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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.

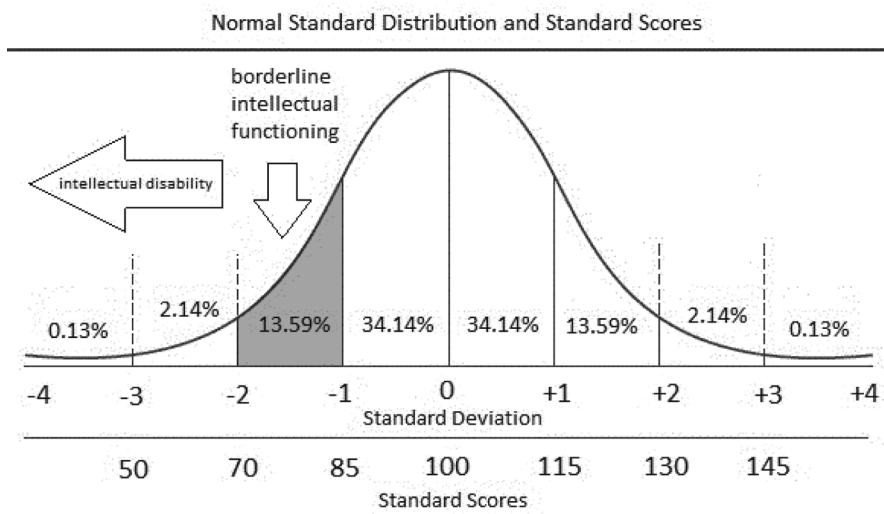


Figure 1. Normal curve of the distribution of intelligence in the general population. The intelligence quotient (IQ) is a score derived from one of the standardized tests designed to assess human intelligence. The median raw score of the normative sample is defined as an IQ of 100. Each standard deviation (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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