

THE DYNAMICS OF THE TREATMENT-ENHANCEMENT DISTINCTION: ADHD AS A CASE STUDY¹

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ABSTRACT

A central issue in the ethical debate on psychopharmacological enhancers concerns the distinction between therapy and enhancement. Although from a theoretical point of view it is difficult to make a clear-cut distinction between treatment (of disease) on the one hand, and enhancement (of normal functioning) on the other, in medical practice and policy debates the counter-positioning of therapy to enhancement is clearly at work. Especially pharmaceutical companies have an interest in occupying the 'grey area' between normal and abnormal, treatment and enhancement.

This article discusses the dynamics of the treatment-enhancement distinction, and argues that practices that could be labelled 'enhancement' can also be understood in terms of medicalisation and 'disease mongering'. The argument is supported by results from a qualitative empirical study into the experiences and opinions of adults diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). Patients are ambivalent about how to understand ADHD: as a disease, a disorder or a normal variation. Intervention with psychopharmacological means can also be understood in different ways. From an insider perspective it is conceived of as a 'normalising' of functioning, whereas from an outsider perspective it can be understood as medicalisation of underperformance, or indeed as performance enhancement. This draws attention to new moral issues which are important but under-recognised in the enhancement debate, and which are related to medicalisation.

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1. Introduction

Should psychopharmacological means be used to enhance normal mental functioning – like mood, memory, or cognitive performance – or should its use be restricted to the treatment of psychiatric diseases and mental conditions? In the ongoing ethical debate about human enhancement this is one of the issues under discussion. A central issue in this debate concerns the distinction between therapy and enhancement, since it appears to be a presupposition that we can – and should – indeed make a distinction between treatment of disease and enhancement of normal functioning.

In this paper we will first argue that although it is difficult to make a clear-cut distinction between treatment (of disease) on the one hand, and enhancement (of normal functioning) on the other from a philosophical point of view, this counter-positioning of therapy to enhancement is clearly at work in medical and social practice and in policy debates. There are many interests involved in occupying the ‘grey area’ between normal and abnormal, treatment and enhancement.

Next, we will illustrate and discuss the dynamics of the treatment-enhancement distinction and argue that practices that could be labelled as either ‘treatment’ or ‘enhancement’ can also be understood in terms of medicalisation and ‘disease mongering’. The argument is supported by results from a qualitative empirical study into the experiences and opinions of adults diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) and by sociological literature on the subject. While from an insider perspective the treatment of ADHD is mostly conceived of as a ‘normalising’ of functioning, from an outsider perspective it can also be understood as medicalisation of underperformance, or indeed as performance enhancement.

Finally, we discuss some of the moral problems that come into focus when the grey area between treatment and enhancement is conceived of in terms of medicalisation. These issues are somewhat different from the moral issues the human enhancement debate usually focuses on.

2. Treatment-enhancement distinction: theory

A central issue in the ethical debate on neuro-enhancers, which we will be concerned with in this paper, is the definition of enhancement and the related issue of the distinction between therapy and enhancement. For the purpose of defining what enhancement is, it is common to make a distinction between medical treatment and enhancement. A well-known definition of enhancement holds that enhancements are “interventions designed to improve human form or functioning beyond what is necessary to sustain or restore good health” (Juengst, 1998: 29). The well-known report of the President’s Council (2003) speaks of interventions that go ‘beyond therapy’.

The general idea behind this distinction is that treatments are good, that they should be paid for by collective healthcare funds, and that they properly belong to the sphere of medicine. In contrast, enhancements are often considered to be bad or at least morally suspicious. If they are to be allowed at all, the common opinion is that they should not be paid for collectively but on an individual basis, and that they do not belong to the proper goals of medicine. The point of making this distinction is that it is supposed to help us categorize new interventions, and decide how they should be looked upon and how they should be regulated. Moreover, when something is defined as an enhancement, this opens up a new ethical space of specific questions: does the use of enhancers constitute a form of cheating? Does it violate principles of justice? Will there be sufficient freedom of choice with regard to the use of enhancers, or will there be coerced use or extreme social pressure? Will enhancement in general violate human nature, corrode important human characteristics and practices, or reinforce our illusion of mastery?

