Surrounded by controversy:

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Summary

Attention Deficit Hyperactivity Disorder (ADHD) is a common psychiatric disorder which is characterized by inappropriate levels of attention, hyperactivity and impulsivity. Prior to the year 2000, ADHD was defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM) as a childhood disorder that fully remitted after adolescence. With the publication of DSM-IV-TR in 2000, amendments were made to make the criteria applicable to adults. As a much more recent disorder, adult ADHD not only inherited the same uncertainties and controversies of its childhood counterpart but also has some specific problems of its own. Childhood and adult ADHD are surrounded by substantial public concerns. In particular, the dramatic increase in stimulant prescriptions to treat ADHD has fuelled public scepticism. This, combined with the complications involved in diagnosing ADHD raises doubts whether the many ADHD diagnosis are 'real ADHD'. In the Netherlands, there is increased political pressure to decrease the number of ADHD diagnoses and stimulant prescriptions. Nevertheless, health professionals and ADHD advocates argue that a group of people experiences problems that can be helped by an ADHD diagnosis and treatment. In short, ADHD is a complex medical and societal problem that is surrounded by uncertainty and debate and, as such, it demands exploration from various perspectives.

To date, the field of ADHD research has been dominated by biomedical and clinical scientists. However, the perspectives of health professionals who work with ADHD on a daily basis and, in particular, the perspectives of people diagnosed with and treated for adult ADHD have rarely been explored. In addressing this knowledge gap, this thesis aims to provide insights into the perspectives of patients and health professionals on adult ADHD and ADHD care in order to contribute to continuing efforts to increase the quality of care and the wellbeing of people with ADHD. Exploring the experiential knowledge of patients and health professionals is important for three reasons: (1) it fills a long-standing knowledge gap; (2) it aligns with current health system reforms which involve patients in research and treatment decisions; and, most importantly, (3) this knowledge, in tandem with existing research evidence, can be used to improve quality of care and to question and to fine-tune clinical recommendations, guidelines and practices.

Theoretical background and study questions

In this thesis, ADHD is first described from a biomedical perspective, namely its aetiology and prevalence, diagnostic process and treatment. This is followed by a short philosophical discussion of the

nature and definition of disease and disorder that underlies the sociological accounts of ADHD. In these accounts, ADHD is typically described as a construct of modern societies, which may have biological causes, rather than a pure biological entity. When placed in the current socio-economic and political landscape, the social study of ADHD helps to understand why disorders of hyperactivity and inattention emerge and are increasingly treated with stimulants. Subsequently, the growing interest in patient-centred care is discussed which is a strong trend in health systems reform. These insights are brought together in a transdisciplinary model of evidence-based practice that includes the experiences, perspectives and needs of patients and health professionals on adult ADHD. Two research questions address the gap of knowledge in the micro-systems of the model:

1. What are the perspectives of adults with ADHD towards ADHD and adult ADHD care?
2. What are the perspectives of health professionals towards ADHD and adult ADHD care?

In order to understand the complex nature of adult ADHD in a wider context, two research questions are formulated that address the higher levels in the model:

3. How do the perspectives of patients and health professionals relate to the broader ADHD debate?
4. What lessons can be learnt in order to contribute to a more person-centred care for adult ADHD?

Methodology

This thesis mainly uses a qualitative, exploratory approach. Qualitative methods are used because they give an in-depth understanding of the experiences, and the meaning of those experiences, of individuals who encounter certain phenomena, such as getting sick and receiving treatment or being a physician who encounters and treats patients.

Addressing the first and third study question we conducted three studies on: (1) the daily life experiences of adults with ADHD; (2) the perspectives of adults with ADHD towards adult ADHD care; and (3) the experiences of adults with ADHD in relation to a strength-based coaching methodology provided by a private coaching centre in the Netherlands. In a fourth study, we addressed the second and third research question by investigating the perspectives of mental health professionals on adult ADHD, its diagnosis and treatment. Finally we addressed the fourth study question by drawing upon the data presented in the first part combined with data from a similar study that explores the perspectives

of people with bipolar disorder, and linking this to recent insights on Patient-Centred Care. Studies 1 and 2 used focus groups and studies 3 and 4 used semi-structured interviews.

Results

In the focus group discussions, a number of topics emerged that are important to adults with ADHD in relation to daily life (chapter 4). First of all, many participants experience the characteristic inattentive and hyperactive-impulsive symptoms of ADHD as problematic. They acknowledged, however, that the real suffering stems from the negative judgments of others rather than the symptoms themselves. Many participants thought they were unable to behave in the way that the social world, i.e. friends, family or work, wants from them which results in problems with their self-image. The majority of participants experienced a lack of understanding from the people around them, including employers, colleagues, friends and family, which resulted in feelings of rejection and alienation and sometimes low self-worth. Importantly, the powerlessness to change behaviour, the negative judgment of others and feelings of low self-worth were explained to be mutually reinforcing.

