Living at the edge of one’s capability: Experiences of parents of teenage daughters diagnosed with ADHD

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Abstract
Living with a child with a disability is often perceived as a permanent stressor to the family and it affects all aspects of family life including the well-being of family members. Since little is known about parenting teenage daughters diagnosed with ADHD, the aim of the study was to gain a deeper understanding of the main problem involved using a grounded theory approach. Interviews were carried out with 12 parents, 11 mothers and 1 father, of teenage daughters diagnosed with ADHD. The parents’ situation was conceptualized as living at the edge of one’s capability with the properties having the sole parental responsibility, fighting for professional support, being on duty around the clock and trying to solve family conflicts. Parents described how their health was negatively affected by their life situation.

Key words: Grounded theory, ADHD, teenage girls, parents, well-being

Introduction
The definition of the symptoms included in what is presently known as Attention Deficit/Hyperactive Disorder (ADHD) has shifted over time: from Minimal Brain Damage/Dysfunction (MBD) through Attention Deficit Disorder (ADD) to ADHD. The diagnostic criteria presented in DSM-IV include either deficits in gaining and maintaining attention, or hyperactivity, which means being easily distracted by stimuli, or both attention deficits and hyperactivity. This means that individuals can be diagnosed with AD and/or HD, whereas girls are more likely to have AD. The prevalence of ADHD is estimated to about 5% of all children (Gillberg, 1996). This makes ADHD one of the major public health problems of our time (Gillberg, 1996).

It is easier to observe symptoms related to the diagnosis ADHD in men then in women (Walker, 1999; Szatmari, Offord & Boyle, 1989), because men diagnosed with ADHD are often more extroverted and have more hyperactivity deficits (Arnold, 1996). Women diagnosed with ADHD seem to have more attention deficits than men do (Gaub & Carlson, 1997; Biederman & Spencer, 1999). Women, for example, often have more introvert difficulties such as depression, shyness, anxiety and difficulties in listening. It has also been suggested that women diagnosed with ADHD have more problems related to their intellectual functions than men do (Nyden, Hjelmquist & Gillberg, 2000). This means that women diagnosed with ADHD are more difficult to identify. Consequently, aspects of having the diagnosis ADHD have only been sparsely studied in women.

It is suggested that in adolescence major changes in the condition of the children diagnosed with ADHD can occur; their attention and hyperactivity deficits may increase or decrease (Gillberg, 1996). For a small number of teenagers the problems decrease, but for many teenagers the problems become increasingly worse. There seems to be a risk of developing drug addictions for teenager with ADHD (Farone, Biederman, Mick, Williamson, Wilens & Spencer, 2000). It is suggested that more teenage girls with the diagnosis
ADHD are smokers (one of five) and have tried some kind of drug (4%) than teenage girls without this diagnosis (Biederman & Spencer, 1999). Further, teenage girls with the diagnosis ADHD have an increased risk of becoming pregnant, as compared with teenage girls without the diagnosis (Arnold, 1996). That is suggested to depend on a misdirected need for confirmation in teenage girls diagnosed with ADHD (Arnold, 1996).

Living with a child with a disability is perceived as a permanent stressor to the family and it affects all aspects of family life. In a long-term perspective, this may affect the well-being of family members (Seltzer, Greenberg, Floyd, Pettee & Hong, 2001). Barkley (1991) has suggested that mothers of teenage girls with the diagnosis ADHD are more critical of their children than are mothers of boys with the diagnosis ADHD. Previous research has shown the importance for the parents of a balance between the subjective feelings of vulnerability on the part of these families and perceived access to support from others in order to develop self-reliance and reconciliation (Trulsson & Klingberg, 2003). Studies have shown that families with a child with a disability are often larger, have a lower level of social activities and the parents work fewer hours than others do (Malick, Greenberg, Floyd, Pettee & Hong, 2001). In families with a child with a disability, the mothers run a particularly increased risk of lower psychological well-being due to the stress in their life situation. Therefore, it is important not only to treat the child with a disability but also to provide the whole family with support and instrumental assistance so they can retain and/or increase their psychological and physical well-being. For parents who adjusted well to their life situation, the quality of the marriage was seen as the greatest source of new energy (Gallagher, Cross & Scharfman, 1981).