Although the distinction between therapy and enhancement is often made and structures much of the debate, it is also much disputed. First, we lack clear and unified concepts of health and disease, so the boundaries are difficult to draw. Moreover, most theories of health and disease agree that a definition of disease also involves normative considerations and is thus not the objective, normatively neutral arbiter it is supposed to be (Kushf, 2007; Daniels, 2000). While there are some cases that are clearly treatments (e.g. chemotherapy for cancer) and others that are clear enhancements (e.g. cosmetic surgery), there are also interventions that are more ambiguous and that are not easy to classify,

like the use of growth hormone in children of short stature, or breast enlargement in women with extremely small breasts. In this so-called grey area it is difficult to say where and how to draw a line between treatment and enhancement.

Second, on closer inspection, the treatment-enhancement distinction does not map nicely onto the moral distinctions. According to some, a descriptive classification of ‘health’ or ‘normalcy’ versus ‘disease’, or ‘abnormality’ cannot do the normative work of determining what doctors should or should not be concerned with, what should or should not be paid for collectively, and what interventions are or are not morally suspect (e.g. Synofzik, 2007). However, this does not necessarily imply that the distinction is useless all together. As Daniels (2000) has argued, we just should not expect too much of it. This means that even if we had uncontested definitions of health and disease, there would remain cases in which this distinction would not provide the sole and sufficient basis for moral judgments.

3. Treatment-enhancement distinction: practice

Although from a theoretical point of view it is difficult to make a clear-cut distinction between treatment (of disease) on the one hand, and enhancement (of normal functioning) on the other, and even more problematic to make moral judgements based on this distinction, in medical practice and policy debates the counter-positioning of therapy to enhancement is clearly at work. By and large, on the policy level, the distinction between treatment and enhancement does its work, even if on a philosophical level this cannot always be justified. The two ends of the spectrum ‘treatment of real diseases’ and ‘enhancement of normal traits or functions’ do indeed answer societies’ questions regarding what properly belongs to the medical domain, and what should be paid for in a collective healthcare-insurance scheme. Most doctors still feel they should only treat or prevent diseases and ameliorate suffering, but that they should not use medical interventions to improve otherwise healthy individuals. The funding of healthcare costs is, in most cases, restricted to the treatment of diseases and disorders and not extended to enhancement of functions or traits that are considered ‘normal’. For many people, the distinction between treatment and enhancement even

determines which types of interventions are morally justified and which ones are problematic. There is a strong belief, at least amongst the Dutch public, that medication should be used only for curing disease, and only if really necessary. Use of medication for improving normal functioning is generally not appreciated².

Finally, there are many interests involved in the labelling of certain conditions as diseases or disorders. Especially pharmaceutical companies have an interest in occupying the ‘grey area’ between normal and abnormal, between treatment and enhancement, because this helps them to sell their products. Some even claim that companies ‘create’ new diseases in order to make more profit. This phenomenon is known as ‘disease mongering’ – it is defined as “the selling of sickness that widens the boundaries of illness and grows the markets for those who sell and deliver treatments”(Moynihan and Henry, 2006: 425).

4. The case of adult ADHD: a view from the inside

In the following sections, we will illustrate the dynamic nature of the treatment-enhancement distinction as it occurs in practice, by taking the example of adult ADHD. Attention Deficit Hyperactivity Disorder is characterized by symptoms like being restless, easily distracted, having difficulty planning, and being overly impulsive and chaotic. About 1 to 3% of the adult population is said to suffer from ADHD. First we will give an impression of ADHD ‘from the inside’, based on an in-depth interview study we conducted with 19 adults with ADHD. In the next paragraph we will then take a look at ADHD ‘from the outside’ and discuss some of the sociological literature on the subject.

One of the questions we asked the respondents in our interview study was how they looked upon ADHD, and whether they thought of it as a disease.

