

Hiding parts of one's self from others – a grounded theory study on teenagers diagnosed with ADHD

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(Received 9 September 2008; accepted 22 June 2009)

The aim of this study was to gain deeper knowledge of how teenagers with the diagnosis of ADHD experience their disorder, treatment and the consequences of diagnosis and treatment in their daily lives. Ten teenagers were interviewed in depth. The interviews were analyzed according to the grounded theory method. In the analysis of the data the core category *hiding parts of one's self from others* emerged. Four other categories were also identified: *being different from others*; *wanting to be like everybody else*; *keeping the medical treatment a secret*; and *feeling worried about the future*. The teenagers strove for normalcy and wanted to be like everyone else. They tried their utmost to conceal their diagnosis and medical treatment from others, such as schoolmates, friends and the reference group.

Keywords: ADHD; grounded theory; identity; teenager

Introduction

Attention deficit/hyperactivity disorder (ADHD) is a contested concept. It describes a range of aspects of behaviour clustered together, forming a diagnosis of psychiatric disorder (DSM IV). The understanding of the concept, the etiology and treatment methods vary from a psychological and social to a strict biological and medical point of view (Lloyd, Stead, and Cohen 2006; Larimer 2005).

ADHD is characterized by an increased activity level and decreased impulse control, attention level and concentration ability in the individual. When significantly increased activity level and decreased impulse control occur, the disorder is often obvious already in early childhood (Zeiner 2004). When the child's ability to concentrate is reduced, but his or her activity level is normal, the symptoms often do not become obvious until adolescence or adulthood (Zeiner 2004). The prevalence of ADHD varies, depending on how the disorder is defined. According to some studies the prevalence is about 7% (e.g., Gillberg and Rasmussen 1982) while other studies suggest a prevalence of 3–5% (e.g., Barkley 1991). More males than females are diagnosed with ADHD, probably owing to generally more extroverted personalities in males (Arnold 1996) and more

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introverted personalities in females (Gaub and Carlson 1997; Biederman and Spencer 1999) which make it easier to discover the symptoms of ADHD in males (Walker 1999; Szatmari, Offord, and Boyle 1989). It is common that ADHD occurs concomitantly with other disorders. The most common concomitant diagnoses are depression and behaviour disorder. According to Gillberg et al. (2004), it is estimated that at least 60% of the patients diagnosed with ADHD have or have had one or both of these diagnosis.

During the teenage period the young person develops his/her identity and develops a sense of being a whole person, i.e., a clear picture of the self or who I am is developed (Goffman 1968). When developing an identity, the young person compares him/herself with significant others from a preferred reference group and (s)he wants to be similar to individuals in this reference group (Trulsson et al. 2002). According to Luk, Wan and Lai (2000), the concept of similarity is important in teenagers developing an identity. These authors claim that the ability to make a comparison of subjective competencies includes comparing oneself with other people in the same social context. During the early years, the independent identity of an individual is formed through the identity of the group (s)he wants to belong to, and also through differences from those (s)he does not want to be like. When teenagers have been diagnosed with the psychiatric diagnosis of ADHD, it can be assumed that the teenager has difficulties in seeing him/herself as a whole person, i.e., who am I in relation to the diagnosis, because (s)he differs from the individuals in the reference group who do not suffer from any disabilities.

Medical treatment of ADHD (Greenhill and Osman 1999) including for example, amphetamines, can be used to relieve symptoms. Positive effects of this treatment have been found in more than 6000 patients worldwide and have been reported in more than 250 international controlled short-term studies (Strand 2004). In Norway and Sweden, amphetamine and methylphenidate, which have similar effects, are available for this patient group. It has been hypothesized that the blood flow in the brain is different in individuals diagnosed with ADHD than in individuals without the diagnosis, and that this abnormality can be reduced using such medication (Zeiner 2004). However, long-term effects of the medication have yet to be thoroughly explored, although there are signs that point in a positive direction (Strand 2004).

A recent study, based on in-depth interviews, reports how parents of teenage daughters diagnosed with ADHD experience their parental roles (Hallberg et al. 2007). The study reveals the extremely strained life situations of the parents, illuminated in the core category 'living at the edge on one's capability'. It is clear that these parents (mostly single mothers) are exposed to long-term stress which affects their physical and psychological health. Furthermore, the single parents also often struggle without support from a partner, society or school.

No matter whether the ADHD is understood as a psychological, social or medical problem, the experiences of living a life where ADHD is on the public agenda and in a public discourse in schools, in the media and in the social and medical care organizations, are of great interest in building knowledge in the field.

The aim of the present study was to gain a deeper understanding of how teenagers diagnosed with ADHD spoke about their daily lives, the diagnosis, its treatment and the consequences of the diagnosis and the treatment on their daily lives.