Aim

The aim of the present study was to explore the main concern of being parents of teenage daughters diagnosed with ADHD.

Method

Grounded theory

In the present study, the inductive qualitative research method of grounded theory was used (Glaser & Strauss, 1967). Grounded theory is rooted in symbolic interactionism and it includes the belief that meaning is constructed and changed by interactions among people (Mead, 1969). Grounded theory is a product of pragmatism and factor analysis (Schreiber, 2001). The aim of the method was to reveal the participants’ perspectives of the main concern under study and to develop a theory, model or concepts in order to explain and/or predict a phenomenon rather than to test a hypothesis based on existing theories. Grounded theory is especially suitable for studying areas where little is yet known, when wanting to gain a deeper understanding of a phenomenon or to gain new knowledge of an area already explored. Grounded theory is also a suitable research method for studying social processes. Grounded theory seemed to be the most suitable research method in the present study because the research question concerned the process of being the parent of a teenage daughter diagnosed with ADHD, which is an area that has only been very little studied to date. Although there have been several attempts to describe the life situation of parents with children suffering from diseases and/or disabilities, few (if any) attempts have been taken to describe the life situation and well-being of parents of teenage daughters diagnosed with ADHD.

Originally, grounded theory was developed by the two sociologists Glaser and Strauss, whose work is now referred to as classical grounded theory (Glaser & Strauss, 1967), in order to develop a new perspective on phenomena that could not be surveyed with quantitative methods. Classical grounded theory can be seen as having an ontological position close to positivism, because it is implicitly assumed that there is a real reality out there that can be discovered by emerging categories without being affected by the “objective” researcher (Hallberg, 2006). According to Glaser and Strauss (1967), “all is data” and what is important in the studied field will emerge. Strauss, in collaboration with Corbin, went on to develop grounded theory, which is now referred to as reformulated grounded theory (Strauss & Corbin, 1990). The basic methodological principles were maintained, but Strauss and Corbin stated that the researcher interprets data rather than categories are emerging. They also stressed the importance of listening to the voice of the informants. Ontologically, their position seems to be more post-positivistic (Hallberg, 2006). Later, Charmaz (1995, 2000) developed a constructivist grounded theory aimed at giving an interpretative picture of the studied area. Ontologically, she argues that there are many realities, rather than the one and only “real reality”, and argues that “grounded theories are constructions of reality” (Charmaz, 2006, p. 10).

Study group

The study group consisted of a strategically selected group of 12 parents (1 father) of teenage daughters.
One of the participants had twin daughters, both diagnosed with ADHD. All were living in western Sweden. According to grounded theory, a strategic sampling of participants is recommended to maximize the variations of experiences in the group studied (Glaser & Strauss, 1967). The sample included single and married parents, parents with both long and short education parents who were native Swedes as well as immigrants, also parents whose daughters were diagnosed for a long time ago and parents whose daughters were recently diagnosed. One of the parents was diagnosed with ADHD. At the end of the data collection, a theoretical sampling was done in order to convey all different types of backgrounds in the participants and to saturate the data. The participants were found by advertisements at the support centre, Dampens Hus, or by advertisements in the local newspaper where they were asked to call the interviewer (UH, a sociologist and doctor of public health science) to schedule a time for the interview. The participants were given verbal and written information about the study. They were also informed that they could terminate their participation at any time without having to justify withdrawal. The interviewer was not known to the participants in advance.