² There is, unfortunately, no scientific research to prove this point; however, in public discussions I have participated in, as well as in interviews we did, this is the dominant opinion. Moreover, the Dutch are among the lowest medication-users in Europe: ‘pharmacological calvinism’ belongs to our nation’s national identity.

Perhaps surprisingly, only a small minority clearly defined ADHD as a disease. “Well, I believe that it is a stupid disease, that you have something... well too little, or too much of something, some substance, is being produced [in your brain]...” said one of them. The majority, however, did not call ADHD a disease, although they did view their condition as somehow abnormal. The terms they used to describe it were quite varied. They called it a ‘mental condition’, a ‘disorder’, ‘an abnormality’, ‘a condition that makes me function differently’, ‘a big impairment’ and ‘an inconvenience’.

Interestingly, a small minority did not consider ADHD to be a disease at all, nor any other kind of medical condition, but saw it as a normal variation of human character traits. As one respondent explained: “The capacity of the human brain has a certain range, which is evolutionary determined. There are a number of variables. And the mix of variables determines your cognitive capacities and all your other abilities. I believe ADHD is no more and no less than a specific mix, a certain set of variables. [...] I do not even believe it is a disease. I do not believe it is a disorder. I believe it is a variation.”

We also asked the respondents what they believed to be the difference between being a chaotic, lively, impulsive or hyperactive person and having ADHD.

Broadly speaking, two opinions could be distinguished: one group believed that there was a clear difference, while others indicated that it was more like a continuum. Arguments from the first group were that ADHD is the lack of a substance in the brain; or that it is clearly different from a normal personality because medication works: “Someone who is just lively and vivacious does not react to Ritalin. And an ADHD-er does react to medication.” “It is not a character trait, it really is a disease. Because a character trait cannot be solved by medication”. Also, they believed that the psychiatrists who made the diagnosis had thorough tests to make the distinction.

The second group, however, indicated that the difference between a normally hyperactive person and a person with ADHD might lie in the fact that people with ADHD have a more extensive set of symptoms, or have certain traits more extremely, or that the difference depends on the degree of problems that you experience due to these character traits. Those respondents implicitly indicated that there was a gradual rather than an absolute difference. Some respondents explicitly stated that

ADHD was just the end of a spectrum. Some respondents even explicitly said that they viewed it as a continuum.

With regard to the use of medication, most of the respondents described their medication as an aid, a help or as a support³. Many saw it as something that helped them to function properly, both in their work or study and in social relationships. These respondents indicated that due to ADHD they were less able to function adequately and often somehow unable to do things they believed they could do. Medication helped to improve their perceived underperformance. “[...] I always felt that there is more in me than appears. And that I am always searching for a direction.” Another: “I could not do the job, while actually it should have been easy for me. I considered that as dysfunctioning.”

Many also indicated that medication helped them to finish an education, complete their PhD thesis, keep a job and relate better to family and friends. Others said that if only they had been diagnosed early in life, their life would have taken a different, better, course; schools could have been completed, careers would have gone better, marriages might have stayed intact, and their life in general would have been more in balance. In general, medication made the respondents feel better and function better, but they clearly perceived this as a kind of restoration to normal levels of functioning. “It helps me to minimize the hindrances that ADHD causes for me. It is not like ‘I can do anything and want something on top of that’, no, it is one step closer to that line... So in that way it is a reparation, restoration”.

5. ADHD in sociological perspective: dynamics of the TE distinction

After this look at ADHD from an insider’s perspective, let’s take a look at ADHD and psycho-stimulant medication from an outsider perspective, that is, from a sociological point of view. Such a perspective shows a slightly different picture. What is now diagnosed as ADHD used to be a ‘problematic personality’ only fifteen years ago. It is only since 1994 that Adult ADHD is recognized as an official psychiatric diagnosis. A study

³ We also interviewed people who declined the use of medication for various reasons. I will not discuss this group here, though.

by Conrad and Potter (2000) shows how the criteria for ADHD have been extended over the years to include more people and include adults as well as children.

