“Striving for the unknown normal: To understand oneself through an ADHD diagnosis”

Introduction

Me: A Ph.D.-fellow at the department of communication and psychology at Aalborg University in Denmark, where I’m a part of a research group called Diagnostic Culture. The group examines the rise of psychiatric disorders from both a historical, discursive and individual perspectives and describe the way diagnostic categories are used as our contemporary time’s way of understanding human suffering. With the term Diagnostic Culture, we refer to the way diagnoses are fundamental when it comes access to resources and privileges, the way diagnoses are portrayed more and more in the media, and how the diagnostic language has become part of our everyday language. So the Diagnostic Culture is characterized by the circulation of psychiatric diagnoses not only among professionals but also among laymen in order to understand existential problems. The diagnostic culture has so to speak adopted the psychiatric way of looking at human suffering, and different ways of understanding the human.

My specific project examines adults’ experiences of getting an ADHD-diagnosis and the process of being offered a diagnostic category and a diagnostic language to understand and to interpret experiences through. We see a dramatic rise in ADHD diagnosed – also among adults - and studies discuss whether we are witnessing a genuine epidemic of ADHD caused by changed life circumstances and institutional changes while others claim that we are pathologizing behaviour and emotions that were previously considered normal. Many sociological studies examine diagnoses as a way of managing uncertainty or the diagnostic process as a result of medicalization and technologies of the self. But what about the diagnosed individuals? What are their experiences of being diagnosed and how do they relate to this diagnosis that by some are said to be just another culturally, trending diagnosis? In my project, I focus on the individual’s being and navigating in the diagnostic culture and I do it by interviewing adults diagnosed with ADHD about their experiences of and living with the disorder. So far, I have interviewed nine adults. I have spent time with them and their relatives and have followed some of them to their psychiatrist in order to get an insight into their everyday struggles with ADHD.
I will try to illustrate how the ADHD diagnosis both answers and produces existential questions on what counts as normal behaviour and emotions. Based on my fieldwork I will show how the diagnosis helps the diagnosed to identify, accept and verbalise problems by offering a language and concrete explanations to diffuse experienced problems. However, I will also illustrate how the diagnostic process is not only a clarifying procedure with a straight plan for treatment and direct effects. It is also a messy affair. In a process of experimenting with drugs determining how or whether the medication eliminates the correct symptoms the diagnosed is put in an introspective, self-analysing position trying to assess if the correct level of ‘normality’ is reached...

**Peter**

I want to tell you about Peter, one of the people I have interviewed and spend time with. Peter is 27 and was diagnosed with ADHD a year ago. He was a trainee at an auto repair shop before he was on sick leave due to stress and symptoms of depression. During Peter's conversations with his doctor, the doctor becomes more and more certain that Peter's depression might be a product of difficulties related to ADHD. And like all of the other people, I have interviewed, Peter welcomes the diagnosis as an explanation to years of experiencing all sorts of diffuse problems. Peter has always had problems with concentrating when he needs to do some kind of task and the diagnosis helps him to understand why he’s different.

Generally, the people I have interviewed describe themselves as different from their peers and report of a childhood with loneliness and feelings of being misunderstood. They have often felt stupid in school and had difficulties making friends. As adults these challenges have continued at work and in relationships. But the diagnosis changes or at least explains this feeling of being wrong or different. With the diagnosis in hand, a doctor has verified the problems as symptoms of a disorder, and instead of blaming themselves for the problems, they draw on the diagnostic terms as a way of disclaiming the blame. “Now I know, I’m not stupid” or “whenever people are puzzled by the way I act, I just tell them that it’s because I have ADHD” these are statements I often meet when I ask what difference the diagnosis has made.
So what Peter previously experienced as general difficulties are now specific problems related to ADHD, and Peter accepts the diagnosis in a pragmatic way: if the doctor says so – that’s how things are.

I want to focus on two elements in how the diagnosis work as an explanatory model: Firstly, how the diagnostic language is used by the diagnosed and secondly, how prospect of treatment links to the neurobiological explanation to ADHD.

**Language and identification**

But to start with the first point: The diagnosis offers a vocabulary and a legitimate frame of interpretation through which the diagnosed understands and experiences him or her self. Peter can now interpret his experiences in a context of symptoms of a diagnosis instead of problems of an outsider. And the explanatory element in the diagnosis works both inwards as liberation from guilt and outwards as a legit explanation to different behaviour and reactions. Since the ADHD diagnosis is so commonly known, Peter doesn’t need to make any further explanations to his behaviour. When he says he has ADHD, people instantly know how to understand his behaviour. Because within the ADHD diagnostic category, Peter's behaviour is symptomatic – it's normal. In a way the diagnosis is making the pathological normal and understandable.

