



**THE VOICE OF THE ADOLESCENT WITH ATTENTION-
DEFICIT/HYPERACTIVITY DISORDER (AD/HD) IN INDIVIDUAL CASE
CONFERENCES: HOW ADOLESCENTS WITH AD/HD MANAGE THE
SYMPTOMS OF THEIR DISORDER AND THE TREATMENT STRATEGIES**

Georgia Carragher

PhD Candidate

Edith Cowan University, Western Australia

Associate Professor Glenda Campbell-Evans

Associate Professor Chris Forlin

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Correspondence to:

Georgia Carragher

Research and Higher Degrees Office

School of Education

Edith Cowan University

2, Bradford Street

Mount Lawley, 6050

Western Australia

Email: g.carragher@cowan.edu.au

The voice of the adolescent with Attention-Deficit/Hyperactivity Disorder (AD/HD) in individual case conferences: How adolescents with (AD/HD) manage the symptoms of their disorder and the treatment strategies.

Introduction

This study (which is a work in progress) is divided into two parts. Each part is further divided into two phases. The aim of part one of this study is to use Grounded Theory methodology to construct theory about the management of Attention-Deficit/Hyperactivity Disorder (AD/HD) for adolescents with AD/HD by adolescents with AD/HD where no such theory currently exists. Despite the recent excellent studies by Cooper and Shea (1998) and Prosser (1999) and earlier studies by Robin (1998) and Tracey and Gleeson (1998) very little is known about how the adolescent with AD/HD perceives their disorder. At the same time there would currently appear to be no information on the how, from their own perspective, adolescents with AD/HD (both male and female) are able to self-manage their disorder. Part two of the study intends to develop (with the aid of the participating adolescents with AD/HD) a youth driven case conference model where the adolescents with AD/HD are their own advocates. The long-term aim of the youth driven individual case conferences, where the adolescent voice is fore-grounded, being to allow the adolescents with AD/HD to regain their self-esteem, thereby raising their educational and social outcomes.

According to Robin (1998) research by Slombowski, Klein, and Mannuzza in 1995 established that low self-esteem in adolescents with AD/HD correlates with poor educational and social outcomes and concomitantly poor adult functioning later in life. Zubrick et al., (1997), in their study on school, health and young people, concluded that self-esteem and academic competence are directly correlated, those adolescents with low self-esteem scoring low on academic competency scales with girls having lower levels of self-esteem than boys. They also indicated that "self-esteem is more of an outcome than a cause of academic and/or other success" (Zubrick et al., 1997, p. 43). Alternatively, Allan (1999, p. 2) argued that "children have a right to be informed and listened to on all matters affecting them". It is the fore-grounding of their 'voice' that may allow doctors, teachers, parents and their peers to better understand the problems with which adolescents with AD/HD are faced

when the diagnosis is made and with the use of stimulant medication and their impact on the adolescents' life course.

While these case conferences will follow the general format developed by the Health Department in conjunction with General Practice, currently these case conferences are not youth driven; parents and the medical profession being the advocates for the adolescents involved.

Background to the study

The motivating rationale for this study stems from my experience as a parent and tutor involved with those with AD/HD and their families, coupled with my research with families with young children with AD/HD, and teachers involved with children with AD/HD in their classroom. It is my argument that if the adolescent with AD/HD is to come to terms with their problem and come to an understanding of how they can best cope in the real world, then a clear understanding of how, why and where they stand viz. a viz. a diagnosis of AD/HD and stimulant medication usage and the management of their disorder, needs to be developed.

Problem summary

AD/HD is a neurodevelopmental disorder affecting 3-5% of the child and adolescent population. It is insidious in its intrusion into home, school and social life and a source of significant distress for many individuals and their parents. A diagnosis of AD/HD and its attendant treatment regimes are currently determined by referral to paediatricians, clinical psychologists and psychiatrists for assessment taking into consideration information from parents and teachers. Adolescent opinions are rarely sought with regard to their disorder and treatment regimes (including stimulant medication): despite research demonstrating their reluctance to continue stimulant medication usage; rather they are expected to comply with, and become active participants in adult determined treatment regimes including the use of stimulant medication.

Children and adolescents with AD/HD are at significant risk of under achievement and under productivity in school, with 35-50% of children with AD/HD being retained in grade as opposed to 10% of children without AD/HD. Suspensions and expulsions, due to conduct problems, are significant issues, with 49% of children with AD/HD (non AD/HD 15%) affected; moreover 10% of children with AD/HD will leave school prior to completion (Barkley, 1997c; Barkley, 1998; Gillberg, 1997; Rubenstein & Brown, 1981). As Jensen and Abikoff (2000, p. 641) stated "many times a child or adolescent may present with such severe ADHD symptoms that he or she is in danger of failing in school or of being suspended or expelled". While in later life the pattern continues with 50% of those with AD/HD being likely to under achieve in employment (Barkley, 1997c; Barkley, 1998; Gillberg, 1997; Rubenstein & Brown, 1981).