Qualitative interviews
An open-ended, audiotaped interview, lasting approximately 60–90 min, was conducted in a conversational style with each participant. The interviews were carried out in a quiet room at the Nordic School of Public Health by one of the members of the research group (UH). An interview guide was used; it concerned the participants’ experiences, thoughts and feelings about being the parent of a daughter diagnosed with ADHD. Themes such as daily family life, the diagnosis, social participation, sibling’s situations and role, and the future were included in the interview and were raised by the parent and/or the researcher in a conversational way. Accordingly, the participants had the opportunity to raise questions of relevance to them and the interviewer asked relevant follow-up and probing questions during the interview. Open-ended interviews require active and engaged involvement of both researcher and participant in responding, clarifying and elaboration of communication. Data was created by this process and the quality of data was influenced by the trustful relationship between researcher and participant (Hammersley, 1987). Data collection and analysis were conducted simultaneously and continued until new interviews did not provide additional information, i.e. until saturation was reached.

Analysis
The interviews were transcribed verbatim and analysed using open and selective coding processes (e.g. Glaser & Strauss, 1967). Open coding means line-by-line reading of the data with questions to the data being raised; “What is being expressed here? What is the meaning of this?” The substance of the data was captured and segmented into substantive codes, which were labelled concretely. The process of open coding resulted 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/properties were sought and data were put together into a new whole. In the selective coding, categories/properties were saturated with additional information, assessed by new interviews or added by re-coding previously assessed data, i.e. theoretical sampling. A core category was identified as a psychosocial process, describing the main concern for parents of daughters diagnosed with ADHD. This core category was central in the data and could be related to four additional categories/properties. During the entire process of analysis, ideas, preliminary assumptions and theoretical reflections were written down in notes or “memos” (Glaser & Strauss, 1967). Finally, the interview transcripts were re-contextualized to ensure that categories were supported by the raw data.

Results
In the analysis of data, five conceptual categories were identified showing the parents’ strained life situation and what it means for them to live with teenage daughters diagnosed with ADHD. The parents in the present study had a significant burden to carry in having responsibility for their teenage daughters; a heavier burden than they felt they could handle appropriately. The core category, living at the edge of one’s capability, describes the main concern for the parents and the related categories further illuminate and explain this core category. The four categories/properties related to the core category were labelled as having the sole parental responsibility, fighting for professional support, being on duty around the clock and trying to solve family conflicts. All categories/properties are further described below and quotations from the interviews illustrate the categories.

Living at the edge of one’s capability
The parents described their life situations as “living at the edge of one’s capability”. This was identified as the core category. Their life situations were
strained: they struggled to live “normally” in spite of significant and repeated problems with their teenage daughters. Sometimes during particularly difficult periods the parents could not relax or sleep because of the heavy burden, for example when they had to watch over their daughters who were threatening to commit suicide, or to take an overdose of medication. Sometimes the participants were unable to sleep for several nights because of their daughters required constant monitoring. Participants claimed that they had no private life at all; their whole life was committed to just taking care of their daughters, sometimes even after they were grown up. This made it difficult for them to enjoy being parents and they felt a sense of resignation. Participants claimed that they had “hit the wall”. They said that they were tired of being a parent and wanted someone else to take over the parental responsibility for their daughters. At the same time, they loved their daughters so much and they wished things would get better for them so they could live a normal life within the family. The mothers in the present study had largely developed stress related diseases themselves, including chronic pain and different physical and/or psychosomatic symptoms. “So I just thought, oh no. I’m giving up on her now. I won’t go out looking for her this time. I just don’t have the energy for it any more.”

Having the sole parental responsibility

Most participants in the study lived as single parents and felt no support from the other parent; i.e. they had the sole parental responsibility for their daughters. In the present study, all daughters who lived with a single parent lived with their mothers and the father was usually an absent parent. The parents had either divorced during the early years of the child’s life or separated before the child was born. A couple of the mothers were widows. The participants had little or no contact with their daughter’s other parent, in this case the father. One of the strategies adopted by the mothers, voluntarily or involuntarily, in order to manage their strained life situation was to struggle alone with the parental responsibility. If the parents were divorced, it was most common, according to the interviews, that the mothers had to be the negotiator between the daughter and her father in order to help them to have some kind of contact. According to the mother’s impression, the fathers could not manage their teenage daughters’ disabilities very well. This made the mothers feel they were alone with the parental responsibility for their daughters. Some of the single parents wished to meet a new partner but felt that it was impossible owing to their daughters’ disabilities. They were disturbed by their daughters in their efforts to start a new, better life situation for themselves and they felt responsible for their children in a way that prevented them from having the time and strength to create a life with a new partner. This made them feel stuck in their responsibility and even more alone with the responsibility for their daughters.