And at the same time, the diagnosis offers a language to speak about and experience diffuse reactions and experiences.

It frustrated me be to begin with, how Peter constantly refers to the diagnosis's listed symptoms when I ask him how ADHD feels and affects him. As a researcher, I’m interested in not only the diagnostic category but also in the phenomenological experience of living with ADHD. But every time I ask Peter how ADHD affects him, he looks at his telephone, browse through websites and reads from his phone: “ADHD is… blablabla” I listen to Peter’s readings but get impatient and a bit annoyed that I cannot get Peter to explain it in his own words. I see how Peter is sitting on the couch, moving his legs restlessly up and down, lighting a cigarette and browsing through his phone while we’re talking. I observe his bodily expressions and
sense how he feels challenged by the staged interview setting that requires his attention and concentration. My voice recorder lies on the table ready to capture Peter’s every word. I ask again: How do you feel it in your body? But Peter keeps referring to the listed symptoms from his phone. Not until several months later, when I read my transcriptions and observations from the interview, I realize that this is a part of how Peter experiences ADHD: through the diagnostic category. To Peter, his bodily experiences and the diagnostic category are naturally intermingled. And of course they are. Because how do you verbalise reactions and sensations that you have always experienced and therefore, even though you might have known that you sometimes differed from your peers, consider to be normal or regular ways of being in the world? That’s difficult. How do you explain being patient? Or longing for something? Personal traits, sensations and reactions are hard to verbalise, but with the diagnostic explanations you have a vocabulary and some descriptions in hand that reflect and verbalise diffuse experiences. The diagnostic descriptions are concrete whereas the bodily experiences are abstract and hard to explain and maybe the descriptions are not only Peter’s way of verbalising and explaining how ADHD feels, but actually also a part of how he experiences ADHD. Having Ian Hacking’s concept of the looping effect concept in mind and how diagnostic descriptions “make up people”, Peter’s reference to the diagnostic category in the description of his experiences can also be interpreted as Peter’s internalization of the diagnosis in his bodily experiences. Diagnosis and experience are intermingled. Or entangled as the anthropologist Margaret Lock would say. The separation of illness and disease makes analytically sense, but in reality these two are entangled, and the embodied experience is always informed by, Lock would say, language, knowledge, expectations, and so on. The ADHD-diagnosis and the diagnostic descriptions are an integrated part of Peter’s experience of ADHD.

The neurobiological explanation and expectations
And Peter takes the diagnosis and its descriptions seriously - which leads me to my second point about the forces of the diagnosis and how it works as a clarifying factor: Peter reads everything he can find on the net about ADHD: Websites from patient communities, guidelines from national institutions and popular science research. Especially the neurological explanations to ADHD are of his interest. And it adds another dimension to the explanatory
part: that ADHD is caused by something in the brain and therefore firstly: it’s not your fault. When behaviour is a product of unconscious processes, neurons and impulses, the disorder acts through you - you are not responsible; and secondly: it’s treatable. If ADHD is caused by a lack of some kind of substance in the brain, as Peter explains to me, then science just needs to find out exactly *what* substance, so you can add it to the brain through medications. I guess Peter is an example of what Nikolas Rose would call a “neurochemical self”, as he understands his condition as caused by - and the solution to his difficulties as treatable by neurochemistry.

However, reality has taught Peter that drugs may help on his symptoms, but they don’t eliminate all his problems. During an interview with Peter and his girlfriend, Annie, they explain to me the hope the diagnosis infused in them and the subsequent disappointment when the drugs didn’t work as intended. Here’s a bit from the interview:

*Annie starts:* you think: just give him the pill to get everything in order. But then when you start up you realize that it doesn’t work like that. You believe that when you go to a psychiatrist, you’ll get the help you need, and then everything will work out fine. But I’ll tell you: you get wiser all right.

*Peter adds:* I also had the idea that it was easily treated... but I guess I was wrong.

*Annie continues:* and when you ask the psychiatrist: why aren’t you medicated appropriately, he just tells you that it might take years before you reach that point.

A diagnosis and access to treatment does not guarantee cure. The idea that mental disorders are diseases that can be chemically addressed with drugs or by what is said to be the “hope technology”, creates exactly that: hope for a cure and a better future. Peter and Annie hoped that Peter’s problems would disappear with the diagnosis and the following treatment. They thought they’d put the responsibility into the hands of the psychiatric system and that there would be a specific solution to what now seemed to be a more specific problem than before the diagnosis was given. However, to be diagnosed and to take drugs are messy affairs that require patience and constantly self-assessment, they realized.
Addressing and assessing symptoms
From the moment you are presented to the diagnosis, you are asked to evaluate yourself, your reactions and sensations. To Peter, answering questions from the psychiatrist and filling out questionnaires, as part of the diagnostic process, was not done easily and he needed help from Annie. I want to read a bit from my conversation with Peter and Annie about filling out the questionnaire from the psychiatrist.

