided into 2 groups: BIF (TIQ 70-85) and mild ID (TIQ 50-70). There was no IQ testing in the RMHC group. BSI symptom profiles among the three groups were compared for MDD and PTSD.

Routine Outcome Monitoring (ROM)

ROM is the systematic use of questionnaires, to determine treatment effectiveness in everyday clinical practice in a reliable and valid way.¹⁷ The primary goal of ROM is providing direct feedback on diagnoses and treatment results to both the mental health care professional and the patient. In addition, ROM is used for benchmarking procedures and research purposes. Rivierduinen (RD), a large regional mental health care provider in the Netherlands, uses ROM for all outpatients with a mood, anxiety or somatoform (MAS) disorder referred for treatment, including outpatients with BIF or mild ID treated in one of the two outpatient Centres for Psychiatry and Intellectual Disability (CPID) (Kristal, Locations Leiden and Gouda). The Leiden ROM, as it is called, consists of an extensive psychometric battery of self-report and observer-rated

measures administered at intake and at follow-up, every 3-6 months. The main screener for psychopathology and general outcome measure for both the regular mental health care (RMHC) centres as the CPID is the Brief Symptom Inventory (BSI).¹² In the CPID, ROM-assessments are completed in an assisted fashion.¹⁵ The assisted administration consists of the following: The assessment is conducted in a one-to-one setting. Both the instruction and the items of assessment instruments are either read together with the respondent or verbatim to the respondent. The answer feedback sheet contained both numerical and written representations. Kellett et al.^{13,18} demonstrated that the assisted completion format does not influence respondent's ratings excessively and does not affect the psychometric properties of a test. Patients are informed about possible use of anonymised data from ROM for research purposes. If people object to such use, their data is removed. A comprehensive protocol safeguards anonymity of the patients and ensures proper handling of the data. The Medical Ethical Committee of the Leiden University Medical Centre (LUMC) approved the regulations and agreed with this policy.¹⁷

Assessment

Primary outcome for the present study was the nature and severity of psychopathological symptoms assessed at baseline using the BSI.¹¹ The BSI is a self-report (or interview administered) symptom scale. It consists of 53 items, covering nine symptom dimensions: *Somatisation* (SOM), *Obsession-Compulsion* (O-C), *Interpersonal Sensitivity* (I-S), *Depression* (DEP), *Anxiety* (ANX), *Hostility* (HOS), *Phobic Anxiety* (PHOB), *Paranoid ideation* (PAR) and *Psychoticism* (PSY). Items are ranked on a Likert scale from 0 (not at all) to 4 (extremely). Rankings characterize the intensity of distress during the past seven days. Scores can be calculated for the nine symptom dimensions and for *BSI total*.¹² In ID patient populations the BSI has been shown not only to have adequate to excellent internal consistency and adequate validity and also to have the same 9-factor model.¹³⁻¹⁵

Statistical analysis

Baseline characteristics are presented as number and as a percentage (categorical variables) or as mean ($\pm$ SD). The three patient groups were compared on gender, age, prevalence of MDD and PTSD and baseline total BSI using chi-square for the categorical variables gender and one-way-Anova for the continuous variables age and baseline total BSI. BSI symptom profiles were compared using Generalised Linear Models, correcting for gender and age. All tests were two-tailed with $p < 0.05$ denoting statistical significance. IBM SPSS for Windows 19.0 was used for data analysis (IBM Corp. Armonk, NY).

Results

Sample and demographic characteristics

From 2007-2012, 4265 patients were diagnosed with a primary diagnosis MDD or PTSD and included in ROM with at least a baseline BSI. Baseline sample characteristics are presented in table 1. A total of 96 patients were classified with BIF (2.2%) and 61 patients were classified as having mild ID (1.4%). In all three groups, most of the participants were women, but the percentage of women was highest in the BIF group (76.0%, $p = 0.01$). There was a significant difference among the three groups in mean age ($p < 0.001$), with the mean age of patients in the RMHC group being eldest (40.4 years) ($p < 0.001$). Therefore, all outcomes were adjusted for gender and age.

Major Depressive Disorder (MDD)

Results of BSI symptom profiles among RMHC, BIF and mild ID patients diagnosed with a primary diagnosis MDD are illustrated in figure 1. Symptom profiles did not differ widely, but we found notable differences in self-reported symptoms on the BSI among the three groups. In MDD patients there was a significant difference among the three groups for *BSI total* (overall $p = 0.03$, adjusted for gender and age) and the subscales *Depression* (overall $p = 0.01$, adjusted for gender and age), *Obsession-Compulsion* (overall $p = 0.01$, adjusted for gender and age) and *Psychoticism* (overall $p < 0.001$, adjusted for gender and age).

Compared to patients from RMHC, BIF patients reported less severe symptoms on *BSI Total* (*BSI Total* scores 1.28 vs. 1.55, $p = 0.01$ adjusted for gender and age) and the subscales *Depression* (DEP scores 1.84 vs. 2.22, $p = 0.01$, adjusted for gender and age), *Obsession-Compulsion* (O-C scores 1.68 vs. 2.03, $p = 0.01$, adjusted for gender and age) and *Psychoticism* (PSY scores 1.19 vs. 1.60, $p < 0.001$, adjusted for gender and age). There were no statistically significant differences in symptom severity on *BSI Total* and the different BSI subscales between patients with mild ID and either patients from RMHC or patients with BIF.

Posttraumatic Stress Disorder (PTSD)

Figure 2 show the results of BSI symptom profiles among RMHC, BIF and mild ID patients diagnosed with a primary diagnosis PTSD. Among the three groups there was a significant difference in PTSD patients for the subscales *Depression* (overall $P = 0.02$, adjusted for gender and age) and *Psychoticism* (overall $p = 0.03$, adjusted for gender and age). There were no statistically significant differences in reported symptom severity on *BSI Total* and the different BSI subscales between BIF patients and either patients from RMHC or patients with mild ID. Patients with mild ID, reported significantly less severe symptoms on the subscale *Depression* than patients from RMHC (DEP scores 1.49 vs. 1.93, $p = 0.01$, adjusted for gender and age). Also, patients with mild ID reported less severe symptoms on the subscale *Psychoticism* than patients from RMHC

(BSI total scores 1.07 vs. 1.42, $p = 0.02$ adjusted for gender and age). BSI symptom profiles of patients with mild ID did not differ from patients with BIF.

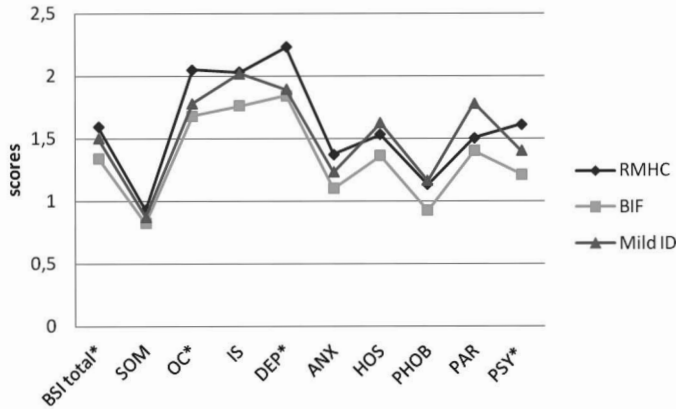


Figure 1. BSI symptom profiles among RMHC, BIF and Mild ID patients with primary diagnosis depression. Outcomes adjusted for gender and age.

RMHC = Regular Mental Health Care, BIF= Borderline Intellectual Functioning, Mild ID= Mild Intellectual Disability. SOM= somatisation, O-C= obsession-compulsion, I-S=interpersonal sensitivity, DEP= depression, ANX= anxiety, HOS= hostility, PHOB= phobic anxiety, PAR= paranoid ideation and PSY= psychoticism. * denotes subscales with significant difference in scores among the three groups ($p < 0.05$)

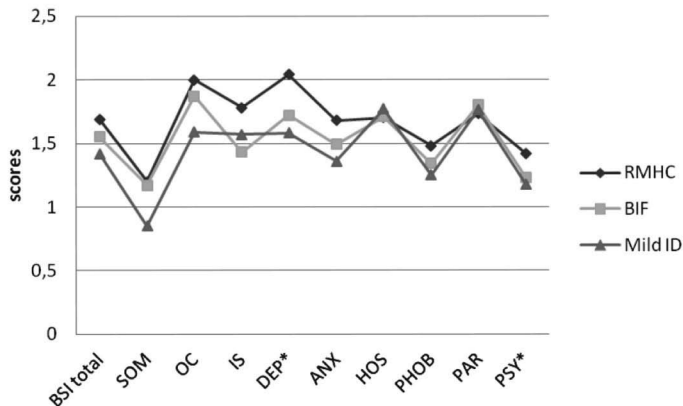


Figure 2. BSI symptom profiles among RMHC, BIF and Mild ID patients with primary diagnosis PTSD. Outcomes adjusted for gender and age.

RMHC = Regular Mental Health Care, BIF= Borderline Intellectual Functioning, Mild ID= Mild Intellectual Disability. SOM= somatisation, O-C= obsession-compulsion, I-S=interpersonal sensitivity, DEP= depression, ANX= anxiety, HOS= hostility, PHOB= phobic anxiety, PAR= paranoid ideation and PSY= psychoticism. * denotes subscales with significant difference in scores among the three groups ($p < 0.05$)

Discussion

The present study explores, in a naturalistic setting, BSI symptom profiles of patients with BIF, diagnosed with either MDD or PTSD to patients from RMHC and patients with mild ID diagnosed with the same disorders. Previous studies have shown the BSI to be a useful screener for psychopathology with adequate internal consistency and validity, including discriminant validity, in patients with both higher ($IQ > 85$) and lower IQs ($IQ < 85$).^{13,15,16} All patients in this study, whether RMHC, BIF or mild ID, scored well above cut-off scores for the BSI, total and subscales, and mostly in the higher range compared to general ROM patient groups.²³ Diagnoses were the official diagnoses as recorded in the registration system of the electronic patient file. All outcomes were adjusted for gender and age.

Results of the present study show that symptom profiles among patients in a naturalistic setting with higher and lower IQs diagnosed with either MDD or PTSD do not differ widely, but there are a few notable differences. BIF patients with a primary diagnosis MDD reported less severe symptoms on *BSI Total* and the subscales *Depression*, *Obsession-Compulsion* and *Psychoticism* than patients from RMHC, but BSI symptom profiles did not differ from patients with mild ID. Comparing patients with PTSD, there were no statistically significant differences in BSI symptom profiles between BIF patients and either patients from RMHC or patients with mild ID.

Since there are no other published studies on MDD and PTSD in BIF nor any studies on symptom profiles in patients with BIF compared to other patient groups, this study is mainly exploratory in nature. We can make some assumptions based on previous studies, from the field of ID.