I met a man and we were a couple for a while but then he couldn’t cope with her any more and I realized she was coming in and disturbing us the whole time. If we were watching TV and she had gone to bed—she lived at home then because she was younger—she would come out and disturb us about every two minutes with ‘I’m hungry,’ ‘I want this or that,’ ‘What are you sitting here for’ She just kept finding reasons to disturb us . . . but he couldn’t cope with her at all, and she was really nasty, and ugh. I tried again five years later but that relationship didn’t work out either, and since then I’ve given up.

Fighting for professional support

The participants felt they had no support from their daughters’ schools or from society in general to increase their well-being and life situation. Often the parents had to fight for many years in order to get a professional examination and diagnosis for their teenage daughters. After diagnosis was finally established they often felt abandoned and without professional support. The parents claimed that the social welfare authorities did not know how to treat or manage their daughters. The participants claimed they never had been informed about what kind of help was available, practical and financial; they had to find out themselves. Almost all the participants stated that they were unable to work full time because of the burden of looking after their teenage daughters. The parents in the study had been forced to take a lot of sick leaves owing to their life situation. This gave them a difficult financial situation and they felt a need for social benefits. Many of the girls in the study went to ordinary schools but all of them had significant problems with their studies. The parents also felt no support or understanding from the teachers or administrators at school and consequently many of the girls had dropped out of school or they were suspended.

School has been a plague since the very beginning. And all the conferences with teachers have been, well, not developmental as they are supposed to be but just, like . . . the worst things you could imagine. They were always so negative. And she was
always the reason if … if anything went wrong at school it was always her fault.

**Being on duty around the clock**

The participants described their control functions over their teenage daughters. They were on duty around the clock in order to help their daughters. They had to make sure that their teenage daughters woke up and got out of the bed in the morning, and took their medicine if they were on medication. They also had to help their teenage daughters through difficult situations, like threat of losing their domiciles because of the many domestic disturbances and other similar situations. The parents sometimes felt controlled by their teenage daughters. The girls phoned their parents several times a day and if the parent did not answer, their teenage daughters were upset. The parents said they had to drop everything and drive where the child was and try to make her feel better. This made it impossible for the parents to go far from their home cities. Going on vacation was almost impossible if they could not find someone else whom their daughters trusted to take over the responsibility while they were away. It was also difficult, if not impossible for the parents to start an educational programme or get a job outside their home town. The parents also felt that they could not trust their daughters in making the right decision and taking control of their own lives. The well-being of their daughters could change rapidly and over a short time, sometimes in an hour. Some daughters of the informants in the present study had made several suicide attempts, which increased the parents’ anxiety and their control function.

Always being on duty, yes, and always being monitoring. Plus the constant concern about what she was up to. Would she get through this day or would she be taking an overdose? Would she be alive tomorrow? It’s that constant worry. And everybody always asking ‘So, how’s your daughter doing?’ and having to answer ‘Well, I don’t know how she is right now but I talked to her two hours ago and she was okay then, but now, who knows …?’

**Trying to solve family conflicts**

The participants described conflicts with their daughters’ other parent. If the parents were still living together, they had daily conflicts with each other about their teenage daughters. The conflicts could concern who had the most responsibility or how to treat and help their teenage daughters. If the mother lived alone, she had repeated conflicts with the absent parent trying to make him take more responsibility for their child or trying to explain to him the needs of their teenage daughter. Some of the teenage daughters had abuse problems, which led to repeated conflicts between the parents and the child. Many of these teenage girls used narcotics or abused prescription drugs and they had friends who also had abuse problems. It was common, according to the participants, that the teenage daughters had assaulted the parents, especially the mothers, so badly the parents had to call the police for help. It was also common that the teenage daughters had called the police or threatened to commit suicide when their parents had tried to put a limit for them or punished them. The participants described how almost every day included major or minor conflicts with either the teenage girl or the other parent that the participants had to solve.