The perspectives of adults with ADHD on healthcare, described in chapter 5, started with the problems with the diagnostic process. For many, obtaining an ADHD diagnosis was a frustrating, long process. Many had previously received care for burnout and depression complaints which had delayed the diagnosis and treatment of ADHD for years; for some it meant they had to push health professionals to seriously consider an ADHD diagnosis. Regarding care, all participants recognized the positive effects of ADHD care on increasing their functioning and well-being; but many also mentioned the limitations of stimulants and the importance of psychosocial therapy. The strict focus of adult ADHD on stimulant treatment and skill training, i.e. the enforcement of strict planning on daily life, caused participants to perceive care as disease-centred. Many participants stressed that care can be improved by a more person-centred approach aligning care with individual strengths, weaknesses and contexts. Clients of a private coaching centre appreciated the centre's person-centred and strength-based approach (chapter 6).

The problems of adults with ADHD go beyond symptoms alone. Participants repeatedly stressed that an individual is more than just a collection of ADHD symptoms and has, instead, unique combinations of competences and problems with their own personal situation. Care, therefore, should not only address the symptoms of ADHD but also have regard for the individual within his or her situation. A wider application of strength-based approaches might be an important resource to help adults with ADHD

increase their level of functioning within society because such an approach treats every individual as unique with a unique combination of strengths, competences and weaknesses. From the stories of patients, it can be concluded that adult ADHD care could be more person-centred, taking the individual, contextual nature of adult ADHD more into account with a stronger focus on positive, strength-based interventions.

As described in chapter 7, the interviewed health professionals generally stressed that adult ADHD is a 'real' disorder that can cause substantial problems in the lives of adults. Many pointed to the clear neurobiological and genetic underpinnings of the disorder to corroborate this position. In response to criticisms challenging the validity of adult ADHD and its treatment, they explained that ADHD is a valid diagnosis, that there is adequate treatment, and that early diagnosis and treatment is important to relieve the suffering of their patients. All respondents emphasized that the diagnostic process for adult ADHD is a complex endeavour that demands critical reflection as ADHD can be obscured by various factors such as the individual context of patients and the demands posed upon by modern society. For both diagnosis and treatment, the current clinical tools were generally found to be of limited help for clinical practice especially since they do not address the complexity practitioners experience in day-to-day clinical practice.

The perspectives of patients and health professionals show many similarities, although there appears to be a tension between health professionals' efforts to take an evidence-based approach and patients' desire for more patient-centred care is apparent. This tension is important for clinical practice and future research in the ADHD field.

Discussion and conclusion

The research presented in this thesis shows that this long-standing controversy surrounding adult ADHD is known by many patients and health professionals, and they regularly reflected on it in the focus groups and interviews. According to health professionals, mental disorders are not solid entities that can be discovered by a simple biological test and cannot easily be disconnected from the situation of individual patients and societal changes. The results of this thesis demonstrate that the ADHD controversy is based on a false dilemma in which the biomedical/naturalistic and socio-cultural/normativist perspectives are treated as mutually exclusive. We found that adults with ADHD and health professionals integrate medical and societal aspects of, and explanations for, ADHD. This is important since most contemporary clinical research evidence ignores or even rejects social and societal

factors. Since patients and health professionals have to deal with both the biomedical and the societal factors of ADHD, the omission of the latter decreases its usefulness of contemporary research evidence for day-to-day clinical practice. We conclude that research is needed that integrates both biomedical and societal aspects and which aims to answer questions relevant to the daily life of adults with ADHD and day-to-day clinical practice.

Adults with ADHD highlight three important aspects which should receive greater priority in their ADHD care. First, care should acknowledge more the importance of the individual. Second, adults with ADHD often expressed the wish for a stronger focus on personal strengths and qualities rather than treatment focused on ADHD deficits. Finally, many patients saw a more pronounced role for peer-contact in future treatment. These improvements to care align with the concept commonly described as patient-centred care. Most health professionals stressed that patient-centred clinical practice is important and that they already worked 'patient centred', but that it is not possible nor desirable at all times. Implementing the concept of PCC, as interpreted by patients, is in practice constrained by health professionals' commitment to evidence-based medicine (EBM) reflected in contemporary clinical guidelines and reimbursement rules (Diagnose Behandel Combinatie, DBCs). When comparing these perspectives, it seems that EBM and PCC are currently at odds with each other. Based on the results of the studies presented in this thesis, however, it can be proposed that these contradictions are also based on a false dilemma. One can imagine the situation in which both perspectives on clinical practice are integrated: where research evidence forms the basis of decisions that work best for individual patients and where experiential knowledge is acknowledged and valued as essential to fine-tune treatments in order to achieve maximal benefits for individual patients. In order to achieve this, a new way of producing research evidence is necessary.

In terms of internal validity, a strength of this research is its rich data. The primary data sources of the studies, interviews and focus groups, were extensively documented. With regard to the internal validity, it was important to ensure that the full variety of perspectives was explored and that data saturation was reached. As the main researcher, I have ADHD myself which was a strength and a potential weakness (bias). Bias has been addressed by involving other researchers in the design, data collection and analysis, and by regularly reflecting on the findings and interpretation within a larger research team. The presented studies have all been conducted in the Netherlands and cannot unequivocally be translated to other health systems.

This thesis has shown that adults with ADHD and health professionals face many challenges with regard to the management of ADHD, adult ADHD care and the debate that surrounds ADHD. To contribute to the well-being of adults with ADHD, further research is needed to inform clinical practice and to address the controversy between the biomedical/naturalist and the socio-cultural/normativist perspective. Research is needed that addresses the public debate surrounding ADHD. For this, it is not only important to involve direct stakeholders but also the wider public.