Mileviciute & Hartley⁷ for instance, compared findings from two self-report questionnaires, Beck Depression Inventory (BDI-II)²⁴ and Automatic Thoughts Questionnaire (ATQ-R),²⁵ to that of an informant questionnaire, the Glasgow Depression Scale – Caregiver Supplement (GDSC)²⁶ in 80 individuals with mild ID of which 30 were diagnosed with a depressive disorder. Unexpectedly, they found that adults with higher IQs in the mild ID range scored less affective depressive symptoms than adults with IQs in the lower range of mild ID. The fact that in our study MDD patients with BIF scored lower on the subscale *Depression* than patients with mild ID could fit in with these findings. Mileviciute & Hartley⁷ hypothesized that mild ID adults with lower IQs utilise a different threshold for judging the severity of their symptoms. If that is the case however, one could wonder where the tipping point is from the lower scores of patients with high level mild ID and BIF, to the higher scores of patients with MDD from RMHC.

We did not find any studies aiding in the explanation of the low scores MDD patients with BIF on the subscales *Obsession-Compulsion* and *Psychoticism*, although it should be noted that even though still adequate, the subscale *Psychoticism* had the lowest internal consistency of all BSI subscales in patients with BIF and mild ID (Cronbach's alpha 0.70).¹⁵ It could be hypothesised that questions of this subscale represent abstract

concepts that are difficult to understand for patients with lower IQs. However, since Cronbach's alpha of the subscales *Depression* (0.86) and *Obsession-Compulsion* (0.81) were considered good, this is probably not a full explanation.

Another hypothesis could be that patients with BIF and mild ID dissimulate answers on questions of the subscale *Psychoticism*, like "the idea that something is wrong with your mind", because of negative connotations and the tendency of especially adults with BIF and higher levels of mild ID to hide their disabilities. Both of these hypotheses should be further examined.

There were no statistically significant differences in reported symptom severity on *BSI Total* and the different BSI subscales among BIF patients and either patients from RMHC or patients with mild ID. PTSD Patients with mild ID, did report significantly less severe symptoms on the subscale *Depression* and the subscale *Psychoticism* than patients from RMHC. These differences should be further examined.

The present study population reflects a naturalistic outpatient population in mental health care. Studies on patients with BIF in mental health care are rare, as are studies comparing mental health problems among patients with different levels of cognitive functioning. This is the first study to compare symptom profiles of MDD and PTSD patients with BIF to patients with higher and lower IQs, using the same reliable and valid self-report assessment instrument. Since psychiatric patients with BIF represent a large minority in mental health care, studying their presentation, nature and severity of psychiatric symptoms is important. Results of the present exploratory study may provide direction for future research.

This study has several potential limitations. First, there was no IQ testing in the RMHC group. Consequently there might be individuals with unidentified BIF in RMHC. Considering BSI symptom profiles however, this most likely results in an underestimation rather than an overestimation of differences. Secondly, even though the group of patients from RMHC was large, the groups of patients with BIF and mild ID were relatively small. Further studies with bigger patient groups might make some of the differences more clear. Third, the BSI is a general psychopathology screener. No specific MDD or PTSD self-report questionnaires were used. The simple reason is, at this point in time, there is no evidenced disorder-specific self-report assessment instrument that can reliably and validly be used in psychiatric patients with average or above average intelligence as well as in patients with BIF and patients with mild ID. Four, no informant-report questionnaires or rating scales were used. Both studies in RMHC and ID-specialised care have described the importance of using multiple sources of information in the assessment of mental health.^{27,28} To prevent agreement on presence of symptoms or distress alone, assessment instruments should preferable be disorder-specific.²⁹ Future research there for should focus on comparing outcomes on disorder-specific self-report questionnaires in patients with BIF to those of informant questionnaires and rating scales like the Comprehensive Psychopathological Rating Scale (CPRS).^{30,31} Future research should focus on expanding the knowledge on

symptom profiles of BIF patients by examining larger patient groups, using different instruments and looking at different psychiatric disorders.

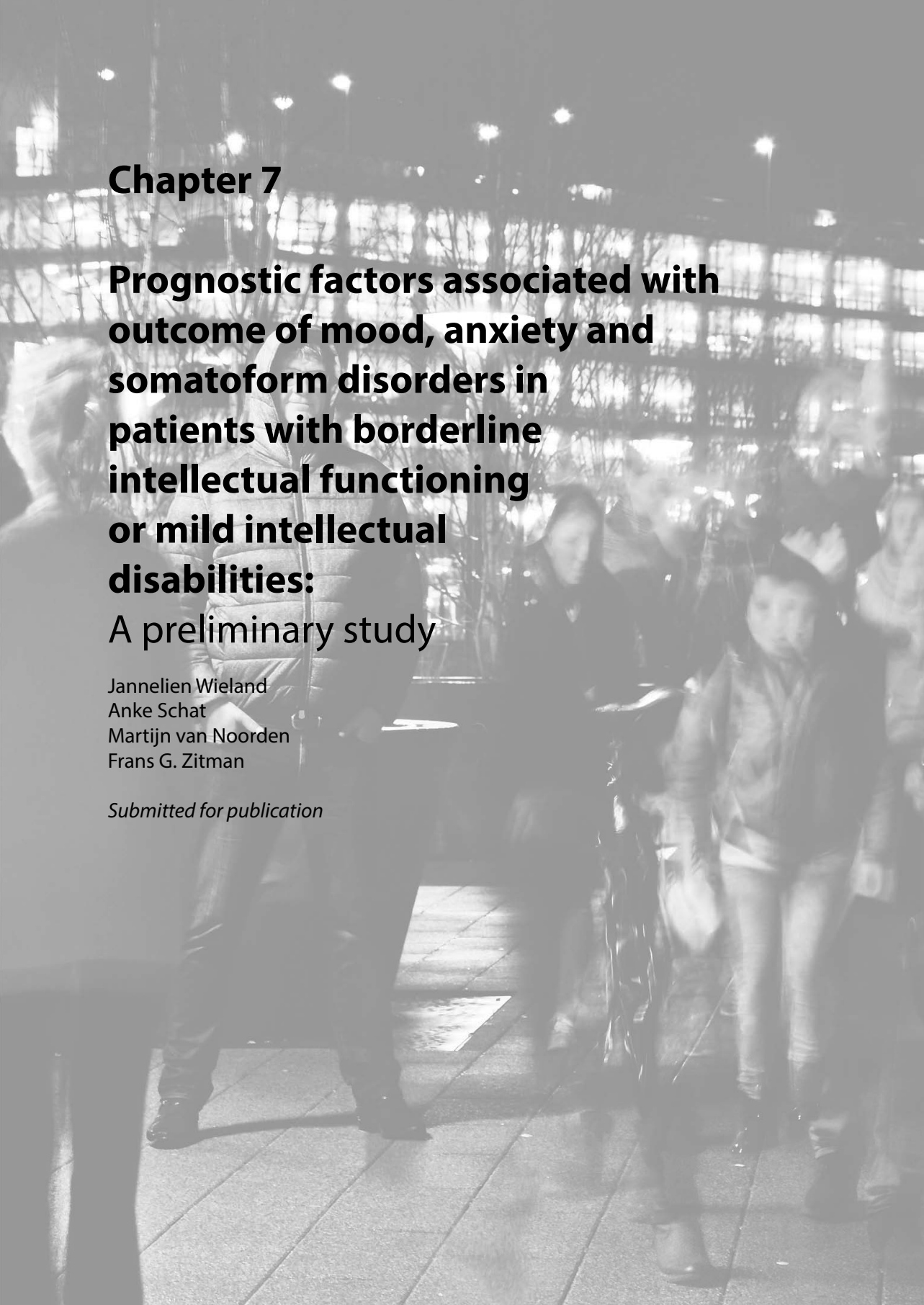
Conclusions

Even though people with BIF are at high risk of psychiatric disorders they represent an understudied patient group in mental health care. There is little research on the impact of BIF on the presentation, nature and severity of mental health problems and it is unclear to what extent general diagnostic and treatment guidelines are applicable to patients with BIF. Results of the present exploratory study imply that even though symptom profiles of patients with BIF and MDD or PTSD resemble those of both patients with higher and lower IQs, there might also be some characteristics unique to patients BIF. These unique characteristics have implications for diagnostics and treatment and separates patients with BIF as a group from both patients from RMHC and patients with mild ID.

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Chapter 7

Prognostic factors associated with outcome of mood, anxiety and somatoform disorders in patients with borderline intellectual functioning or mild intellectual disabilities:

A preliminary study

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Submitted for publication

Abstract

Introduction Mood, anxiety and somatoform (MAS) disorders are considered to be highly prevalent among people with borderline intellectual functioning (BIF) or intellectual disability (ID), but there has not been a wealth of published research. Treatment protocols of MAS disorders in patients with BIF or ID mostly do not differ from general treatment protocols. In nondisabled MAS outpatients, age and cluster B personality traits were found to be associated with an adverse treatment outcome in routine clinical practice. The aim of the present preliminary study was to explore whether gender, age, level of ID and cluster B personality disorders (PD) is associated with treatment outcome.

Methods We used a naturalistic cohort of 93 adult outpatients referred to one of the two centres for psychiatry and intellectual disabilities of Rivierduinen (a large regional mental health care provider in the Netherlands) between 2007 and 2012, with a follow-up of up to 2 years. Outcome was measured using the Brief Symptom Inventory. Cox regression models were used to analyse gender, age, level of ID and cluster B PD as prognostic factors associated with outcome.

Results Although we found no statistically significant differences, results suggest that there may be an associations between treatment result and gender, age and cluster B PD. Hazard Ratios could be interpreted as an indication that females, young adults and people with a cluster B PD, may respond less favourable to treatment. Having either BIF or mild ID did not seem to be associated with treatment response.

Discussion This study is a first exploration into the prognostic factors associated with outcome in outpatients with MAS disorders and either BIF or mild ID. Major limitation of the present study is the limited sample size. Future studies are needed to replicate these findings in larger samples and to identify other possible associated factors influencing outcome in MAS disorders and in other psychiatric disorders in patients with BIF or ID.

Introduction

Mood, anxiety and somatoform (MAS) disorders are considered to be highly prevalent among people with borderline intellectual functioning (BIF) (Total Intelligence Quotient (TIQ) 70-85) or mild intellectual disability (ID) (TIQ 50-70 and concurrent deficits or impairments in present functioning).¹⁻⁴ Both BIF and ID have been identified as risk factors for the development of MAS disorders in both men and women.^{3,5-7}

According to the normalized intelligence quotient (IQ) distribution, up to 15% of the population has a TIQ of 1 to 3 standard deviations (SD) below average, e.g. a TIQ of 50-85; BIF or mild ID. People with BIF or mild ID participate in society up to a great extent. For instance, they generally have work, have relationships, and in contrast to people with more severe ID (TIQ < 50) they have minimal care and have to fulfil high expectations. It is important to know how to treat MAS disorders in these patients and which factors are associated with treatment outcome in daily clinical practice.

However, even though MAS disorders are prevalent in patients with BIF and ID, there is no wealth of published research on the subject. There have only been a few clinical trials concerning the treatment of MAS disorders in patients with ID, using mainly self-report questionnaires is advocated but rare and there are no studies on the treatment of MAS disorders in BIF.⁸⁻¹⁰ In most countries, people with BIF are not considered a separate group in mental health care. BIF is not a focus of attention and patients are treated according to the same guidelines as patients with average or above average IQs. Likewise in daily clinical practice most treatment protocols in patients with MAS disorders and co-morbid ID do not differ from general treatment protocols.¹¹

We know most of these treatments to be evidence based in nondisabled (non-ID) patients, and we know that outcome in non-ID MAS outpatients in naturalistic settings is associated with a number of factors, among others whether someone is married and employed.¹²⁻¹⁵ In addition, a lower level of education¹⁶ and having a co-morbid personality disorder¹⁷⁻²¹ were associated with an adverse treatment outcome. To the best of our knowledge there are no published naturalistic studies on prognostic factors associated treatment outcomes in patients with either BIF or ID and MAS disorders. For patients with BIF or ID this means, when it comes to treating MAS disorders, there is a large group of patients being treated with uncertainty about the level of evidence of most of these treatments. And it is virtually unknown which factors predict the outcome of these treatments.

