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 en 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 ore 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 Institute[14] 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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