Aside from experiencing low self-esteem, and being at significant risk of under achievement and under productivity in school (Jensen & Abikoff, 2000), adolescents with AD/HD have also been shown to have low compliance rates for treatment particularly stimulant medication use (Greenhill, Halperin, & Abikoff, 1999 and Brown, Borden, Wynne, Spunt, & Clingerman in 1987). This is despite the well-documented need for adolescents with AD/HD to maintain stimulant medication throughout their formal education (Faigel, Sznajderman, Tishby, Turel, & Pinus, 1995). For, as a study by Garland (1998) indicated, the benefits from medication only continue while it is being taken. The reluctance of the adolescent with AD/HD to continue stimulant medication usage over extended periods is, according to Faigel, et al., (1995) and Sleator, Ullman, & von Neumann (1982), related to behavioural changes observed by the adolescent, the reactions of their peers as well as a pervasive

dislike by adolescents for taking stimulant medication in general. In the opinion of Sleator et al., (1982, p. 478 and also Rudd, 1993; Sackett & Snow, 1979) these findings are consistent with other research that identified adolescents as "nonusers of prescribed drugs". Their reluctance to continue stimulant medication usage may also correlate with the general tendency of researchers and clinicians to ignore the relationship between treatment and the views of those being treated, in this case the adolescents with AD/HD (Baxley, & Turner, 1978; Bowen, Fenton & Rappaport, 1991). Although research has indicated that this reluctance on the part of the adolescents' may be attributed, in no small degree, to negative social perceptions of AD/HD and stimulant medication usage particularly where these negative perceptions influence the adolescents' perceptions of self (Faigel, et al., 1995). These views are corroborated in a recent study undertaken by Prosser (1999) who also criticised the use of the medical label to define AD/HD as being inappropriate and out of touch with experience particularly in schools (where the focus is on actual behaviour rather than the biological considerations of AD/HD) as it serves to marginalise the individual with AD/HD.

While adolescence is well documented as a time when individuals are faced with new tasks and challenges, it is also a time of increased risk-taking behaviour associated with a heightened sense of invulnerability and a need to impress peers as a means of strengthening self-esteem (Bjorkundland, 1995; Kazdin, 1989; Rice, 1992). For the adolescent with AD/HD these tasks, challenges and behaviours taken on new meaning from those of younger children with AD/HD (Barkley, 1998); according to Barkley (1998), they have been shown to demonstrate a higher level of risk-taking behaviour than their peers without AD/HD. For instance: adolescents with AD/HD are at increased risk of motor vehicle incidents i.e. speeding tickets, accidents, license suspensions and revocations, and early experimentation with sex and concomitant increased incidences of teenage pregnancy and sexually transmitted disease (Barkley, 1998). At the same time those families who have an adolescent with AD/HD have been found to experience greater stress and conflict than is normally associated with adolescence (Robin, 1998), while the adolescents themselves will experience peer relationship problems with a few being friendless (Jensen & Abikoff, 2000; Rotenberg & Hymel, 1999). According to Parkhurst and Hopmeyer (1999) it is the biological deficits present in AD/HD which tend to result in low self-esteem that may indirectly contribute to their friendless state and concomitantly to their loneliness, this is particularly so when peer rejection and social rejection occur due to behaviours regarded as unacceptable. Robin (1998, p. 21) concurs with these views stating that "clinicians should not underestimate the tremendous negative impact of low self-esteem and sadness resulting from life failure experiences caused by ADHD".

Purpose of the research

While the purpose of this research and the primary focus of this study is on constructing theory about how West Australian adolescents with AD/HD currently manage the symptoms of disorder and the treatment strategies; the study also aims to test the usefulness of youth driven case conferencing where the adolescent is their own advocate. A multi-disciplinary model for children with chronic conditions that impact on their schooling is currently being trialed in Western Australia. It is this model that will form the basis for a youth driven case conference model to be developed in conjunction with the adolescents with AD/HD, in which the 'voice' of the adolescent with AD/HD may be heard and contribute to the determination of their own treatment strategies. As Baxley and Turner (1978) and more recently Jensen and Abikoff (2000) argued, children are rarely, if ever, consulted about their treatment yet it is they who are "expected to ingest the medication and become active participants in their own treatment" (Baxley & Turner, 1978, p. 172).

This study in progress, is presently, through face to face conversational interviews, engaging with Western Australian adolescents diagnosed with AD/HD (male and female) according to two subtypes, AD/HD combined type and AD/HD predominantly inattentive type with no comorbidities. In order to capture their 'voice' on issues associated with their diagnosis of AD/HD, treatment strategies and the use of stimulant medication. It is uncovering the effect they perceive these have on their home, school and social life and the problems they are experiencing that are the objectives of this phase of the study. Thereafter the research intends to design (with the assistance of four of the participating adolescents with AD/HD) youth driven individual case conferences in which they may assert their right to speak and be their own representatives as their own advocates in determining their own treatment strategies.