In a recent naturalistic cohort study of 892 regular mental health care (RMHC) outpatients with MAS disorders and a large independent replication cohort of 1392 RMHC outpatients from the Leiden Routine Outcome Monitoring (ROM) study, it was found that older age, MAS co-morbidity, a somatoform disorder and high scores on cluster B personality disorder traits (affective lability, intimacy problems and self-harm) were independently associated with poor treatment outcome.²²

The aim of the present preliminary study was to explore whether some of these factors were also associated with treatment outcome in a naturalistic cohort study of outpatients with MAS disorders and BIF or mild ID. Following the study of van Noorden et al.²² next to gender and age, we explored the association with treatment outcome of cluster B personality disorder (PD). Furthermore, because both BIF and ID are considered to be a risk factor for the development of MAS disorders, we explored level of ID, BIF versus mild ID, as a prognostic factor of treatment outcome.

Methods

Routine Outcome Monitoring

Routine Outcome Monitoring (ROM) is a method for the systematic collection of relevant treatment data, using reliable and valid assessment instruments.²³ The goal of ROM is to assess treatment effectiveness in naturalistic setting by collecting data about nature and severity of psychiatric symptoms in every day clinical practise. Primarily, ROM is intended to provide direct feedback on diagnoses and treatment results to the psychiatrist and the patient. Furthermore, ROM is used for benchmarking procedures and research purposes. If ROM data is used in research patient-identifiable data are removed from the database in order to secure patients' confidentiality. The use of these anonymised data for research purposes has been approved by the Ethical Review Board of the LUMC.

ROM is used for all outpatients referred for treatment of a MAS disorder to Rivierduinen (RD), a large regional mental health care provider in the Netherlands and the Leiden University Medical Centre. The Leiden ROM consists of an extensive psychometric battery of self-report and observer-rated measures administered at intake and at follow-up, every 3-4 months. In the two outpatient Centres for Psychiatry and Intellectual Disability (CPID) of RD (Kristal, Locations Leiden and Gouda) a much leaner ROM test-battery is administered, at intake and follow up every 4-6 months. ROM consists mostly of self-report questionnaires.

In the CPID, ROM-assessments are completed in an assisted fashion. Kellett et al.^{24,25} described this "assisted completion format" using the Symptom Checklist-90 (SCL-90; a widely used self-report instrument evaluating a broad range of psychological problems and symptoms of psychopathology²⁶ and concluded that the assisted completion format was shown not to influence respondents' ratings of symptoms excessively and did not affect the psychometric properties of the test.^{24,25} The assisted administration consists of the following: The assessment is conducted in a one-to-one setting. Both the instruction and the items of assessment instruments are either read together with the respondent or verbatim to the respondent. The answer feedback sheet contains both written and numerical representations. Patients with more severe ID (e.g. moderate to severe ID; TIQ < 50 and concurrent deficits or impairments in present adaptive functioning) are as a rule not included in ROM because there is no research

into reliability and validity of the self-report assessment instruments used in ROM in patients with more severe ID and because practical utility of these instruments these patients is unknown.

Patients

We used a cohort of adolescent and adult outpatients (aged 16 to 61) referred to one of the two CPID between 2007 and 2012. The cohort consisted of patients diagnosed with (a) MAS disorder(s) and either BIF or mild ID, who were included in ROM with at least one BSI. Flowchart of in- en exclusion is shown in figure 1. Diagnoses were the official diagnoses as recorded in the registration system of the electronic patient file, based on the *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision* (DSM-IV-TR). DSM-IV-TR diagnoses were formulated using the Diagnostic Manual-Intellectual Disability (DM-ID) criteria²⁷ and based on the integrative approach of Došen.^{28–30} The DM-ID provides guidelines for making accurate psychiatric diagnoses in patients with various levels of IDs and where necessary offers adaptations of DSM-IV-TR diagnostic criteria. The integrative assessment considers the developmental perspective as a fourth dimension, in addition to the three dimensions of the bio-psychosocial model. Patients were assessed multidisciplinary by at least an experienced psychiatrist, an experienced mental health psychologist and an experienced psychiatric community worker.

Level of intellectual functioning was based on IQ testing, using the Wechsler Adult Intelligence Scale (WAIS-III-NL).^{31–33} Based on DSM-IV-TR criteria participants were divided into two groups: BIF and mild ID. Psychiatrists and mental health psychologists of the CPID provided treatment according to Dutch evidence-based treatment guidelines; adapted where needed (preferably evidence-based and otherwise practice-based) to the special needs of patients with BIF or ID. Treatment consisted mainly of psychotherapy, pharmacotherapy or a combination of both, often together with treatment supporting management. The goal of this treatment supporting management is to facilitate, among others, psycho-education, therapy adherence, generalization and crisis management.

The predictive value of baseline, treatment-independent patient characteristics were the focus of the present analyses. Therefore management, treatment and therapist characteristics were not taken in to account.

Assessment of outcomes

Primary outcome for the present study was severity of psychopathological symptoms assessed at baseline and follow-up using our main screener for psychopathology and general outcome measure the BSI.²⁶ The BSI is essentially the brief form of the SCL-90-R.^{34,35} It is a self-report (or interview administered) symptom scale consisting of 53 items, covering nine symptom dimensions: *Somatisation* (SOM), *Obsession-Compulsion* (O-C), *Interpersonal Sensitivity* (I-S), *Depression* (DEP), *Anxiety* (ANX), *Hostility* (HOS),

Phobic anxiety (PHOB), *Paranoid ideation* (PAR) and *Psychoticism* (PSY). Rankings characterize the intensity of distress during the past seven days.

Each item is ranked on a 5-point Likert scale ranging from 0 (not at all) to 4 (extremely). Scores can be calculated for the nine symptom dimensions and for 3 global indices of severity of psychopathology: The average score on all 53 items together, the number of items with non-zero responses (or: the number of symptoms experienced by the respondent) and the severity of the existing symptoms (or: the total score divided by the number of symptoms experienced by the respondent).³⁶ Several studies support the use of the BSI in patients with BIF and mild ID.^{25,37,38} The BSI has adequate internal to excellent internal consistency with Cronbach's alphas ranging from the Dutch BIF or mild ID population from 0.70 to 0.96.³⁸ Using normal varimax rotation Kellett et al.³⁷ derived 8 interpretable factors. Confirmatory factor analysis showed that the underlying structure of the BSI could be described by the same 9-factor structure of the original BSI.³⁸ Response was defined as at least 50% improvement on the BSI.^{22,39}

Prognostic factors of 2-year outcome

Because of the limited number of patients in our cohort we could only explore a small number of prognostic factors. Following the results from the naturalistic cohort study of Van Noorden et al.²² in two large cohorts of non-ID MAS outpatients and knowing that ID is considered a risk factor for the development of MAS disorders, the prognostic factors taken into account were gender, age, level of ID and cluster B PD.

Because the transition from late adolescence into young adulthood is seen as a high-risk developmental period in BIF and mild ID^{40,41}, age was divided into young adults (age < 24), adults (age 24–40) and older adults (age > 40). Level of ID was divided into borderline intellectual functioning and mild ID.⁴² Cluster B PD consist of antisocial PD, borderline PD, histrionic PD and narcissistic PD.⁴² In the analyses, presence of cluster B PD was dichotomous variable.

Statistical analysis

Baseline characteristics are presented as number and percentage (categorical variables). or as mean ($\pm$ SD) together with the interquartile range (IQR) (continuous variables). In- and excluded patients were compared on gender, age, level of ID, prevalence of cluster B PD and baseline total BSI using chi-square for the categorical variables gender and cluster B PD and independent samples t-test of the continuous variables age and baseline total BSI.

Follow-up was censored at 24 months. Because the exact point in time of achieving response is unknown, the moment of response was defined as the midpoint between the assessment at which response was registered and the assessment before that one. Associations between time to response and the predictor variables gender, age, level

of ID and cluster B PD were examined with Cox proportional hazards analysis. Univariate hazard ratios (HR) and 95% confidence intervals (CI) for response (50% improvement relative to baseline scores on the BSI) were computed for baseline categorical and continuous predictor variables. Kaplan-Meier survival curves were constructed for all variables. Kaplan-Meier analysis was used to calculate the percentage of cumulative response in the total sample, the median duration of follow-up was assessed using the reverse Kaplan Meier method.⁴³ All tests were two-tailed with $p < 0.05$ denoting statistical significance. IBM SPSS for Windows 19.0 was used for data analysis (IBM Corp. Armonk, NY).

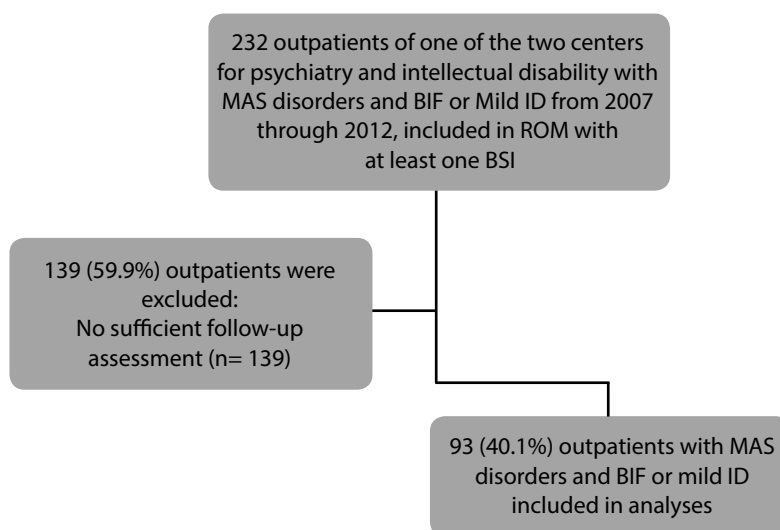


Figure 1. Flowchart of inclusion and exclusion.

MAS= Mood, Anxiety and Somatoform. ROM= Routine Outcome Monitoring. BIF= borderline intellectual functioning. ID= intellectual disabilities. BSI= Brief Symptom Inventory

Results

Sample and demographic characteristics

From 2007-2012, 232 patients diagnosed with one of more MAS disorders and BIF or mild ID, were included in ROM with at least one BSI. A total of 139 patients were excluded because they did not have (sufficient) follow-up assessment. A total of 93 outpatients (40.1%) were included in the analyses. There was no difference between the included and excluded patients in the presence of the different MAS disorders and co-morbidity ($p = 0.46$), the level of ID ($p = 0.16$), age ($p = 0.49$), prevalence of cluster B PD ($p = 0.18$) and total BSI score ($p = 0.50$) at baseline. There was a trend towards

significance for gender (24.7% men in the included group versus 35.5% in the excluded group; $\chi^2 = 3.57$, $p = 0.06$).