I ask: The questionnaire – how was it to fill out the form?

Annie: Well he couldn’t see that something was wrong – the descriptions just matched how he is.

Peter: To me it’s normal. Those things described in the form were just things I normally do. I don’t even remember what it said.

Annie continues: but you don’t know how to listen to yourself and your body, so to be able to see yourself from the outside that doesn’t really work with you. Not until I explained it to you: when you do like that or like that – I could give you tons of examples... then you realised: what you assessed to be ‘mild degrees’ were maybe to be located in the other end of the scale. So it took some time to fill out the form.

Me: so when you say you ticked the box indicating ‘mild degree’ it was because you thought: everybody feels this way? You didn’t think of it as something special?

Peter answers: Not at all. I thought it was normal. Well it wasn’t, I realized.

I ask: so you were surprised that Annie wanted you to tick another box?

....

Annie says: you disagreed.
Peter replies: I totally disagreed. Until she started to explain it to me in a way I could understand. And then it made sense. Because with my ADHD, I sometimes need to have things explained differently in order to understand what you’re saying.

According to Peter and Annie, it’s difficult for Peter to pay attention to and his bodily symptoms. The self-analysing position is unfamiliar to Peter and his uneasiness raises the relevant question: when do you know if the way you're feeling and reacting is normal or not? And what exactly is meant by normal? Normal to Peter is the way he's always felt. So what is normal in the sense of how the majority is feeling? Peter has the same difficulties determining if the drugs are working in the right way. Annie, his girlfriend, thinks he’s more easy going with the kids and notices that Peter has changed somehow – he’s more happy in general, she tells me. But when I ask Peter if he feels the difference as well, he just shrug his shoulders with a “naaa” and continues: "well that’s not something you walk around thinking of or pay attention to yourself."

Peter only experiences the effect of the drugs in small glimpses. When he is suddenly more patient with his kids, and when he can concentrate on doing the dishes or performing other everyday tasks. But the effects are hard to single out and verbalise when he is asked by me, the anthropologist, or by his psychiatrist. Moreover, Peter is not only taking different kind of drugs, he is also suffering from unwanted side effects and is therefore constantly changing labels and amounts of medication. So how to differentiate between the different effects, side effects and your regular change of mood and behaviour?

The unknown normal
I think Peter’s story demonstrates the ambiguity in the diagnostic process and the following experimental process of finding the right treatment. Peter finds it difficult to do the required introspective, self-analysing manoeuvre during the process. Because what are symptoms of ADHD and what is just Peter-behaviour? Both the questionnaire and the psychiatrist’s questions regarding adjustment of the medical treatments require some sort of self-evaluation.
Moreover, there is a remarkable discrepancy between the expectations Peter and Annie had to the diagnosis and the treatment of his brain disorder and the process Peter is now experiencing. There is no quick fix and chemical substitute that can balance the brain impulses perfectly. And on top of this, the treatment’s success is dependent on Peter’s ability to evaluate and pay attention to his reactions to the drugs, which as illustrated is difficult.

We talk about our contemporary time and culture as a diagnostic culture. Diagnoses and drug treatment are our way of handling human suffering, and as researchers we may ask if the pathologization of inattentive and hyperactive behaviour has gone too far. I guess the common answer is yes. However, in this presentation, I have tried to take a different approach in my critique of the consequences of diagnosing.

As individuals we’re trying to navigate in this diagnostic culture with all its medical and social technologies. The people I interview are well aware of the critique of the ADHD-diagnosis and they also question if too many people are being diagnosed and if medical treatment is always the only answer to their suffering. However, they are filtered into and products of and agents in the diagnostic culture and just trying to manage.... Peter is making use of the available option. He benefits from the diagnosis and the treatment, but he is also somehow lost in the procedures. The diagnostic process is an experimental process, and Peter needs to learn the language and the logics of the system and figure out how he can take part of the treatment in his striving for the unknown normal.

My point today is to emphasize how a diagnosis not only answers but also produces existential questions on what counts as normal behaviour and emotions. Even though Peter has always known that he was different somehow, he had never known exactly how. But the diagnosis tells him what makes him different from others. It clarifies things and answers Peter’s questions. But then at the same time, the diagnosis asks Peter to consider how he needs to change in order to eliminate his differentness. How to be more normal.