

Struggling with and for A Grounded Theory of Parents Managing Life with Hard-to-Treat ADHD Teenagers

Berit Støre Brinchmann, University of Nordland and University of Stavanger
Henrik Sollie, Norwegian University of Science and Technology

Abstract

The aim of this study was to develop a grounded theory of being a parent of hard-to-treat teenagers with the diagnosis of ADHD. Caretakers of 11 adolescents with ADHD were interviewed and analyzed according to the principles of classic grounded theory. The parents' main concern was how to handle everyday challenges with the teenagers and how to get the help they needed and required. *Struggling with and for* is the core category in our findings. In addition, we identified four sub-categories: *good "mothering", advocating, seeking support, and giving up*. The meeting with the helping services causes just as many problems as the relationship with the teenagers. Professionals should be able to identify family strengths and capabilities. In that way, professional support can be built upon coping strategies with which a family is already familiar.

Keywords: ADHD, coping strategies, grounded theory, parents, professional services, teenagers

Introduction

Attention-deficit/hyperactivity disorder (ADHD) is one of the most common childhood psychiatric conditions. The core symptoms of inattention, hyperactivity and impulsivity affect the child's adaptive functioning. In addition, a high proportion of children with ADHD present with comorbid conditions such as oppositional and conduct disorders, anxiety and depressive disorders, tics, and Tourette's disorder, with implications for impairment and clinical interventions (Barkley, 2006; Brown *et al.*, 2001; Gillberg *et al.*, 2004; Steinhausen *et al.*, 2006). Studies have also shown that co-occurrence of clinically significant ADHD and autistic symptoms are common (Reiersen & Todd, 2008). An extensive review estimates an ADHD worldwide prevalence rate of 5.3 percent, but with a substantial variability across studies (Polanczyk, de Lima, Horta, Biederman & Rohde, 2007). Methodological characteristics such as diagnostic criteria, source of information, and the requirement of impairment for the diagnosis were associated with the different prevalence rates. A majority of children diagnosed with ADHD continue to meet criteria for the condition during adolescence (American Academy of Child and Adolescent Psychiatry, 2007; Faraone, Biederman & Monuteaux, 2002; Mannuzza, Klein & Moulton, 2003), but the symptoms of hyperactivity and impulsivity tend to decline at a higher rate and at an earlier age than the inattention symptoms (Biederman, Mick & Faraone, 2000).

Compared with parents of children in normal population samples, parents of children with ADHD report consistently more demanding, disruptive, disorganized and impulsive child behavior with a significant impact on homework, family routines and playing with other children (Coghill *et al.*, 2008). Children with ADHD and comorbid disorders display poorer functioning than children with ADHD alone, and negative effects on quality of life have been reported across several psychosocial, achievement, and self-evaluation domains (Booster, DuPaul & Eiraldi, 2012; Danckaerts *et al.*, 2010; Escobar, Soutullo, Hervas, Gastaminza, Polavieja & Gilaberte, 2005; Wehmeier, Schacht & Barkley, 2010). Two comprehensive reviews present studies documenting associations between child ADHD and family and parental characteristics; such as higher rates of parental psychopathology, conflicted parent-child relationships, disturbances in marital functioning, inconsistent parenting practices, and reduced parenting self-efficacy (Johnston & Mash, 2001; Deault, 2010). Several studies also report high levels of parenting stress among families of children with ADHD (Anastopoulos, Guevremont, Shelton & DuPaul, 1992; Reader, Stewart & Johnson, 2009). The elevated levels of stress may result from the ADHD symptoms themselves, comorbid conditions, and the demands and challenges experienced by parents because of the child's behavior.