Baseline sample characteristics, including predictor variables and DSM-IV-TR diagnoses of the 93 patients included in the study are presented in table 1. The majority of the cohort consisted of females (75,3%). Mean age was 32.9 (SD= 12.1). Most patients had BIF (68.8%). Mild ID was present in 31.2% of the sample. A single anxiety disorder was the most common MAS disorder (54.8%). A single mood disorder was prevalent in 18.3% of the sample. Single somatoform disorders were seen in 7.5% of the sample. MAS comorbidity was present in 19.4% of the sample.

Table 1. Baseline characteristics of 93 outpatients diagnosed with a MAS disorders.

Categorical variables	n	%
Female gender	70	75.3
Single DSM-IV-TR Mood disorder	17	18.3
Single DSM-IV-TR Anxiety disorder	51	54.8
Single DSM-IV-TR Somatoform disorder	7	7.5
MAS comorbidity	18	19.4
Cluster B PD co-morbidity	12	12.9
Comorbid Alcohol abuse or dependence	6	6.5
Comorbid Drug abuse or dependence	1	1.1
BIF (TIQ 70-85)	64	68.8
Mild ID (TIQ 50-70 and concurrent deficits or impairments in present functioning)	29	31.2
Continuous variables	Mean (SD)	IQR
Age	32.9 (12.2)	21.5-42
BSI Total score	1.35 (0.69)	0.82-1.85

DSM-IV-TR= Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (Text Revision).

MAS= mood, anxiety and somatoform. PD= personality disorder. BIF= borderline intellectual functioning.

ID= intellectual disability. TIQ= total intelligence quotient. BSI= Brief Symptom Inventory.

SD=standard deviation. IQR= inter quartile range

Univariate prognostic factors of response

The median follow-up was 504 days (IQR = 278-730). At 2 years, 35 patients (37.6 %) had reached an endpoint, 15 patients (16.1%) still continued treatment. Gender, age, level of ID and having a cluster B PD as predictors of response are shown in Table 2.

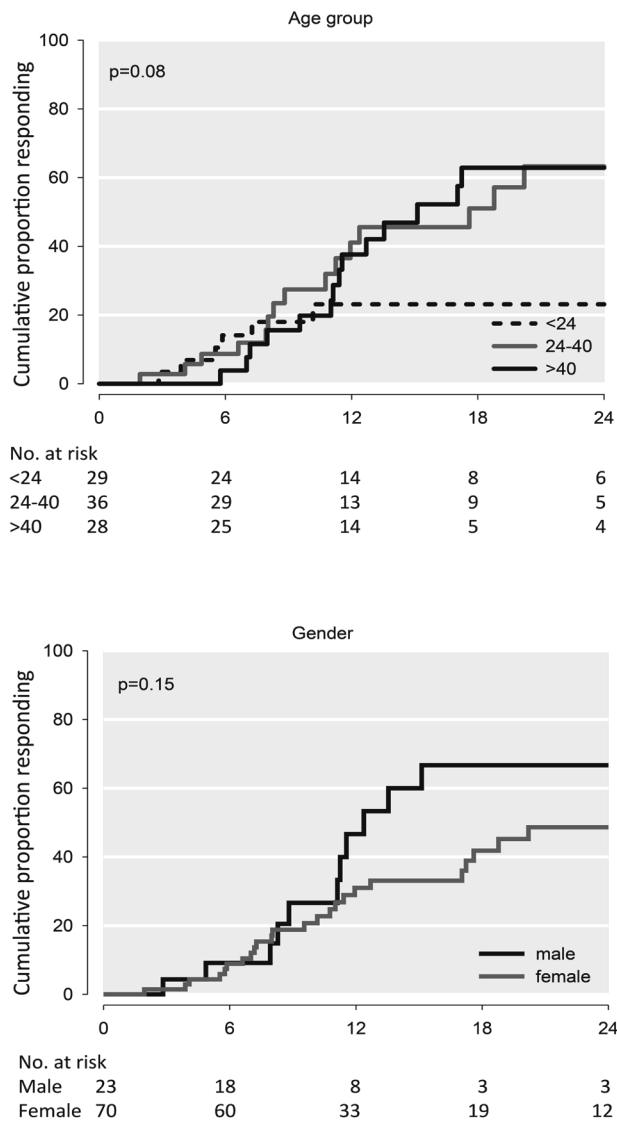
Table 2. Univariable hazard ratios of response according to the baseline predictor variables age, gender and cluster B personality disorders of 93 patients with MAS disorders and borderline intellectual functioning or mild to moderate intellectual disabilities.

Predictor variables (categorical and continuous)	HR (95% CI)	p-value
Gender		
Female	1.00	
Male	1.69 (0.83-3.46)	0.15
Age		
> 39 years	1.00	
24-39	0.99 (0.5-2.0)	0.98
< 24 years	0.43 (0.16-1.1)	0.08
Level of ID		
BIF	1.00	
Mild ID	0.87 (0.44-1.7)	0.99
Cluster B PD	0.21 (0.03-1.5)	0.12

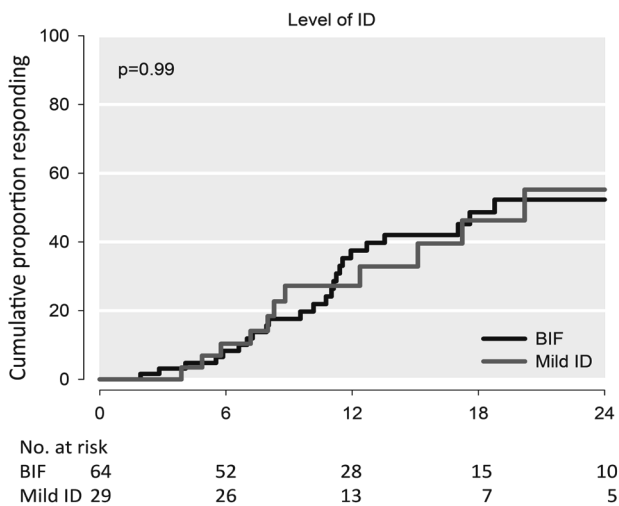
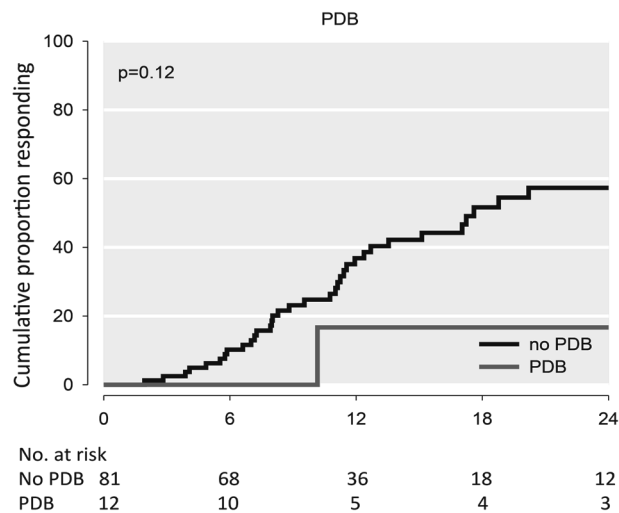
MAS= mood, anxiety and somatoform. HR= Hazard Ratio. CI= confidence interval. BIF= borderline intellectual functioning. ID= intellectual disability. PD= personality disorder. Response was defined as $\geq 50\%$ reduction on the Brief Symptom Inventory

HR's for response over the 2-year follow-up were 1.69 (95% CI 0.83-3.46) for the male gender, 0.43 (95% CI 0.16-1.1) for young adults, 0.87 (95% CI 0.44-1.7) for mild ID and 0.21 (95% CI 0.03-1.5) for cluster B PDs. Results failed to reach statistical significance, indicating reliability of findings is insufficient to meet the criterion of $p < 0.05$.⁴⁴ However, the magnitude of the differences between groups could be interpreted as an indication that a difference in treatment response between the groups for gender, age and cluster B PD might exist. Analyses should be repeated in a larger sample in order to gain more reliable results. Level of ID (BIF versus mild ID) does not appear to be a predictor of treatment outcome. Figure 1 shows the Kaplan-Meier survival curves for the predictors gender, age, level of ID and cluster B PDs of naturalistic treatment response over the 2-year period of follow-up.

Figure 2. Kaplan Meier curves for response according to the baseline predictor variables age, gender and cluster B personality disorders of 93 patients with MAS disorders and borderline intellectual functioning or mild intellectual disabilities.



Continuation Figure 2.



PDB= cluster B personality disorders. BIF= borderline intellectual functioning.
ID= intellectual disabilities

Discussion

This study is a first exploration into the prognostic factors associated with outcome in outpatients with MAS disorders and either BIF or (mild) ID. The results suggest that there may be an associations between treatment result and gender, age and cluster B PD. The confidence intervals of our results were wide and included 1, but HRs could be interpreted as an indication that females, young adults and people with a cluster B PD, may respond less favourable to treatment. Level of ID did not play a role.

In the Leiden Routine Outcome Monitoring Study, Van Noorden et al.²² found no difference in treatment effect between males and females in a naturalistic psychiatric outpatient setting of non-ID MAS disorder patients. Older age and several cluster B PD traits (affective lability, intimacy problems and self-harm) were associated with poor outcome. However, their study did not include patients with BIF or mild ID.

To our knowledge, this study is the first study on prognostic factors associated with treatment outcome in outpatients with MAS disorders and co-morbid BIF or mild ID. Strengths of this study lie in the well-defined patient group with MAS disorders and the carefully applied label of BIF and mild ID using extensive IQ testing. Another strength is the use of ROM and the use of a proven reliable en valid self-report questionnaire, the BSI.

Apart from the relatively small sample size, which limited the numbers of prognostic factors that could be explored, this study had several potential limitations. The design may be subject to selection bias. The CPID of RD treat patients with all levels of intellectual disability, but patients with more severe ID (e.g. moderate to severe ID) are mostly not included in ROM. Also, because ROM had a working-up phase there was a loss in follow-up during the first years after the start of data collection. Referral pathways are well established and there is a focus on patients with BIF as a separate group. Referral of patients with BIF and psychiatric disorders to specialized mental health care is the default procedure. Even so there might be patients with (unknown) higher IQs in the BIF range in regular mental health care. This means that patients included in ROM might differ from patients not included in ROM. Second, as in other naturalistic studies involving ROM^{22,39}, attrition is high and even though we know that this is at least in part due to absence of follow-up in the ROM implementation phase, we do not know the reasons for loss to follow-up in later stages during the study. Third, treatment consisted of either psychotherapy, pharmacotherapy or a combination of both, following existing guidelines from regular psychiatry and our own adapted care programs, but we did not include information on the specific types of treatment. Fourth, the BSI may not be specific enough to fully capture clinical changes in all MAS disorders. Even though they were not very prevalent, this might especially hold true for somatoform disorders.⁴⁴ Finally, due to the design of the study exact point of response could not be inferred and patients who did not reach the response criteria in 2 years were labelled as non-responders. Also possible relapse after initial response was not taken into account.