It is important to note that the symptoms of ADHD, like being easily distracted, or doing too many things at the same time, are rather common – one only qualifies for the diagnosis, however, when these symptoms are present to a degree that is ‘maladaptive’ and causes: ‘clinically significant impairment in social, academic, or occupational functioning’ (DSM IV, criteria for ADHD). This is a crucial aspect of the diagnosis, but it implies that important normative considerations are brought into the diagnostic process (see also Hawthorne, 2007).

This dynamics of diagnostic categories as shown by Conrad and Potter suggests that the diagnosis may come to apply to more and more persons in the future, since both the demands of society and the norms for normal or adequate functioning are changing. This may result in a shift in what behaviour will be regarded as maladaptive, or what level of functioning will be regarded as impaired. When norms of performance are getting higher, the area of the ‘normal’ will shrink, while that of ‘underperformance’ will expand. Therefore, people will need to enhance their performance in order to keep up with societies’ demands. Formerly ‘normal variations’ in capacities, character and behaviour come to be seen as disorders that can (and should) be treated.

This dynamic was also apparent in the interviews. For example, one respondent, a salesman, was at home with sick-leave, partly because he could not handle the increasing administrative demands of his job. He said that due to ADHD he was not very good with paperwork and administration and he could not handle the increased pressure at work. It was not him who had changed over the years, though (he might always have had ADHD, but never really noticed it); it was his working conditions and the demands made on him.

Another respondent said: “[...] medication improves the way I am functioning to a certain extent. I have been trying to set up a PhD research project for myself for almost a year now. Just a study in the area of my discipline, nothing much. And then my children are intervening. And I just can’t have that.” She considered it a failure that she could not get herself to set up and finish a PhD project, next to her job and children.

6. Treatment, enhancement, and medicalisation

In summary, from an insider perspective the treatment of ADHD is conceived as a ‘normalising’ of functioning, a way to enable one to function better and to overcome one’s impairments. Our respondents did not regard ADHD-medication as an enhancement in the sense that it made them better than well. They considered it as an aid to function normally, and to live up to their potential. As one respondent said: “It helps to minimize the hindrances that ADHD causes for me”.

From an outsider perspective, however, the expansion of diagnosis and treatment of ADHD can be understood as medicalisation of underperformance, as Conrad has called it. In contrast to the nineteen seventies, when the term ‘medicalisation’ was coined, the emphasis may now be less on controlling deviant behaviour and more on enhancing suboptimal performance, in a society in which the social norms for performance are getting higher and the socially acceptable range of variation in performance is getting smaller.

In this sense, ‘enhancement’ of human functioning may be well under way. Not as some transhumanist project of extending our capacities beyond the realm of the ‘naturally human’, but simply as the logical extension of the project of medicine: improving human lives by medical-technical means. This only works, however, by first defining more and more conditions as ‘abnormal’ or ‘problematic’, or even as disorders. The area of traits and behaviours that stand in need of medical attention will grow.

Another factor in this process is the availability of medication. Interestingly, one of the most important reasons our respondents gave for considering ADHD a disorder was the fact that there was medication for it: “Well, because there is medication for it, so, yes, then I think you really have something. Because you would not take medication for nothing,” said one respondent. Having a disorder legitimised the use of medication (‘you would not use it for nothing’) but at the same time, medication itself functions as a proof for the existence of a disorder. This circular argument is not only found in lay-people (if we can call patients that) but also among experts: a positive reaction to a trial of psycho-stimulant medication is often considered to be a confirmation of the diagnosis. This type of thinking, however, would turn any positive effect of pharmaceutical substances into a clue that the user has some

abnormality or dysfunction. If a trait or function can be improved, it must have been defective before, this type of reasoning suggests. In this way, the development of new substances that have positive effects on human functioning will likely lead to expansion of disease- or disorder-categories. Rather than concluding that these substances are ‘enhancers’, it will be concluded that a sub-class of formerly under diagnosed or unrecognised patients can now finally receive proper treatment.