When ADHD persists into adolescence, the youth and the parents are faced with additional challenges related to normal developmental tasks of autonomy and individuation. The teens may question both the label of the diagnosis and different treatment regimes, impulsivity may result in potentially dangerous activities, and, increasingly, attentional and organizational capacities are required for academic success (McCleary, 2002; Williamson, Koro-Ljungberg & Bussing, 2009). The parents must cope with stressors that arise from the child's behavior. Lazarus and Folkman (1984) define coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984 p. 141). Coping research has identified two major groups of coping strategies: efforts to alter the cause of the stress (problem-focused coping), and efforts to regulate the emotional responses to stressors (emotion-focused coping). The problem-focused coping may include active problem-solving and aggressive interpersonal coping. Emotion-focused forms of coping involve strategies such as denial, detaching from the demanding situations, or blaming oneself for the problems (Judge, 1998), but also efforts to reduce emotional distress confronted with stressors not easy to change.

The challenges faced by parents when rearing a child with ADHD may be perceived in different ways, resulting in different coping strategies. Experiences from living with a child with ADHD have been described by several authors (Bull & Whelan, 2006; Firmin & Phillips, 2009; Hallberg, Klingberg, Reichenberg & Møller, 2008; Harborne, Wolpert & Clare, 2004; Moen, Hall-Lord & Hedelin, 2011), and more specifically, different family management styles have been described (Kyle, Conlon, Strassle, Vinh & Trout, 2008; Kendall, 1998; Kendall & Shelton, 2003). Seeking professional support is an important theme in parents' coping with the challenges related to the rearing of a child with ADHD. In Norway, children with ADHD have a high level of service use compared with children with internalizing problems, and most children with ADHD have been in contact with school services and special mental health services (Heiervang *et al.*, 2007). This may be due to the disruptive and academic consequences of the ADHD symptoms. In addition, a diagnosis of ADHD is required to initiate a medical

treatment. Even if the rate of service use is substantial for children and youth with ADHD, too little is known about the perceived helpfulness of these services.

The aim of this study was to develop a grounded theory of being a parent of hard-to-treat teenagers with the diagnosis of ADHD.

Data and Method

The informants were recruited from a follow-up study of parents of children who had been assessed and diagnosed with ADHD at one of five child psychiatric outpatient clinics in middle Norway. Because the aim of the study was to develop a grounded theory of being a parent of hard-to-treat teenagers with ADHD, the participants were recruited from a subsample of the participants in the follow-up study. The participants were recruited by at random from this subsample until we regarded the number of informants as adequate by using saturation of data as a guiding principle. Caretakers of eleven adolescents were interviewed and the informants were seven mothers, three fathers, one adoptive mother, two stepmothers and two stepfathers. Four of the mothers were single caretakers. At the time of the follow-up-study – one year before the interviews – all children except one fulfilled the parent-rated symptom criteria of ADHD Combined type, and all children were medicated for their ADHD symptoms. Three of the children were girls and eight were boys, and at the time of the interviews, the children were between 12 and 16 years of age.

The first author conducted eleven qualitative interviews with the parents in the period 2009–2010. Some parents preferred to be interviewed alone, others with their partner. The participants were encouraged to speak openly about the experiences that were most important, relevant, and problematic to them. The interviews focused on the youth's development in relation to significant persons and arenas, the parents' process of seeking help, and satisfaction with the help they achieved. Field notes were taken during the research process or immediately after data collection. Data collection and analysis occurred simultaneously.

All interviews were tape recorded and transcribed verbatim. In accordance with classic Grounded Theory (Glaser & Strauss, 1967; Glaser, 1978) the transcripts were analyzed several times and line-by-line using the constant comparative method. The analysis comprised open and selective coding, writing memos and theoretical sorting and coding. A core category and four subcategories were identified.

Fit, work and grab

Glaser & Strauss (1967) do not use the terms validity and reliability. The point is not whether another researcher will find the same categories to interpret the data, but if the findings are attention worthy. It is the final grounded theory that is evaluated, the theory must fit, have grab, and work (Glaser, 1978). Fit implies that the generated categories are indicated by data, and can be led back to data. This means that the researcher must be meticulous and accurate when data are coded, so that the categories represent data; one lets the data speak. This process must be conducted thoroughly, so that data are not forced into unfinished codes and categories that result in premature theory. This means that the theory explains what happens, predicts what will happen, and interprets what

happens. In other words, that the theory is useful in practice and meaningful for practice. Grab means that the theory is relevant for the participating group in practice. That the theory has grab will also imply that it is the easiest and the most striking one, that the material captivates the reader. During the research process, the findings were presented at national and international research conferences, and received good feedback from professionals who know the field and the issue.