In summary, this study is a first exploration into the prognostic factors associated with outcome in outpatients with MAS disorders and either BIF or mild ID. Even though CI's were wide and all included 1, HR's seem could be interpreted to indicate that being female, being a young adult and having a cluster B PD is associated with decreased chances of treatment response. Having either BIF or mild ID does not seem to be associated with treatment response. Since in our CPID the same essential treatment protocols are used but adapted to level of cognitive functioning, this might mean that when patients are treated according to their cognitive abilities, it does not matter for treatment outcome whether they have BIF or mild ID.

Future studies are needed to replicate these findings in larger sample sizes and to identify other possible associated factors influencing outcome in MAS disorders and in other psychiatric disorders in patients with BIF or an ID. In the absence of further data, the results suggest that practitioners should be aware that patients with the characteristics mentioned above need extra attention.

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Chapter 8

Summary, general discussion and conclusions



Summary and main findings

The aim of this thesis was to explore prevalence of psychiatric disorders and nature and severity of psychiatric symptoms of outpatients with borderline intellectual functioning (BIF) in mental health care.

Chapter 2 provides an overview of the concept of BIF and its place in past and present DSMs and other classification systems like ICD. In the history of the DSM, BIF had different names and different boundaries and the classification BIF travelled through earlier DSMs until it literally ended in last place in DSM-5. IQ test scores, the last criterion left in the classification of BIF in the DSM-IV, are removed from the diagnostic description in DSM-5, leaving the concept without a clear definition.

In our overview we describe the importance of a well-defined classification and renewed regard to the concept of BIF. People with BIF, or an IQ between 70 and 85, are a vulnerable group both in society and in mental health care. At the same time, they present a largely hidden patient population. People with BIF are rarely identified in general mental health care and almost invisible in research.

Chapter 3 describes the results of a cross-sectional anonymized medical chart review among patients from the Dutch regional mental health care provider Rivierduinen. The aim of the study was to explore the rates of different axis I psychiatric disorders in outpatients with BIF, in order to learn more about psychiatric morbidity of patients with BIF in comparison to patients from regular mental health care (RMHC) (i.e. not selected on IQ), and patients with mild intellectual disabilities (ID).

Official DSM-IV-TR axis I diagnoses as they were registered in the electronic patient file were compared among 235 patients with BIF, 152 patients with mild ID and 1026 patients from RMHC. All three groups consisted of outpatients registered on January 1st 2011.

Results show that depressive and psychotic disorders were less common classifications in psychiatric outpatients with BIF compared to outpatients from RMHC. PTSD and V-codes were more common. Compared to outpatients with mild ID, psychotic disorders were significantly less common.

In **chapter 4** the rates of all DSM-IV-TR axis II diagnoses of personality disorder (PDs) were compared among the same 235 outpatients with BIF, 152 outpatients with mild ID and 1026 outpatients from regular mental health care.

We found that the rate of PD diagnoses in outpatients with BIF in daily clinical practice was very high (52.8%) compared to both outpatients from RMHC (19.3%) and outpatients with mild ID (33.6%). PD not otherwise specified (NOS) and borderline PD were the most frequently diagnosed PDs in outpatients with BIF. In all three groups the vast majority of outpatients diagnosed with a PD had one or more

co-morbid axis I disorder. Mood, Anxiety and Somatoform (MAS) disorders were the most prevalent axis I disorders in all three groups.

Chapter 5 presents the results of a study into the utility of the Brief Symptom Inventory (BSI) in psychiatric outpatients with BIF or mild ID. The BSI is a widely used standardised self-report questionnaire in general psychiatry. It can be used across a wide range of symptoms and diagnoses and can be applied across different therapeutic interventions. It is one of the primary screeners and general psychopathology outcome measures of ROM in regular mental health care.

All participants in this study were new patients of the two CPID of the regional mental health care provider Rivierduinen between April 1st 2008 and October 1st 2009. In total, 224 psychiatric outpatients with either BIF or mild ID participated. The BSI was used in an assisted fashion and for part of the sample ($n = 43$) a list of 'difficult items' was kept. The assisted fashion meant that participants were always aided by a mental health care professional, were needed, in completing the self-report questionnaire. A question was considered difficult when it was not completely or properly understood. Internal consistencies were good to adequate, ranging from 0.70 – 0.96. Subscale intercorrelations showed differentiation between the subscales. Discriminant validity was shown for the subscales *Depression*, *Anxiety* and *Phobic Anxiety*. Confirmatory factor analysis showed that the underlying structure of the BSI could be described by the same 9-factor model as reported in previous studies. It was concluded that the BSI is a useful screener and general outcome measure for psychopathology in people with BIF or mild ID.

There is little available research on the impact of BIF on presentation, nature and severity of co-morbid psychiatric disorders. Therefore, the aim of the study described in **chapter 6** was to explore, in a naturalistic outpatient setting, BSI symptom profiles of patients with BIF diagnosed with a primary diagnosis of either major depressive disorder (MDD) or posttraumatic stress disorder (PTSD) to patients from RMHC and patients with mild ID diagnosed with the same disorders. We used a cohort of outpatients (aged 16 to 88) referred to either one of the centres for RMHC or one of the two CPID between 2007 and 2012. The sample consisted of patients with a primary diagnosis MDD or PTSD, who were included in ROM with at least a baseline BSI. All outcomes were adjusted for gender and age. Results showed that compared to patients from RMHC, BIF patients with a primary diagnosis MDD reported less severe symptoms on *BSI Total* and the subscales *Depression*, *Obsession-Compulsion* and *Psychoticism*. There were no statistically significant differences in reported symptom severity on *BSI Total* and the different BSI subscales between BIF patients with PTSD and either patients from RMHC or patients with Mild ID. Patients Mild ID, did report significantly less severe symptoms on the subscale *Depression* and on the subscale *Psychoticism* than patients from RMHC.

Since there were no other published studies into symptom profiles in patients with BIF compared to either patients with higher or lower levels of cognitive functioning, the study was mainly exploratory in nature.

Last, **chapter 7** offers the results of a preliminary study exploring the association between gender, age, level of ID and cluster B PD to treatment outcome in outpatients with mood, anxiety and somatoform (MAS) disorders. We used a naturalistic cohort of 93 adult outpatients referred to one of the two CPID of Rivierduinen between 2007 and 2012, with a follow-up of up to 2 years. Outcome was measured using the BSI. Gender, age, level of ID and cluster B PD were analysed as prognostic factors of outcome using Cox regression. Although confidence intervals were wide and included 1, based on hazard ratios (HRs) the results suggest that there may be associations between treatment result and gender, age and cluster B PD. Hazard Ratios could be interpreted as an indication that females, young adults and people with a cluster B PD, may respond less favourable to treatment. Having either BIF or mild ID did not seem to be associated with treatment response. Future studies in larger samples are needed to replicate these findings and identify other possible associated factors influencing treatment outcome.

General discussion

In mental health care, up until now, there has not been much regard for BIF. In research BIF is almost invisible. This is striking, since BIF actually represents a large minority in both society and mental health care. This thesis examines psychiatric disorders and the nature and severity of psychiatric symptoms of outpatients with BIF in mental health care for the first time. Also novel is the comparison of outpatients with BIF to both patients from RMHC and patients with mild ID. Being able to identify and compare these different patient groups is important because of the possible implications for specific attention and/or adaptation of diagnostic and treatment programs.

In this thesis we showed that patients with BIF in secondary outpatient mental health care have a different mix of psychiatric disorders than patients in regular mental health care and patients with mild ID. This is important knowledge in the organisation of mental health care for this patient group. A high percentage of patients with PTSD implies a need for well trained EMDR therapists, coached in using these techniques in patients with low IQs. A high rate of PD signifies a need for adapted therapies. Currently used therapies in general mental health care, like Dialectical Behaviour Therapy (DBT)^{e.g.1} and Mentalisation Based Therapy (MBT)^{e.g.2,3} are heavily cognitively based and require a level of abstraction that is too difficult for most people with low IQs. For patients with BIF, treatment needs to be more concrete with smaller treatment steps, containing more repetitions and with more attention to generalisation. The two CPID have adapted programs for stabilisation and EMDR. For BIF patients with PD

a customised emotion regulation treatment and skills training was developed.⁴ An important outcome of this thesis is the feasibility of the BSI in patients with BIF and mild ID. For one, routine outcome monitoring (ROM) has become an important part of mental health care. The use of ROM in patients with low IQs ($TIQ < 85$) however was lagging behind because there has been a lack of psychometrically tested self-report questionnaires. Self-report questionnaires are an important part of ROM. They are also important for patients with BIF and mild ID, especially for mapping more internalising psychopathology. Demonstrating the utility of the BSI contributed to the development of ROM for patients with low IQs. Meanwhile ROM has become an important part of specialised mental health care throughout the Netherlands and the BSI has become an important screener and outcome measure in several specialised mental health care facilities.

Secondly, by using the same questionnaires in both people with higher and lower IQs, it allows for examining similarities and differences in nature and severity of symptoms, treatment effect and for instance efficacy of different treatments among patients functioning at different cognitive levels in daily clinical practice. In this thesis we explored some of these possibilities by comparing BSI symptom profiles among patients with BIF, patients from RMHC and patients with mild ID, diagnosed with either MDD or PTSD. We also explored possible predictors associated with treatment outcome in patients with lower IQs. Results so far show that patients with BIF do not differ widely from either patients in RMHC or patients with mild ID, but there might be some aspects unique to patients with BIF that need to be further investigated and might have clinical implications.

Strong point of this thesis is the fact that all IQs of patients in the two CPID were assessed using a standardised IQ test.⁵⁻⁷ Therefore the label of either BIF or mild ID was always carefully applied. The classification of BIF, used in this thesis, is the classification of the V-code BIF as it is formulated in the Diagnostic and Statistical Manual of Mental Disorders, revised 4th edition (DSM-IV-TR). In daily clinical practise next to IQ level, in the CPID the developmental perspective is always taken into account, including social and emotional development and level of adaptive functioning in interpreting psychiatric symptoms and classifying psychiatric disorders.⁸⁻¹¹

Major limitation in the present study is the limited visibility of BIF in mental health care. Even though Rivierduinen has two special CPID, and referral pathways are well-established, referral still depends on recognition. It is unknown how many individuals with unidentified BIF are treated in regular psychiatric services and to what extent and with respect to which characteristics the group referred to the CPID is a selection. Based on prevalence of BIF in the general population and increased risk of for the development of mental health problems prevalence of BIF in mental health care is probably higher than generally assumed. Furthermore, results in this thesis come from studies done in secondary specialised mental health care; results cannot evidently be generalized to other patient groups or the general population.

Another limitation is the fact that, although they were made multidisciplinary and integrative, psychiatric diagnoses were mostly clinical diagnoses and not based on a structured interview. The reason can be found in the lack of existing valid and reliable assessment instruments for people with BIF. The Mini International Neuropsychiatric Interview (MINI)¹², used to establish psychiatric diagnoses in ROM in general mental health care, does not fit in with the cognitive abilities of people with low IQs. Questions in the MINI are made up of long compound sentences. Also the MINI relies heavily on memory and the ability to estimate timelines. All demands that are quite difficult to meet for most people with low IQs. Psycho-diagnostic instruments developed for people with ID, were not readily available.¹³ As yet, there is no psycho-diagnostic instrument available that can be used in both people with higher and lower IQs. The size of the study population unfortunately was limited. The two CPID are small and treat a vast variety in clinical diagnoses. Establishing a sufficiently homogeneous research population proved to be difficult. Also, time and funds were limited during the course of this thesis. Cutbacks in mental health care shifted focus to the primary process of treatment, leaving little time and resources for care development and research. Last, because of largely absent previous research, studies in the present thesis were largely exploratory in nature.