Finally, the interests of the pharmaceutical industry and the market-driven nature of much of present-day medicine also stimulate this process. “The manufacturers of enhancement technologies will usually exploit the blurry line between enhancement and treatment in order to sell drugs. Because enhancement technologies must be prescribed by physicians, drug manufacturers typically market the technologies not as enhancements, but as treatments for newly discovered or under-recognized disorders.” (Caplan and Elliott, 2004: 173). Likewise, Conrad has concluded that “in a culture of increasingly market-driven medicine, consumers, biotechnological corporations, and medical services interact in complex ways that affect social norms in changing definitions of behaviours and interventions.” (Conrad, 2005: 11).

7. Moral problems between treatment and enhancement

As discussed above, what we can see happening in the grey area between treatment and enhancement is that the borderline is shifting to include more people in disease and disorder categories. This turns interventions one might call ‘enhancements’ into ‘treatments’. What we see happening, in other words, is medicalisation⁴. Medicalisation can be a moral good: many people who experience real problems may be helped by the new therapies they receive. There are, however, also some morally problematic aspects to it.

First, the harm-benefit ratio of medication deserves constant attention. While the risks and side effects of medication are acceptable if

⁴ By medicalisation we mean a normatively neutral, descriptive term, indicating the process in which more aspects of daily life are come to be seen in medical terms, and problems come to be understood in a medical framework.

they greatly improve the quality of life of people, it must not be forgotten that pharmacological substances always have risks and side-effects, and that for new substances these are often unclear. The smaller the benefit that is created by pharmacological intervention, the more serious the possible risks and the lack of information regarding long-term effects should be taken.

A second problem of medicalisation is the focus on medication or other medical interventions as *the* solution to problems that may be much more complex than the simple 'lack of a substance in the brain' but may also include social or psychological factors. This leaves less room for alternative approaches like psychotherapy, diet, pedagogical measures, or lifestyle changes, that may have less side-effects than medication, or may even be more effective. On a more moralistic note, one could argue that medicalising behavioural- or performance-problems would diminish the effort that people have to put in themselves and that this would make people lazy, or would corrode good character (e.g. President's Council on Bioethics, 2003). I do not fully agree here (Schermer, 2008) but it is a legitimate point of attention.

Thirdly, an important related problem is that social factors contributing to problems are downplayed in comparison to individual biological and psychological factors. With adult ADHD, for example, the increased pressure to perform and to keep up the pace of our hectic society is not really recognized as part of the problem. The problems that patients encounter are individualized instead of socialized. In the Netherlands, there is currently an increase in the number of young adults who get social benefits on the basis of being handicapped and thus unable to work. This increase is due to the increasing numbers of young adults that are diagnosed with ADHD and related disorders like ADD or PPD-NOS. Instead of retaining or creating fitting working-conditions for them, these young people are excluded from participation in society.

Finally, in some cases it appears as if medicalisation works by emphasising and magnifying existing problems, or by exploiting or even stimulating feelings of insufficiency, insecurity, unhappiness or underperformance in people. In brief: in the process of medicalisation people are made to feel miserable first, in order to help relief this misery afterwards by offering a treatment. The most striking examples of this are cases of disease-mongering, where advertisements and other marketing instruments are employed to 'sell sickness'. People are talked into

believing they have a problem that they did not realize they had before. Such a practice should be understood as a violation of the principle of non-maleficence, and is therefore morally problematic.

8. Conclusion

We have discussed the philosophical difficulties in drawing a sharp distinction between treatment and enhancement, but argued that in practice this distinction does have effects. The case study of ADHD was used to illustrate how in medical and social practices, the distinction between health and disease, normality and abnormality is created, and how it's dynamics work. We argued that what is actually happening in the grey area between treatment and enhancements is a process of medicalisation. Finally we discussed some of the moral problems that such medicalisation might bring with it. These are not so much the concerns raised in the enhancement debate about 'playing for God' or about our human nature, but rather familiar worries about risk-benefit ratios, about individualisation of social problems and about choosing the best means to improve human well-being.

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