Research ethics

All informants had received written information about the project. Confidentiality and anonymity were safeguarded according to ethical research guidelines. Informed consent was obtained from all participating parents. The study was approved by the Regional Committee for Medical Research Ethics, Health Region IV, and by the Norwegian Data Inspectorate.

The pre-understanding of the researchers

The first author is a researcher with a specialty in qualitative research methodology. She is also the parent of an adult with ADHD. The informants were informed about this, and it seemed that this inspired them to speak openly about their situations. The researcher was not only interested as a researcher or a professional, but she also had experience as a parent. The second author is a psychologist with long clinical experience with families of children with ADHD. He has conducted a follow-up study of parents of 217 children diagnosed with ADHD, and recruited the participants from the follow-up study in cooperation with the first author.

Struggling with and for

The parents' main concern was how to handle everyday challenges with the teenagers and how to get the help they needed and required. Their main challenge can be summed up as follows: How to cope with the everyday challenges of ADHD teenagers in the family?

The main category, struggling with and for, explains how the parents deal with their challenging situation with the help of the subcategories good "mothering", advocating, seeking support and giving up.

The teenagers are identified in three main typologies, as *elf*, *clown* or *bully*, while others may have features from more than one, for example, as elf and clown, bully and elf, or bully and clown. Both boys and girls may have features as elf, bully or clown. The clown does funny things, and acts as a type of Gyro Gearloose. He or she is well liked, and has many friends because they always come up with something strange or funny. Since they are mischievous and come up with so many ideas, both friends and family may become exhausted. The elf is quiet and withdrawn. A typical elf is the quiet and withdrawn ADD girl, who is introverted, has problems initiating, and can be easily overlooked. Both boys and girls had attributes from the elf. The boys are usually interested in computers, and some seem depressed, as they are lonely and have few friends. A last typology is the bully. When the kids were young and the parents picked them up from kindergarten, commonly, other kids told them about something bad that he or she had done that day. The bullies are seen as mean, and the other kids are often

scared of them. The bullies are angry and aggressive; they fight, are loud, and initiate unprovoked acts. While the clowns are charming and popular, the bullies are often lonely and without friends like the elves. Because they push people away by their behavior, both children and adults become scared and worried. The teenagers (*elf, clown and bully*) have immense problems concentrating and initiating, and need to be initiated and followed up in a different way than other teenagers.

Good "mothering"

Good "mothering" contains these strategies for the parents: nagging, cleaning, follow-up, motivating, supporting, consolidating, facilitating, helping with friends, helping with homework, medicating, controlling chaos, and building structure. The teenagers need support and follow-up in relation to diet, medication, and physical activity. The parents are continuously working on setting limits. One mother told that every night she had to go to sleep at the same time as her 15-year old son, so that he would calm down and fall asleep. The parents describe endless hours of homework help, much more than what is common for teenagers in the same age group. Providing homework help can be experienced as a great burden.

It is sad to see your son or daughter not having friends. When the kids were young, the parents could help to some degree in making friends, by involving other parents, teachers and other adults. Many of these teenagers have younger friends and lack a best friend. This is because they do not understand the social codes completely, and do not see themselves and what they do with others. The parents do everything they can to facilitate and create friendships, but to make friends for others is almost impossible. It is experienced as burdensome and exhausting to always nag, follow-up and watch out for the children. These teenagers with their "invisible" handicap are difficult for others to understand. The parents feel powerlessness and experience a lack of understanding from their surroundings. Moreover, they become tired of nagging. There are almost no limits to how far some parents would go to help and support their son or daughter.

I am there and work for her. You can manage what you want to, you will achieve everything you want to. I am sure you can move this mountain. I have to always work on her self-esteem. Usually you have to lower it down somewhat, but she must be built and built and built. But that is fine - I do that for her.