General conclusions and recommendations for further research

Results from the studies in this thesis show that it is possible to focus on BIF as a separate group in mental health care. Focusing on BIF in mental health care is important because people with BIF represent a large minority that up until now has not been well addressed.

According to the Dutch Social Cultural Research Institute¹⁴ about 2.2 million people in the Netherlands have an IQ between 70 and 85. In their report “Care better understood”,¹⁴ the Dutch Social Cultural Research Institute concludes that care needs of people with BIF have increased six fold between 1998 and 2011.¹⁴ Social developments like reduced availability of simple work, higher demands in education and increasing digitisation are main explanations for this growth in care needs. Nonetheless, despite or maybe because of increasing care demands, the Dutch government decided to become more reticent in the delivery of specialised care to people with BIF. This limits possibilities of preventive care increasing the risk of not only psychosocial and health problems but especially the development of psychiatric disorders.

Often patients with BIF present in mental health care with a combination of problems in cognitive, social-emotional and adaptive function, multiple complex psychiatric disorders and a mix of psychosocial problems. In order to adequately address this complex interaction of BIF, psychiatric disorders and psychosocial problems, active detection of BIF in mental health care is essential. Professionals should be trained in recognizing BIF and in the extra communication and practical skills needed to diagnose and treat psychiatric disorders in patients with BIF.^{e.g.15}

To develop affordable stepped care that fits in with the possibilities and limitations of psychiatric patients with BIF, future research should focus on diagnostics of psychiatric disorders in patients with BIF and investigate treatment programs on utility and effectiveness of care tailor-made for the large minority of mental health care patients that have gone unnoticed for far too long.

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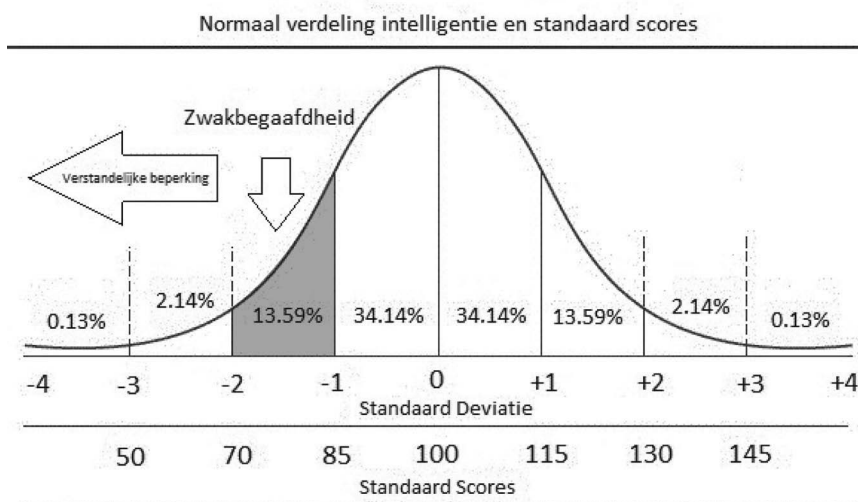
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Nederlandse samenvatting



Zwakbegaafdheid

Dit proefschrift gaat over psychiatrische stoornissen bij mensen met zwakbegaafdheid. Met zwakbegaafdheid bedoelen we een niveau van intellectueel functioneren dat lager is dan bij 'normale' of gemiddelde intelligentie en hoger dan bij een verstandelijke beperking. Dat is het beste uit te leggen met behulp van de normaalverdeling van intelligentie (zie figuur 1). Een verstandelijke beperking wordt gedefinieerd als een intelligentie quotiënt (IQ) van 2 of meer standaard deviaties (SD) onder het gemiddelde van 100 op de normaalverdeling. Zwakbegaafdheid wordt gedefinieerd als een IQ tussen 1 en 2 SD onder het gemiddelde. Grofweg komt dit overeen met een IQ op een gestandaardiseerde IQ test tussen 70-85. Volgens de normaalverdeling valt 13,59% van de bevolking in deze categorie; ofwel meer dan 2 miljoen Nederlanders.



Figuur 1. Normaalverdeling van intelligentie in de algemene bevolking. Intelligentie quotiënt (IQ) is een score zoals die behaald wordt op een gestandaardiseerde test ontworpen om menselijke intelligentie te meten. De mediane ruwe score van de normatieve steekproef wordt gedefinieerd als een IQ van 100. Elke standaarddeviatie (SD) naar boven of beneden staat gelijk aan 15 IQ punten. Door deze definitie scoort ongeveer tweederde van de bevolking een TIQ tussen 85 en 115. Zwakbegaafdheid wordt gedefinieerd als een IQ tussen 1 en 2 SD onder het gemiddelde (IQ 70-85) en verstandelijke beperking wordt gedefinieerd als een IQ van 2 SD of meer onder de gemiddelde (IQ < 70).

Zwakbegaafde mensen vallen niet op in de maatschappij. Ze zijn niet makkelijk te herkennen aan bepaalde uiterlijke kenmerken, persoonlijkheidstrekken of gedrag. Ze proberen over het algemeen juist angstvallig om hun beperking te verbergen en 'normaal' te zijn. En dit lukt hen over het algemeen heel goed. Als mensen hun zwakbegaafd-

heid goed weten te verbergen helpt dit hen om zich te handhaven in de maatschappij. Maar de keerzijde is dat deze mensen altijd op hun tenen moeten lopen. Dit maakt hen kwetsbaar en verhoogt het risico op het ontstaan van psychische problemen en psychiatrische stoornissen. Dat dit zo is, is ook aangetoond in onderzoek. Toch lijkt het er op dat zwakbegaafde mensen minder vaak behandeld worden voor hun psychische problemen. En als ze al behandeld worden krijgen ze vaker medicatie en minder vaak psychotherapie. Daar komt bij dat ze vaak te hoog ingeschat worden. Ze krijgen dan een uitleg over ziekte en behandeling die voor hen te ingewikkeld is.

In dit proefschrift wordt onderzoek beschreven naar de aard en ernst van psychische symptomen en psychiatrische stoornissen bij mensen met zwakbegaafdheid die in verband met ernstige psychische klachten verwezen werden naar een gespecialiseerd centrum waar zwakbegaafdheid een specifiek aandachtspunt is.

Zwakbegaafdheid als diagnostische categorie

Zo eenvoudig als we net zwakbegaafdheid hebben uitgelegd is de diagnostiek ervan helaas niet. Zwakbegaafdheid is natuurlijk veel meer dan alleen een 'slechte score' op een IQ test. Maar om precies uit te leggen wat zwakbegaafdheid dan wel inhoudt, is ook moeilijk. Zwakbegaafdheid is altijd een ingewikkeld begrip geweest. In de verschillende edities van de *Diagnostic and Statistical Manual of mental disorders* (DSM), het meest gebruikte classificatiesysteem voor psychiatrische aandoeningen, heeft de classificatie zwakbegaafdheid in één of andere vorm altijd een plek gehad. Maar de classificatie heeft onder verschillende namen en op verschillende plekken in de DSM gestaan. Zo was zwakbegaafdheid, toen lichte mentale retardatie genoemd, in de eerste edities van de DSM de lichtste vorm van wat we nu een verstandelijke beperking noemen. Het was dus een stoornis. Vanaf de derde editie van de DSM, DSM III, werd zwakbegaafdheid niet langer gezien als het hoogste niveau van wat ze toen zwakzinnigheid noemden. Deze plek werd nu ingenomen door lichte zwakzinnigheid (IQ 50-70). Later is dit lichte verstandelijke beperking gaan heten. Zwakbegaafdheid werd vanaf die tijd een zogenoemde V-code. V-codes worden gebruikt voor andere problemen of aandoeningen die in verband staan met een in de DSM beschreven psychische stoornis. Dat zwakbegaafdheid een V-code werd, betekende dat het niet langer beschouwd werd als stoornis. Immers, V-codes worden in de DSM gedefinieerd als 'bijkomende problemen die een reden voor zorg kunnen zijn'. Het gaat dus niet om stoornissen. Daar komt bij dat de IQ-grenzen (en dus de criteria) van de classificatie meerdere malen zijn aangepast. Wat het extra lastig maakt is dat er in de nieuwste versie van de DSM, de DSM-5, helemaal geen IQ grenzen meer gegeven worden voor zwakbegaafdheid. Daarmee is het nog moeilijker geworden om zwakbegaafdheid goed te classificeren. Nu zwakbegaafdheid niet meer in het lijstje voorkomt met de niveaus van ernst van verstandelijke beperking en zelfs geen duidelijke criteria meer heeft, lijkt het wel alsof de classificatiesystemen van psychische stoornissen samenzweren met zwakbegaafde

mensen om hun psychische problemen te verbergen. Daarom is het niet verwonderlijk dat er weinig aandacht is voor zwakbegaafdheid als bijkomende diagnose bij andere psychiatrische stoornissen.

Specialistische zorg voor zwakbegaafde psychiatrische patiënten

In de meeste landen worden zwakbegaafde mensen in de geestelijke gezondheidszorg (GGZ) niet als aparte groep gezien. Ze worden behandeld in de ‘reguliere’ GGZ. Bijzonder in Nederland is het feit dat mensen met een IQ tussen 70 en 85, zwakbegaafdheid, wél in aanmerking komen voor behandeling in gespecialiseerde centra voor psychiatrie en verstandelijke beperking.

Helaas wordt zwakbegaafdheid dan vaak niet expliciet benoemd maar worden de zwakbegaafde patiënten samengevoegd met patiënten met een lichte verstandelijke beperking tot één groep met de naam Licht Verstandelijk Gehandicapten (LVG), of -tegenwoordig- Lichte Verstandelijke Beperking (LVB). Hiermee wordt dus een grotere groep mensen bedoeld dan de mensen volgens de classificatie van de DSM een lichte verstandelijke beperking hebben.

Rivierduinen, een grote regionale GGZ aanbieder in de Randstad, heeft een gespecialiseerd centrum voor mensen met psychiatrische stoornissen en een verstandelijke beperking met de naam Kristal Centrum Psychiatrie en Verstandelijke Beperking. Kristal heeft twee locaties; één in Leiden en één in Gouda. Kristal biedt integratieve multidisciplinaire diagnostiek en behandeling voor psychiatrische patiënten met een $IQ < 85$. Bij Kristal wordt gewerkt vanuit het ontwikkelingsperspectief. Dit betekent dat er in de diagnostiek en behandeling van psychiatrische stoornissen niet alleen rekening wordt gehouden met het IQ, maar ook met de sociale en emotionele ontwikkeling en het niveau van adaptief functioneren. Omdat de in verstandelijke beperking gespecialiseerde centra van Rivierduinen bij alle patiënten een IQ bekend is, kunnen we bij deze gespecialiseerde centra wél onderscheid maken tussen zwakbegaafdheid en een lichte verstandelijke beperking.