Currently, as with theory associated with perceptions of adolescents with AD/HD, it would appear that no such case conference model (where the adolescent with AD/HD is their own advocate) exists in Western Australia. Presently adolescent advocates in case conferences or discussions are the parents or a member of the medical profession. The subjective perspective of the male and female adolescent with AD/HD of his or her situation has largely been ignored; although recent significant research undertaken by Cooper and Shea (1998) and Prosser (1999) have begun to address these issues when they explored the perceptions of adolescents with AD/HD with regard to the impact of their condition on schooling experience. Notwithstanding the importance of these studies there are still other issues to be addressed for adolescents with AD/HD as research by Tracey and Gleeson (1998) recognised. In their opinion the social and personal problems experienced by adolescents with AD/HD cannot be addressed without their own direct involvement in the resolution of the issues. While research undertaken by Bowen, Fenton and Rappaport (1991) found that children's dislike of medication and decreased levels of medication compliance (often as a result of their perceptions of adverse effects or lack of effectiveness) would continue unless the children themselves became involved in their treatment and a flexible approach to medication regimes was adopted. The secondary focus of this study, which is the design of a new and unique case conference model created by the adolescents with AD/HD for adolescents with AD/HD, that will then be tested in the case conference scenario, is specifically aimed at offering a possible solution that may address their needs.

As Barton and Clough (1995), Ballard (1999) and Oliver and Barnes (1991) have argued, those with disabilities have a right to be their own voice seeking their own justice. Accordingly the adolescent with AD/HD should be afforded the opportunity to contribute to any discussion on the management of their disorder, treatment regimes and case conferences. The aim of the youth driven individual case conference model is to determine treatment/support strategy guidelines that meet the needs and problems that have been identified by the adolescents with AD/HD. The understanding is that the direct involvement of the adolescents with AD/HD in the development of the protocols for the youth driven individual case conference model may lead to them, and adolescents with AD/HD in the future, experiencing improved levels of self-esteem with concomitantly improved social and educational outcomes. It is through the design, trialing and evaluation of youth driven case conferences that the theory of how adolescents with AD/HD are able to manage their disorder and treatment strategies may be further extended.

The relevance of this individual case conference model as a strategy designed by adolescents with AD/HD for adolescents with AD/HD is highlighted in Prosser's (1999) study when it was pointed out that many adolescents with AD/HD struggle in private to cope with issues such as: anger, stress, drug use, depression, suicidal thoughts, violence, aggression, defiance, poor motivation and resistance; their success in negotiating these problems depends to a large extent on the support of their families, school communities and society as a whole. If a case conference model can be designed that allows the adolescents the facility

for making their 'voice' heard and of negotiating their own treatment strategies then this study, in the process of building a Grounded Theory of about the management of AD/HD for adolescents with AD/HD by adolescents with AD/HD, may also serve to improve levels of self-esteem and social and educational outcomes for West Australian adolescents with AD/HD.

The belief that adolescents with AD/HD need to be involved in designing their own individual case conference plans is driven first, by the knowledge that adolescents experience significant changes in life course behaviours and attitudes during puberty (Berger, 1988), while at the same time they seek to establish their own autonomy. Second (and perhaps more importantly), while the popular image of adolescence is of an interlude of storm and stress (though this is not strictly accurate), it is also a time of challenges both in the home and school environment, yet, uniquely adolescent studies associated with AD/HD and stimulant medication usage and management of their disorder are outnumbered 10-1 by other AD/HD research (Berger, 1988; Garland, 1998). The argument is, therefore, that it would be relevant not only to allow those adolescents with AD/HD to contribute to the design of the individual case conference programme but also ultimately to allow them to become their own advocates (their own voice) in the management and determination of any treatment regimes and self-help strategies that are to be implemented for them so that they accord with their own beliefs and wishes. As the literature has demonstrated, adolescents with AD/HD are rarely consulted about their specific opinions, experiences, needs and problems either before or after their diagnosis of AD/HD and the commencement of stimulant medication; rather AD/HD and its treatment regimes are informed by adult perceptions.

Conclusion

In conclusion initially the aim of this study is to use Grounded Theory methodology to construct theory about how AD/HD in adolescence is managed by adolescents with AD/HD where no such theory currently exists. The unique perceptions of West Australian adolescents with AD/HD relating to the symptoms of their disorder and the treatment strategies and the theory that will be generated from this study will make a further contribution to the knowledge base of AD/HD. This information coupled with the development of a youth driven case conference model designed specifically by adolescents with AD/HD to assist adolescents with AD/HD in the negotiation of their treatment strategies (that is to be developed in the later phases of the study) seeks to further expand the thinking and knowledge associated with AD/HD.

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