Advocating

The support system seems confusing. Parents have to deal with a variety of helping agencies and professionals, everything from school teachers and nurses, to psychological-pedagogical services, child and adolescent psychiatric outpatient clinics, the GP, psychiatrists, psychologists and child protection services. Despite noteworthy exceptions, and a few exceptional and positive individuals, meeting with professional services is experienced as discouraging. Lack of understanding, expertise, continuity, missing applications, and a general mess is common: "No one understood what we were really talking about," "I never met the GP," "Papers are sent back and forth - and then they end up just laying around."

The ADHD parents often experience just as many challenges in the meetings with the professional services as in their relationships with their teenagers. Paradoxically, the helping agencies that are supposed to support the families are experienced as an added burden. The parents therefore often act as the defense attorney for the teenager. Parents are looking for system cooperation. They often need to fight for their own rights and for those of the teenager. What they want and look for are professional services based on compassion and flexibility. They want helpers who show professional discretion, and they want more practical help. The strategies they use as parents are fighting, nagging, discussing, calling, writing letters and inquiring. The parents experience a lack of following up from the helping agencies, and despair and frustration when confronted with the rules and paragraphs. The consequence is that the parents grow tired of nagging those who are there to help:

What I feel is the most tiresome is that I have to watch that those who are supposed to be doing things are doing it. I always have to call and nag and nothing happens. Always fight. I do not have the rules in front of me but those who ask me do. Sometimes it seems they are asking unfair questions to prevent me from getting what is required.

Seeking support

We have now focused on the fight of the parents with the teenagers and their fight with the professional services. Frustrations and challenges are common, but also help and support from professionals and from their own network. The parents use the following strategies to seek help: being open about difficulties, using their own network, sharing experiences, and fighting for relief. Different things are helpful for the parents. Usually, it is about reasonable, wise and well-meaning individuals, whom they can trust, who can communicate and listen, and who are able to show discretion. Helpful relationships are of great importance. Parents wish that the teenagers can meet supportive adults. This is often about good flexibility, discretion, and continuity. A mother told about an opportunity to use user-driven assistance tools to pay her, instead of bringing strangers into the house. It was also possible to use these means for someone to clean, so that she could spend her time with her son.

It is not always easy for the surrounding social milieu to understand what type of challenges these families have to face. For that reason, they do not always receive the necessary support from family and friends. It is often easier to gain understanding from other ADHD parents and parents of children with other disabilities. Many speak about good support from trainers in sports teams and from foster parents. It often pays off to be open concerning the issues with the parents of classmates. Many parents are divorced and experience support and relief from their ex-partners. Many benefit greatly from foster parents and relief on weekends, especially on farms with animals:

We get to take a break one weekend each month. They have a small farm, and she enjoys being there. 'Mom, when you die, I will move there!' They have lots of dogs, chickens, sheep, rabbits and all kinds of animals, just great!

Giving up

Several parents of ADHD-teenagers are single mothers. Many are divorced with a new partner. Only two teenagers in the study lived with both biological parents. This may suggest that many marriages in families with ADHD kids are broken because of the strain and burdens in the family. The strategies used by the parents in this category are: divorce, react destructively, and boycott. Aggression and despair is common, which in many cases lead to escape, separation and divorce. Some speak of violence and abuse, and in many cases, the child protective services are involved. Earlier, we mentioned that ex-partners can be supportive, because they can contribute to relief. The relationship with ex-partners can also be demanding, because they and their new partners may boycott the correct diet and medication. Moving between homes and visiting parents with new partners and families can also be challenging, and are experienced as insecure for these teenagers, who more than others need a stable environment.

Discussion

The parents' main concern was how to handle everyday challenges with the teenagers and how to get the help they needed and required. The main challenge can be summed up in the following way: How to cope with the everyday challenges of having an ADHD teenager in the family. *Struggling with and for* is the main category. The parents of teenagers with ADHD fight a daily battle with the teenagers but also with the helping agencies to ensure the rights of the teenagers and themselves. When they struggle with and for, four different sub-categories are used: *good "mothering," advocating, seeking support and giving up*.