Method

Grounded theory

The qualitative method of grounded theory (Glaser and Strauss 1967; Strauss and Corbin 1998; Charmaz 2000) was used in the simultaneous collection and analysis of data because such a method is suitable for studying peoples' experiences and the social processes they are involved in. The method can also be used to gain new perspective on an area already studied, or when a topic has been insufficiently explored. Daily life for teenagers and development of identity have already been studied, while teenagers diagnosed with ADHD have not yet been the subject of such studies. The grounded theory method is inductive by nature, the aim is to generate a theory, model or concepts from empirical data, through interpretations of the participants' reality that can explain and/or predict the phenomenon under study. The method also has deductive features, such as when emerging categories are tested against new data (Dellve et al. 2002).

Grounded theory has its theoretical roots in symbolic interactionism, including that meaning is constructed and changed by interaction between people. Symbolic interactionism stresses that: (1) human beings act on things according to the meaning those things have for them; (2) the meaning of such things is derived from, or arises out of, social interaction; and, finally, (3) meaning is interpreted in each encounter. This means that meaning is constructed and changed in interaction between individuals, and individuals' perceptions of the world change from their interaction with it (Mead 1969; Blumer 1969). Empirical data reflect the participant's interpretation of his/her reality and the researcher analyzes/interprets this data, i.e., interpretations of interpretations. However, the researcher's interpretation must be as unprejudiced as possible, characterized by 'disciplined restraint' rather than being directed by the researcher's own preconceptions (Hallberg 2006).

Study group and procedure

Ten teenagers (five male), between 13 and 18 years of age, living in Norway and Sweden participated in the study. There was no gender perspective during data collection and analysis; instead we were open to the informant's experiences regardless of gender. All, except one female, were on medication for their ADHD. Three teenagers were Swedish and were recruited from the neuropsychiatric clinic in western Sweden. The others were from Norway, and were recruited from a Norwegian outpatient clinic for teenagers with neuropsychiatric disorders. The informants were selected both from rural and suburban areas. An information letter was given to the presumptive participants, asking if they were willing to take part in the study. If so, they were requested to call one member of the research team in Sweden (UH) or Norway (WS) to schedule a time for the interview. Before the interview, the teenagers and their parents received verbal and written information about the study and the procedure, and they were informed that their participation was voluntary and that they could discontinue participation at any time without giving any reason. The interviewer's role was to be open (bracketing pre-understanding), listen carefully to the informants and to ask probing questions. The interviews were conducted at the informant's school, home or at the office of the interviewer, in accordance to the wish of the informants. The interviewers were not known to the participants in advance and were not involved in the professional

treatment of the teenagers. The study was approved by the Research Ethics Committee at the University of Göteborg and by the Research Ethics Committee in northern Norway. Requirements concerning informed consent and confidentiality were promised and secured for the participants.

Analysis of the data

The interviews were transcribed verbatim and analyzed using hierarchical coding processes. Glaser and Strauss (1967) describe two coding processes: open and selective coding. Open coding means that the substance of the data was captured and segmented into substantive codes, labelled concretely. The process of open coding ended up in clustering substantive codes with similar content into summarizing categories. These categories were given more abstract labels than the substantive codes belonging to it. Relationships between categories were sought and verified in the data and by this data were put together into a new wholeness. In the selective coding, categories were saturated by additional information, from new interviews or added from re-coding previously assessed data. A core category was identified, *having to hide parts of one's self from others*, describing a psychosocial process. This core category was central in the data and could be related to all other categories. During the entire process of analysis, ideas, preliminary assumptions and theoretical reflections were written down in notes or memos (Glaser and Strauss 1967). Finally, the interview transcripts were re-contextualized to secure that categories were supported by the raw data.

Results

Hiding parts of one's self from others

The participants' apprehension about having been diagnosed with ADHD and the medication related to it were strongly associated with feelings of lack of normalcy and fear of being regarded as different from others by friends and schoolmates. They viewed the diagnosis and the medication as essential to their health and well-being, but had to keep both as absolute secrets from their schoolmates and reference groups. The participants described how they would lose their dignity if they had to tell others about their neuropsychiatric diagnosis and the medical treatment they were prescribed for it. In everyday life they tried their utmost not to deviate from other schoolmates and friends, but rather to show normalcy and to be like everyone else, and also not to talk too much so as to avoid disclosing weakness or anxiety. The category 'hiding parts of one's self from others' describes how difficult and stressful it was for these teenagers to live normal lives with their diagnosis. They balanced between their own acceptance of the diagnosis and the medication and a wish for normalcy and being like everyone else. In company with schoolmates and friends they struggled to be seen as normal people, and tried to keep their diagnosis a secret all the time by hiding parts of themselves. This, however, forced them to always think about their deviation from normalcy. With their families they could be relaxed and 'open' because their parents and siblings knew about their diagnosis and treatment, and they could be accepted and loved as the people they actually were:

I don't want the whole school knowing I have ADHD, I don't really want anybody to know. People who take medications get bullied, I was afraid of being bullied.