Gedurende de 10 jaar van haar bestaan heeft Kristal veel klinische ervaring opgebouwd met het diagnosticeren en behandelen van psychiatrische stoornissen bij patiënten met een laag IQ. Het diagnostisch proces en de behandeling van Kristal zijn aangepast aan de cognitieve, sociaal-emotionele en adaptieve vaardigheden van patiënten met een IQ onder de 85 en beschreven in een eigen zorgprogramma “Psychiatrie en Verstandelijke Beperking”.

Routine Outcome Monitoring

Binnen de geestelijke gezondheidszorg willen wij graag het effect van de behandeling volgen. Om die reden worden voor, tijdens en na de behandeling de klachten en problemen van de patiënt gemeten met behulp van vragenlijsten. Het herhaald meten van klachten en problemen wordt *Routine Outcome Monitoring* (ROM) genoemd.

De resultaten van deze ROM-metingen worden door de behandelaar met de patiënt besproken. Door het vergelijken van resultaten op verschillende meetmomenten kunnen patiënten zien welke klachten en problemen verbeteren en welke niet. Indien nodig kan de behandeling worden aangepast.

De resultaten van de metingen worden ook gebruikt voor wetenschappelijk onderzoek. Dit gebeurt anoniem. Patiënten weten dit en kunnen hier bezwaar tegen maken: als mensen niet willen dat hun ROM-gegevens voor onderzoek gebruikt worden, dan worden deze gegevens verwijderd.

Ook bij Kristal Centrum Psychiatrie en Verstandelijke Beperking wordt gebruik gemaakt van ROM. Toen we hier in 2009 een start mee maakten was het afnemen van vragenlijsten, met name zelfrapportage vragenlijsten, bij mensen met een lager IQ iets heel nieuws. Inmiddels wordt er in bijna alle centra gespecialiseerd in psychiatrie en verstandelijke beperking gebruik gemaakt van ROM.

Omdat we graag patiënten met hogere en lagere IQs met elkaar willen kunnen vergelijken, maken we zoveel mogelijk gebruik van dezelfde vragenlijsten als in de ‘reguliere’ psychiatrie, oftewel de regionale centra van Rivierduinen. Of dit mogelijk was, moesten we natuurlijk wel eerst bekijken. Een belangrijke stap in dit proefschrift was daarom het onderzoeken van de bruikbaarheid van de Brief Symptom Inventory (BSI), een veel gebruikte zelfrapportage vragenlijst in de ‘reguliere’ psychiatrie, bij mensen met een lager IQ.

Om ROM goed te kunnen gebruiken bij Kristal hebben we de werkwijze wel iets moeten aanpassen.

We vragen niet zomaar aan mensen om zelfstandig vragenlijsten in te vullen. Hun behandelaren helpen ze daar bij. We noemen deze werkwijze het ‘assisted completion format’. De behandelaar kan instructies of vragen samen lezen of voorlezen en eventueel de taal van sommige vragen aanpassen als deze voor de patiënt te moeilijk blijkt te zijn.

Doelstelling

Het algemene doel van dit proefschrift was om meer zicht te krijgen op de aard en de ernst van de psychiatrische symptomen en psychiatrische stoornissen van poliklinische patiënten gediagnosticeerd met zwakbegaafdheid en onder behandeling in de tweede-lijns GGZ. We gebruikten hiervoor geanonimiseerde diagnostische informatie uit het officiële registratiesysteem van het elektronisch patiëntendossier, onderzochten het nut en de psychometrische eigenschappen van de BSI en gebruikten vervolgens ROM-gegevens van patiënten uit de ‘reguliere’ GGZ en patiënten met zwakbegaafdheid of een lichte verstandelijke beperking om te kijken naar symptoomprofielen en voorspellende factoren voor behandeling.

Belangrijkste bevindingen

In **hoofdstuk 1** van dit proefschrift worden, net als in deze samenvatting, de theoretische achtergronden en de klinische praktijk beschreven. In **hoofdstuk 2** wordt een overzicht gegeven van het begrip zwakbegaafdheid. Wat is de betekenis van de classificatie zwakbegaafdheid en op welke plekken kun je zwakbegaafdheid terugvinden in internationale classificatiesystemen voor psychiatrische stoornissen zoals de DSM? We beschrijven hoe zwakbegaafdheid in de loop van de tijd beetje bij beetje een andere betekenis kreeg en hoe de classificatie door de verschillende edities van de DSM ‘reisde’ om uiteindelijk in de nieuwste editie letterlijk als laatste classificatie te eindigen. En zonder duidelijke definitie. Immers het laatste criterium voor het vaststellen van zwakbegaafdheid, een IQ tussen 70 en 85, wordt niet meer genoemd in de DSM-5. In ons overzicht beschrijven we het belang van een goed gedefinieerde classificatie en hernieuwde aandacht voor zwakbegaafdheid. Zwakbegaafde mensen vormen een kwetsbare groep in de maatschappij én in de geestelijke gezondheidszorg. Tegelijkertijd blijven ze in de zorg op dit moment een grotendeels verborgen. Zwakbegaafdheid wordt zelden herkend in de geestelijke gezondheidszorg en is grotendeels onzichtbaar in onderzoek.

In **hoofdstuk 3** beschrijven we de resultaten van een onderzoek naar het voorkomen van verschillende psychiatrische stoornissen bij zwakbegaafde poliklinische patiënten onder behandeling bij Kristal Centrum Psychiatrie en Verstandelijke Beperking. Op die manier wilden we meer te weten komen over welke psychiatrische stoornissen veel voorkomen bij zwakbegaafde patiënten en of dit anders is dan bij patiënten met een hoger of een lager IQ. We vergeleken de officiële psychiatrische diagnoses, uit het elektronische patiëntendossier van drie groepen patiënten: zwakbegaafde patiënten, patiënten met een lichte verstandelijke beperking en patiënten onder behandeling in de ‘reguliere’ psychiatrie. In het onderzoek zaten 235 zwakbegaafde patiënten, 152 patiënten met een lichte verstandelijke beperking en 1026 patiënten uit de ‘reguliere’ psychiatrie ofwel de regionale centra van Rivierduinen.

Depressieve stoornissen en psychotische stoornissen bleken minder vaak gediagnosticeerd te worden bij zwakbegaafde patiënten in vergelijking met patiënten in de ‘reguliere’ tweedelijns psychiatrische zorg. Posttraumatische stressstoornissen en V-codes kwamen, in vergelijking met patiënten in ‘reguliere’ tweedelijnszorg, vaker voor. In vergelijking met patiënten met een lichte verstandelijke beperking kwamen psychotische stoornissen minder vaak voor.

In **hoofdstuk 4** bestudeerden we, bij dezelfde drie groepen patiënten, het voorkomen van persoonlijkheidsstoornissen. We ontdekten dat zwakbegaafde patiënten heel vaak gediagnosticeerd waren met een persoonlijkheidsstoornis (52,8%). Veel vaker dan patiënten in de ‘reguliere’ zorg (19,3%) en ook vaker dan patiënten met een lichte verstandelijke beperking (33,6%). De persoonlijkheidsstoornis ‘niet anderszins om-

schreven' en de borderline persoonlijkheidsstoornis kwamen het vaakst voor. Voor alle drie de groepen gold dat de mensen die gediagnosticeerd waren met een persoonlijkheidsstoornis in het merendeel van de gevallen ook een andere psychiatrische stoornis hadden, meestal een stemmingsstoornis of een angststoornis.

Hoofdstuk 5 beschrijft de resultaten van een studie naar de toepasbaarheid van een veel gebruikte vragenlijst in de psychiatrie, de Brief Symptom Inventory (BSI), bij mensen met een lager IQ. De BSI is een zelfrapportage vragenlijst die in de geestelijke gezondheidszorg veel gebruikt wordt om psychische klachten in kaart te brengen en om bijvoorbeeld het effect van behandelingen te meten. Het voordeel van de BSI is dat je er veel verschillende symptomen mee in kaart kunt brengen en dat hij dus bruikbaar is bij een grote verscheidenheid aan psychiatrische stoornissen. De BSI heeft een totale score maar ook een aantal subschalen waarvoor je apart scores kunt berekenen. Zo heeft de BSI een subschaal *Depressie*, een subschaal *Angst*, een subschaal *Cognitieve problemen* en nog een paar subschalen. Het is één van de meest gebruikte vragenlijsten in de ROM.

In totaal werd de BSI afgenomen bij 224 patiënten met ofwel zwakbegaafdheid of een lichte verstandelijke beperking. De vragenlijst werd altijd samen met de patiënt ingevuld en voor een deel van de patiënten hielden we precies bij welke vragen ze moeilijk vonden. Mensen mochten zelf aangeven welke vragen ze moeilijk vonden, maar we controleerden ook of ze de vragen goed begrepen hadden.

De vragenlijst bleek een goede interne consistentie te hebben. Een goede interne consistentie betekent dat verschillende vragen in de BSI die hetzelfde willen meten (bijvoorbeeld of iemand angstig is) dat ook daadwerkelijk doen. Discriminante validiteit, ofwel of de vragenlijst onderscheid kan maken tussen verschillende begrippen, werd aangetoond voor de subschalen somberheid, angst en fobische angst. Met confirmatieve factoranalyse, een statistische techniek waarmee je kunt onderzoeken hoe de verschillende vragen van een vragenlijst het beste gegroepeerd kunnen worden, lieten we zien dat de onderliggende structuur van de BSI bij mensen met een lager IQ het model volgt, dus dezelfde subschalen, zoals eerder voor de BSI beschreven bij een groep mensen die niet waren geselecteerd op grond van hun IQ. Conclusie uit dit onderzoek was dat de BSI een nuttige vragenlijst is voor het meten van psychische klachten bij mensen met zwakbegaafdheid of een lichte verstandelijke beperking.

Omdat er nog maar weinig onderzoek gedaan is naar het effect van zwakbegaafdheid op het soort en de ernst van de psychische klachten, oftewel hoe psychiatrische stoornissen er uit zien, bestudeerden we in **hoofdstuk 6** de meetresultaten op de BSI, direct de eerste keer dat hij werd afgenomen, bij zwakbegaafde patiënten met ofwel een depressieve stoornis, of een posttraumatische stressstoornis. We vergeleken de scores op de verschillende subschalen van de BSI en de BSI totaalscore van zwakbegaafde patiënten met de scores van mensen in de 'reguliere' psychiatrische zorg en mensen

met een lichte verstandelijke beperking. Om er voor te zorgen dat verschillen in scores niet veroorzaakt werden door leeftijd of geslacht werd hiervoor gecorrigeerd.

Uit dit onderzoek bleek dat zwakbegaafde depressieve patiënten minder ernstige depressieve klachten aangaven dan depressieve patiënten onder behandeling in de regionale centra van Rivierduinen. Ze gaven ook minder klachten aan op de subschalen *Problemen in de cognitieve functies* en *Teruggetrokkenheid*.