The teenagers in our study are identified as three main types – *elf, clown* and *bully*. These typologies are not comparable with the ADHD subtypes of inattention and hyperactivity-impulsivity, but rather a mixture of ADHD symptoms and symptoms of other disorders such as ODD, anxiety, autism spectrum disorders, and associated developmental problems. This finding is in accordance with studies that point to the high proportion of children with ADHD who present with several comorbid conditions (Barkley, 2006; Brown *et al.*, 2001; Gillberg *et al.*, 2004; Steinhausen *et al.*, 2006; Reiersen & Todd, 2008).

What I find most difficult is to distinguish what is what. What is ADHD? What is Tourette's? And what is teenage defiance? And then you have the third, Asperger's. It is not easy.

Because of the mixture of diagnoses and associated problems, many parents find it difficult to know what would be the best treatment and care for their children. For the parents, the diagnosis was not the most important aspect, but how to handle the multitude of daily challenges related to their child and family life. The challenges and the mastering strategies that our informants use match earlier qualitative research. A recent Norwegian study describes the parents' despair and sorrow, coping and hope, interacting with the social network, and dealing with people who are supposed to help (Moen *et al.*, 2011). The parents compare the child's receiving of the ADHD diagnosis to a grieving process. This study also focuses on the parents' ongoing struggle with the helping agencies, which is a main finding in our study as well. ADHD doesn't show outside. "Interaction with the network and professionals felt cumbersome and as such, became a burden." (Moen *et al.*, 2011, p. 447). In a Swedish study with parents of teenage daughters 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 (Hallberg *et al.*, 2008). These findings correspond in particular to our findings *good "mothering"* and *advocating*. This study also focuses on the high level of stress and conflict that often take place in these families. Many ADHD parents live as single parents, and thus have an extra parental responsibility (Hallberg *et al.*, 2008).

Some American studies present and discuss different family management styles: chaotic family, ADHD-controlled family, surviving family, and reinvested family (Kyle, Conlon, Strassle, Vinh & Trout, 2008; Kendall, 1998; Kendall & Shelton, 2003). The chaotic family is characterized by extreme stress, little internal and external support, and often overprotection, violence and other maladaptive parental behavior. The other management styles seem healthier and more functional. Kendall & Shelton (2003) suggest that the ADHD-Controlled family, the surviving family and the reinvested family could be viewed as a trajectory. "Where a family was located on this trajectory could be viewed as a function of the age of the child with ADHD and the length of time since diagnosis." (Kendall & Shelton, 2003, p. 278). Only one or two families in our study might suit the chaotic family management style. We agree that family management styles might be viewed as a trajectory. This also corresponds with the child's receiving the ADHD-diagnosis as a grieving process (Moen *et al.*, 2011). Parental management styles tend to correspond with the severity of the child's symptoms and the amount of support from the social network and the professionals.

As mentioned in the introduction, Lazarus & Folkman (1984) have identified two major groups of coping strategies: efforts to alter the cause of the stress (problem-focused coping) and efforts to regulate the emotional responses to stressors (emotion-focused coping). The problem-focused coping may include active problem-solving and aggressive interpersonal coping. Emotion-focused forms of coping involve strategies such as denial, detaching from the demanding situations, or blaming oneself for the problems (Lazarus & Folkman, 1984). In the light of coping research (Lazarus & Folkman, 1984; Judge, 1998), our categories *good "mothering"*, *advocating*, and *seeking support* are mainly problem-focused and include active problem-solving. As found in other studies (Bailey, Barton & Vignola, 1999), most parents used problem-solving coping strategies such as rational problem solving and seeking social support. *Advocating* might also involve aggressive interpersonal coping, when struggling with the helping agencies and professionals who don't seem to understand or seem unable to help. The category *giving up* is more emotion-focused. We would like to add, however, that emotions are also important for the parents' motivation and willingness to keep on fighting and struggling (*good "mothering"*). The parents seem to appreciate wise and well-meaning professionals whom they can trust, who can communicate and listen, and who are able to show discretion, are sensitive and understanding, problem-focused and emotion-focused. These parents experience an extreme amount of stress in their family life. It is understandable that their coping strategies include; problem-focused coping, aggressive interpersonal coping and emotion-focused coping depending on the child's impairment and support from the professional services (Moen *et al.*, 2011; Kendall & Shelton, 2003).