I wish that this diagnose vanished, so I became normal, as everyone else.

Being different from others

According to the interviews, the participants' self- image was that they deviated from normalcy and thus they were different from others. Before they had received their diagnosis, when they were younger, they had not at all thought about themselves as deviating from normalcy or being different from others in their age. But after receiving the diagnosis of ADHD they began to think about themselves as deviant, with special characteristics and habits, and they started to compare themselves with their school mates and friends. The feeling of not being like others in the reference group was difficult for the teenagers to bear. Although they felt that they deviated from normalcy, they expressed in the interviews that it was difficult for them to build a personal identity or a realistic image of themselves because they did not feel comfortable incorporating the diagnosis of ADHD:

I wish I could get rid of my diagnosis, it holds me back in relation to girls // I'm active, talk a lot and sometimes I say something dumb when I get my steam up, can't keep a handle on what I'm saying, which I find upsetting. // Just the idea of talking to a girl alone, I don't dare to try it. I see ADHD as a disability.

Wishing to be like everybody else

This category revealed how ashamed the teenagers were of their diagnosis. All the time at school or with schoolmates they tried their utmost to be 'normal'. They felt objectified and embarrassed about having been diagnosed with such a (as they thought) humiliating diagnosis. All participants explicitly stated that if they could choose freely they would not want to have a neuropsychiatric diagnosis (such as ADHD) owing to the shame associated with psychiatric diseases. They also described how they wanted and struggled to function cognitively just like everyone else. Having to put so much effort into trying to be like everyone else and not to deviate from 'normalcy' took a lot of energy from the teenagers when they was at school or with their friends:

I stay calm in class at school so no one will notice I have ADHD, at least I think I stay calm. I try not to talk too much. // I laugh too much, and I think people may find it painful, so I have to stay calm, I'm afraid of not being taken seriously, that's upsetting.

Keeping the medical treatment secret

The teenagers who were on medical treatment all felt that the medication had positive effects on their health, and that the problems associated with the diagnosis decreased. Taking the medication was acceptable as long as none of their schoolmates knew about their diagnosis and treatment. If it had been possible, they would have stopped taking the medicine out of fear of what other people would think about them. They had an ambivalent attitude toward their treatment – it reduced their disease-related symptoms, but it made them different from others. It was stigmatizing that other

people could have negative thoughts about them owing to their medication with amphetamines:

I think taking medicine is a problem, I don't tell anybody I take medicine. I'm so scared of being caught that I go home from school to take my medicine. I live near school.

Feeling worried about the future

The teenagers stated in the interviews that they were worried about the future and that they had feelings of being less good and competent than others. They perceived the future as unpredictable and insecure. They did not know whether they would be able to get an education that would lead to a meaningful job or if they would be able to find a partner to love and with whom they could settle down and live together. It was a common opinion about the future that having a diagnosis of ADHD meant being different from others and that nobody would want to marry or live together with a person who is different and deviant from normalcy. The teenagers were worried about the possibilities of getting a real job and being able to manage it. Would anybody offer them a job and would they be able to wake up in the morning without daily help from their parents? They wished to have flexible jobs where they themselves could decide about the structure and timetable for the day. They thought that if they told a future employer about their diagnosis, they would not get the job at all:

Without mom I wouldn't be able to function, she makes sure I get my medicine at the right time, that I take food along to school, and she arranges my breakfast. I'd be late for school otherwise. Without her my everyday life wouldn't work out, she's the most important person in my life. I'm not at all sure how things will be in the future, when I have to move away from home.

Overview over the results

In the analysis of the data, *having to hide parts of one's self from others* emerged as the core category and described the participants' every day struggle of hiding parts of themselves from others when being diagnosed with ADHD. Four categories related to the core category also emerged in the data and were labelled *being different from others*, *wanting to be like everybody else*, *keeping the medical treatment secret* and *feeling worried about the future*. These categories further described the participants' everyday lives and their having to hide parts of themselves from others. Their wish was to adjust to social norms and to be just like other teenagers. They felt comfortable and satisfied in their families, but at school and together with their reference groups or their schoolmates they did their utmost to 'fit in' and be just like everybody else by hiding parts of themselves. The participants described how they feared facing disclosure of both having a neuropsychiatric diagnosis and being on medical treatment for it.