Er waren geen grote verschillen in BSI scores tussen patiënten met een posttraumatische stressstoornis uit de verschillende groepen. Wel scoorden licht verstandelijk beperkte patiënten met een posttraumatische stressstoornis lager op de subschalen *Depressie* en *Teruggetrokkenheid* dan patiënten uit de regionale centra van Rivierduinen. Omdat dit de eerste studie is die op deze manier psychische klachten vergelijkt tussen mensen met een hoger of een lager IQ wilden we vooral deze verschillen laten zien, maar we kunnen ze nog niet zo goed verklaren.

De laatste studie, die we beschrijven in **hoofdstuk 7**, is een eerste verkennende studie naar het verband tussen geslacht, leeftijd, IQ en cluster B persoonlijkheidsstoornissen en behandeluitkomst bij poliklinische patiënten met stemmings-, angst- en somatoforme stoornissen. We spreken in de psychiatrie van een persoonlijkheidsstoornis als iemand een vaste, starre manier van reageren heeft ontwikkeld op zeer uiteenlopende omstandigheden en daardoor persoonlijk of sociaal vastloopt. Mensen met een Cluster B persoonlijkheidsstoornis zijn impulsief en vinden het moeilijk om met hun emoties om te gaan.

Voor deze verkennende studie gebruikten hiervoor de resultaten zoals die werden vastgesteld met de BSI die tenminste twee keer was afgenomen: de eerste keer voor het begin van de behandeling en de tweede keer als de behandeling al een eind gevorderd is of is beëindigd. Bij 93 patiënten van Kristal keken we op die manier naar de invloed van geslacht, leeftijd, IQ en cluster B persoonlijkheidsstoornissen op het effect van de behandeling. Waarschijnlijk door het relatief kleine aantal patiënten was het voor de uitkomsten van dit onderzoek niet mogelijk om geheel uit te sluiten dat de uitkomsten niet op toeval berusten. Daarom kunnen we slechts voorzichtig zeggen dat het er op lijkt dat vrouwen, jong volwassenen en patiënten met een comorbide cluster B persoonlijkheidsstoornis, minder goed reageren op behandeling. Het maakte voor het effect van de behandeling niet uit of mensen zwakbegaafd waren of een lichte verstandelijke beperking hadden. Zwakbegaafde patiënten reageerden niet beter of slechter op behandeling dan patiënten met een lichte verstandelijke beperking.

Dit is een kleine, eerste, verkennende studie. Het zou mooi zijn als hij herhaald kan worden met grotere groepen patiënten. Dan kunnen ook andere factoren die mogelijk van invloed zijn op het effect van behandeling onderzocht worden.

Algemene discussie

Er is weinig aandacht voor zwakbegaafdheid in de GGZ en er wordt nauwelijks onderzoek naar gedaan. Dat is vreemd. Zwakbegaafdheid komt namelijk veel voor. Het gaat om een grote minderheid, zowel in de maatschappij als in de GGZ. In dit proefschrift bestuderen we, voor de eerste keer, psychiatrische stoornissen en de aard en ernst van psychische klachten bij zwakbegaafde poliklinische patiënten. Het is daarbij heel bijzonder dat we de mogelijkheid hadden om zwakbegaafde patiënten te vergelijken met zowel patiënten uit de ‘reguliere’ psychiatrie als patiënten met een lichte verstandelijke beperking.

Het herkennen en vergelijken van deze verschillende patiëntengroepen is belangrijk vanwege de mogelijke implicaties voor diagnostiek en behandeling.

In dit proefschrift lieten we zien dat sommige psychiatrische stoornissen vaker of juist minder vaak worden vastgesteld bij zwakbegaafde patiënten dan bij patiënten in de ‘reguliere’ zorg of bij patiënten met een lichte verstandelijke beperking. Dit is belangrijke informatie omdat het invloed heeft op de manier waarop je de geestelijke gezondheidszorg voor deze groep patiënten organiseert. Dat veel zwakbegaafde patiënten een posttraumatische stressstoornis hebben bijvoorbeeld, betekent dat er behoefte is aan goed opgeleide behandelaren, die weten hoe ze behandelingen voor posttraumatische stressstoornissen kunnen toepassen, specifiek toegespitst op mensen met een lager IQ.

Dat zwakbegaafde patiënten vaak een persoonlijkheidsstoornis hebben betekent dat ook daar aangepaste behandelingen nodig zijn. In de ‘reguliere’ psychiatrie worden over het algemeen erg ‘cognitieve’ therapieën gebruikt, zoals *dialectische gedragstherapie* (DGT) en *Mentalisation Based Therapy* (MBT) die voor veel patiënten met een lager IQ te moeilijk zijn. Psychiatrische patiënten met een lager IQ hebben behoefte aan een behandeling met kleine concrete stappen en veel herhaling. Terwijl patiënten met een gemiddeld of hoger IQ zelf in allerlei situaties kunnen toepassen wat ze in de therapie in een enkele situatie hebben geleerd, moet dat zwakbegaafde mensen in veel meer situaties geleerd worden: er moet meer aandacht zijn voor generalisatie. Kristal Centrum voor Psychiatrie en Verstandelijke Beperking heeft de expertise voor aangepaste behandelingen voor posttraumatische stressstoornissen en voor persoonlijkheidsstoornissen.

Een belangrijke uitkomst van dit proefschrift is de bruikbaarheid van de BSI bij patiënten met zwakbegaafdheid of een lichte verstandelijke beperking. Dit heeft de mogelijkheden van ROM absoluut vergroot. Omdat de BSI zowel bij mensen met een hoger als met een lager IQ gebruikt kan worden, kan er met behulp van deze vragenlijst gekeken worden naar overeenkomsten en verschillen tussen deze patiëntengroepen. Je kunt bijvoorbeeld kijken of er verschillen zijn in de aard en ernst van psychische

klachten of kijken naar de effectiviteit van verschillende behandelingen bij mensen die op verschillende intellectuele niveau's functioneren.

In dit proefschrift hebben we deze mogelijkheden verkend door BSI symptoomprofielen, ofwel scores op de verschillende subschalen en scores van de BSI totaal, van zwakbegaafde patiënten te vergelijken met patiënten uit de regionale centra van Rivierduinen en patiënten met een lichte verstandelijke beperking. Ook onderzochten we met behulp van de BSI mogelijke voorspellers voor het effect van een behandeling.

Algemene conclusies en aanbevelingen voor verder onderzoek

De resultaten van de studies in dit proefschrift laten zien dat het mogelijk is onderzoek te doen naar zwakbegaafdheid in de geestelijke gezondheidszorg. Focus op zwakbegaafdheid is belangrijk omdat zwakbegaafde patiënten in de GGZ een grote –en tot nu toe zeer beperkt herkende- groep vormen.

Volgens het Sociaal Cultureel Plan Bureau heeft ongeveer 2,2 miljoen mensen in Nederland een IQ tussen 70 en 85. In hun rapport “Zorg beter begrepen”, concludeert het Sociaal Cultureel Plan Bureau dat de zorgbehoeften van zwakbegaafde mensen tussen 1998 en 2011 verzesvoudigd zijn. Maatschappelijke ontwikkelingen zoals verminderde beschikbaarheid van eenvoudig werk, hogere eisen in het onderwijs en toenemende digitalisering zijn de belangrijkste verklaringen voor deze toename van de zorgbehoefte. Ondanks, of misschien wel vanwege deze toenemende zorgvraag heeft de Nederlandse regering besloten terughoudender te worden in het aanbieden van gespecialiseerde zorg voor zwakbegaafde mensen. Dit vermindert de ruimte voor preventieve zorg en begeleiding waardoor niet alleen het risico op psychosociale en gezondheidsproblemen toeneemt maar met name het risico op het ontwikkelen van psychiatrische stoornissen

Veel zwakbegaafde patiënten in de GGZ hebben een combinatie van vaak complexe psychiatrische stoornissen, een verscheidenheid aan psychosociale problemen en passend bij hun zwakbegaafdheid, cognitieve beperkingen en beperkingen in het sociaal emotionele en adaptieve functioneren.

Om deze complexe interactie tussen zwakbegaafdheid, psychiatrische stoornissen en psychosociale problemen adequaat aan te pakken is een actieve opsporing van zwakbegaafdheid in de geestelijke gezondheidszorg essentieel. Professionals moeten worden getraind in het herkennen van zwakbegaafdheid en in de extra praktische en communicatieve vaardigheden die nodig zijn voor adequate diagnostiek en behandeling van psychiatrische stoornissen bij zwakbegaafde patiënten.

Er is behoefte aan onderzoek naar bestaande diagnostische - en behandelmodules op bruikbaarheid en effectiviteit bij zwakbegaafde psychiatrische patiënten. Op die manier organiseren we betaalbare zorg op maat voor een grote groep aan GGZ patiënten die veel te lang ongezien is geweest.

List of abbreviations

ADD	Attention Deficit Disorder
ADHD	Attention deficit hyperactivity disorder
ANOVA	Analysis of variance
ANX	Anxiety
BIF	Borderline intellectual functioning
BSI	Brief Symptom Inventory
CFI	Comparative fit index
CI	Confidence interval
CPID	Centres for psychiatry and intellectual disability
DEP	Depression
DM-ID	Diagnostic Manual-Intellectual Disability
DSM	Diagnostic and Statistical Manual
EDIT	Early detection and intervention team
FACT	Functional assertive community treatment
HR	Hazard ratio
ICD	International Classification of Disease
ID	Intellectual disability
IQ	Intelligence quotient
I-S	Interpersonal Sensitivity
LVB	Lichte verstandelijke beperking
LVG	Licht verstandelijk gehandicapt
LUMC	Leiden University Medical Centre
MAS	Mood, anxiety and somatoform
MDD	Major depressive disorder
NFI	Normed Fit Index
NOS	Not otherwise specified
O-C	Obsession-Compulsion
OR	Odds ratio
PAR	Paranoid ideation
PHOB	Phobic anxiety
PD	Personality disorder
PDD	Pervasive developmental disorder
PSY	Psychoticism
PTSD	Posttraumatic stress disorder
RMSEA	Root mean square error of approximation
ROM	Routine outcome monitoring
SCL	Symptom checklist
SD	Standard deviation
SOM	Somatisation
SPSS	Statistical Package for the Social Sciences
TIQ	Total intelligence quotient
WAIS	Wechsler Adult Intelligence Scale

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Curriculum Vitae

Jannelien Wieland was born on October 7th 1975 in Dordrecht, the Netherlands. After graduating from secondary school (VWO) in 1994, she studied abroad for a year at Rutgers University, New Brunswick (USA). In 1995 she started medical school at the Catholic University of Leuven (Belgium). She obtained her medical degree magna cum laude (met grote onderscheiding) in 2002. From 2002-2003 she worked as a resident in liaison psychiatry at the department of psychiatry of the Leiden University Medical Centre.

From 2003-2009 she received her training as a psychiatrist at the Leiden University Medical Centre and the regional mental health care facility Rivierduinen, including a subspecialisation in psychiatry and intellectual disability. From 2009 onwards she works as a staff psychiatrist at Kristal Centre for Psychiatry and Intellectual Disability, a department of Rivierduinen in Leiden. The research which resulted in this thesis was initiated in that same year.

Since June 2015, next to her clinical work and research, she is a manager and program director for Kristal Centre for Psychiatry and Intellectual Disability.

Jannelien is married to Friso Versluijs and together they have three amazing daughters, Soetie (9), Enne (9) and Marte (5).

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