In this article, we wish to emphasize in particular the parents' struggle with the professional services. It is remarkable, and a great paradox, that the struggle with the support services can be experienced almost as intensely as the daily struggle with the teenagers. Similar findings are also reported in other qualitative studies with parents of

ADHD-children (Hallberg *et al.*, 2008; Harborne *et al.*, 2004; Moen *et al.*, 2011), by parents of disabled children (Brinchmann, 2005), and by family members of home ventilator patients (Dybwik *et al.*, 2011).

Limitations and strengths of the study

Many qualitative studies recruit the participants from parent associations (Moen *et al.*, 2011) or by advertisements (Hallberg *et al.*, 2008). One strength of the present study is the recruitment of parents from a follow-up study of children from regular child psychiatric outpatient clinics. All children except one fulfilled the parent-rated symptom criteria of ADHD Combined type, and all children were medicated for their ADHD symptoms. We haven't found similar studies on parents of hard-to-treat ADHD teenagers. However, the families were all native Norwegians, and they lived within a restricted geographical area in the middle of Norway.

The first author is the parent of an adult with ADHD. This information seemed to inspire the informants to open up, as the researcher was not only interested as a researcher or a professional, but also had experience as a parent. Combining the role of researcher and parent might cause problems, because personal experiences might lead to biases. We would consider this more problematic if she had had children at the same age as the parents in our study. The second author participated in the analysis, to manage possible researcher bias. The findings were also presented at national and international research conferences, and received good feedback from professionals who know the field and the issue.

Conclusions

The informants in our study often experienced just as many problems with the helping agencies as with their teenagers. The professional services that were supposed to support the family were seen as an added burden. The parents experienced that they had to act as the defense attorney for the teenager. They sought out cooperation with the system, and had to fight for their own rights and the rights of the teenagers. What they wished for and sought out was a support system based on compassion and flexibility. They wanted helpers who showed professional discretion and they wanted more practical help. The mastering strategies of the parents were fighting, nagging, arguing, writing letters, and seeking out. However, the picture was not all dark. The parents also told us about different things that were helpful to them, including the reasonable, wise and benevolent individuals who they could trust and who could communicate and listen and use discretion. Some informants spoke about helpful relationships and how they wished that the teenagers could meet these supportive adults. This was often about their flexibility, discretion, and continuity.

Implications for the clinics

The parents' experiences with the children's core symptoms of ADHD combined with additional difficulties and comorbid conditions underline the need for differentiated and tailor-made treatment options. Children in need of long-term comprehensive and coordinated health and social services are in Norway entitled to an Individual Plan and a

service provider or coordinator with responsibility for following up the Individual Plan. The parents evaluated many single professionals in a positive way, but at the same time, they experienced professional services that were not coordinated. Based upon the parents' experiences, an individual plan combined with motivated and responsible coordinators seemed to be important for most parents who participated in the study.

As found in other studies (Bailey *et al.*, 1999), most parents used problem-solving coping strategies such as rational problem solving and seeking social support. It is important that professional helping agencies are able to identify family strengths and capabilities. In that way, professional support can be built upon coping strategies with which a family is already familiar.

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Competing interests

The authors declare that they have no competing interests.

Authors' contributions

Both authors were responsible for the study conception and design. The first author performed the data collection, and drafted the manuscript. The first author was responsible for the primary analysis of the data. Both authors participated in and discussed the analysis of the data, and made critical revisions to the paper for important intellectual content. Both authors read and approved the final manuscript.

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