Discussion

The aim of the study was to reveal the main concerns about daily living with the diagnosis of ADHD as experienced and narrated by ten teenagers in Sweden and Norway. Everyday living is influenced by having the diagnosis of ADHD. According to the study, the teenagers were not necessarily fully aware of the difficulties in their

situation. The participants had a desire to be like everyone else and not to deviate from others, while their self-perceptions were influenced by their efforts to hide both their problems (behavioural and others) related to the diagnosis in everyday life and the medical treatment they received. Feeling apart and not like others was central to the everyday lives of the participants. It has previously been reported that young individuals with the diagnosis ADHD have a distorted sense of self (Krueger and Kendall 2001; Shattell, Bartlett, and Rowe 2008), and this is probably one reason why several investigations have reported low self-esteem (e.g., Barber, Grubbs, and Cottrell 2005; Ek et al. 2008). The attitudes towards ADHD in society, for example the way media reports criminality in individuals with ADHD or debating medication with stimulants, could play an important role in this respect. Especially young individuals without a stable identity are vulnerable to media exposure (Trulsson et al. 2002). Another reason for the low self-esteem could be that ADHD is more stigmatizing than many other medical conditions (Law, Sinclair, and Fraser 2007; Walker et al. 2008), which many young people with ADHD are likely to be well aware of. However, this was not revealed in the interviews as of any major concern for the informants. Instead the informants' descriptions in relation to self-esteem referred more to being ill or not feeling well. The background for the stigmatization is not fully known, but again the role of media as well as lack of knowledge about ADHD in the society in general are likely to play a role. A possible stigmatization of individuals with ADHD points to needs for better information, maybe targeting children's or peer's knowledge and attitudes.

The reference group, the group you belong to or the groups to which you have a desire to belong, was important to the participants. During the teenage period, the reference group takes over the family's role as normative (Trulsson et al. 2002). The reference group has an important role to play in the development of the young individual's identity, which was also significant in the category 'being different from others'. Previous studies have also shown the importance of being like others in the reference group (Trulsson et al. 2002).

The category *being different from others* describes how difficult it is for teenagers diagnosed with ADHD. The diagnosis is embarrassing and they want to hide it from others, and they also have feelings of shame. They are afraid of being disclosed and regarded as someone else other than the person they want to be. This is important to bear in mind for professionals who meet teenagers with the diagnosis ADHD. The concept of shame is often discussed in relation to disability (Scheff 1997). The findings of the participants being ashamed of having ADHD is in agreement with findings from the USA (Krueger and Kendall 2001; Kendall et al. 2003).

Keeping the medical treatment secret describes how the participants are ambivalent towards their medication. They experience that the medication makes everyday life easier but at the same time they consider it important that no one else discover that they are on medication. Our identity is strongly associated with how we are seen by others (Frones 1994), and we construct ourselves by letting other see us in a special way. To be seen as a drug user and as a person whose brain does not function without medicine is a risk project for the teenagers. It is important for the teenagers to follow the norms set by the reference group. Keeping medication secret has been suggested to be associated with shame of the diagnosis in previous studies (Krueger and Kendall 2001; Kendall et al. 2003). This strengthens the findings in the present study. It is only logical to try to keep shameful properties secret. Medication

itself is also a very tangible reminder of the underlying neuropsychiatric problem, and thereby a bearer of the stigma the informants described.

It is well known that medical diagnoses, especially diagnoses involving neuropsychiatric or psychiatric problems, imply an increased risk of stigmatization (Corrigan 2007), and that these ideas can be internalized by people with illnesses. Participants in the present study described living lives in which every day and every situation were affected by the neuropsychiatric diagnosis. The existence of the problem points out the great need for support to individuals with ADHD from an early age, targeting both the school situation/achievement and social interaction with others. Furthermore, society needs more information and education about different disorders, including neuropsychiatric disorders, in order to prevent ignorance and prejudice (Crisp et al. 2005; Thornicroft et al. 2008).

Being dissatisfied with oneself is not unusual in western society, where we value beauty, vigour, intactness and health (Cronan 1993), which are all challenged by having a diagnosis of ADHD and being on medication. Thus teenagers are afraid of being regarded as less attractive to others. Earlier research shows that people like others who share their backgrounds and references (Newcomb 1956, 1961), to find out if that is the case, individuals need to get to know each other on a deeper level, which is time consuming (Ernulf 1995). The participants in the present study described how they did not want others to know about their diagnosis and it was considered as important to make a positive impression on others.

The primary finding in the present study is that teenagers with the diagnosis ADHD strive to be like everyone else and therefore experience having to hide part of themselves from others in relation to other teenagers, in order to live up to social norms in society and in their reference groups. They are afraid that if their diagnosis was known to their reference group, they would be excluded.

Acknowledgements

The authors are grateful to all the participants who shared their thoughts and feelings with them. The authors thank Västra Götalands regionen, Handikapp kommittén, for financial support to the present study.

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