“I’m going into town to be with my friends.”
“No,” I said, “you aren’t going out that door”. “Oh yes I am.” And then, well of course there was chaos again. So she pulled out a … carving knife. Fucking bitch, I am going into town. Do you get what I’m saying? I’m going into … I’m going to be with my friends. And it [the carving knife] was waving around, and she threatened to take her own life because she is in such bad shape and all that.

**Discussion**

This study reveals the strained life situation of parents with teenage daughters diagnosed with ADHD. The core category “living at the edge on one’s capability” illuminates how these parents are exposed to long-term stress, which affects their physical and psychological health. Parents in the study also described how their health was affected by their life situation. Further, mothers also often struggle without support from the other parent and without support from society or from their teenage daughters’ schools. They also had a control function over their daughters in their efforts to increase their daughters’ well-being and prevent their suicide attempts. In addition, they had to solve family conflicts, sometimes both with the other parent and conflicts with their teenage daughters. They sometimes had to seek help from the police in order to resolve these conflicts.

The basic question we have tried to elucidate in the present study is “what problems are associated with being a family with a teenage daughter with the diagnose ADHD?” As is clear from the interviews the burden of stress is heavy especially on the mothers. This is in line with research showing that having a
child with attention deficit problems generates more stress than having a child with “only” a motor disability (Wade, Taylor, Drotar, Stancin & Yeates, 1998; Warfild & Hauser-Cram, 1996; Henderson & Vandenberg, 1992). Mothers of children diagnosed with ADHD have also previously described how they always feel “on alert” and with no “normal” routines in their lives (Cronin, 2004). Especially the mothers describe particular stress related to the family situation, and it has been proposed that special efforts aimed at the mothers should be offered (Kendall, Leo, Perrin & Hatton, 2005). Neuropsychiatric problems can lead to unforeseen actions (behaviours) that are difficult to handle. The attitudes of society are also often negative towards this kind of problem.

The core category, “living at the edge of one’s capability”, and the four categories/properties related to the core category, all encompass aspects of the parent feeling abandoned and left with little support, alone in fighting for professional support, trying to solve family conflicts and being on duty as a parent 24 hours a day. One way of looking upon these all-embracing tasks is to acknowledge that because the mother is the person the daughter puts all her trust in, the mother is the person whom to insult and offend. While the mother all the time looks for guidance and relief, she perceives that no one but she herself, manages to care for her daughter.

Several teenage girls in the present study took daily stimulant medication in order to make their life situation better. The parents described how the stimulant medication became problematic because the girls had difficulties in managing to take the correct doses themselves. Often the girls wanted to take more medication than the doctors had prescribed and accordingly the parents had to “guard” the medication to prevent overdoses. Parents of teenagers going on stimulant medication for their ADHD diagnosis revealed a dilemma for the desirable effects of the medication and the undesirable feelings on letting their children take the medication (Hansen & Hansen, 2006). Teenagers themselves describe how the medication helps them to lead normal lives (Knipp, 2006).

As often in this kind of research (and perhaps in “real life”) the fathers are absent. This was also true in the present study where mostly mothers were interested in participating. The focus of this study has mainly been on problems as perceived by mothers. Of course, it would also be possible to focus on coping strategies used by the mothers, or on coping resources among mothers, or on the relationship between the mothers and fathers, or on disabling barriers in society, or on positive aspects of being a mother of a girl with the diagnosis ADHD.

There seem to have been a shift in the studies of families with a child with a disability in any respect during the latest decades. Focus has changed from almost exclusively pathology or deviations in these families (regarding stress, family system, family function, presence of psychiatric disorders, etc.) to including adaptation strategies correlating with “positive” and “negative” developments in the families, and even positive aspects of having a child with a disability. In the area of disability research, the focus today is on disabling barriers in society hindering persons with disabilities and their families from living full lives. All these aspects are subjects for future research.

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