ADHD Family Support Group: A Hospital-based Model in Taiwan

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Abstract

Attention deficient hyperactive disorder (ADHD) is one of the most common childhood psychiatric disorders worldwide. In Taiwan, its prevalence is estimated at between 7.5% and 9.9%, however, according to analysis of the National Health Insurance dataset, as few as 20% seek medical help for the condition. This action research project consisted of forming a hospital-based ADHD family support group and evaluating how well it functioned. First, the formation of a hospital-based family support group in central Taiwan was announced by newspaper, following a news report on 21 August 2008 of a local teacher tying a hyperactive child to a chair. After attending lectures or receiving services at this hospital, some parents and teachers asked to participate in the ADHD support group. A family support group was organized in 2011 and the research team helped apply for public education funding from pharmaceutical companies like Eli Lily and Janssen. In January 2013, to evaluate the group's functioning and the program results, we identified core leaders in the group and started interviewing them using an oral history approach. One child psychiatrist, eight family members, and two patients were selected for interviews. This family support group has demonstrated high motivation and efficiency in addressing its members' concerns, as well as convincing therapeutic benefits. There is a need for pragmatic solutions that cannot be satisfied by purely scientific or therapeutic public discourse. For this reason, the family support group needed autonomy to respond to their own needs and to develop a new sense of identity.

Keywords: ADHD, family support group, Hospital-based Model

Introduction

Attention deficient hyperactive disorder (ADHD) is one of the most common childhood psychiatric disorders worldwide (American Psychiatric Association, 2000). It is a chronic and debilitating condition that can cause significant academic, social, emotional problems as well as interfering with the daily life of families (Deault, 2010; Segal, 2000; Segal & Hinojosa, 2006). Its prevalence in Taiwan is estimated at between 7.5% and 9.9%. Mothers of children with ADHD in Taiwan reported greater psychological distress and perceived less support from their families than did mothers of controls (Gau, 2007). Yet the rate of seeking medical help for ADHD is as low as 20% in Taiwan, according to analysis of the National Health Insurance dataset. The main obstacles to seeking medical help are inadequate knowledge and misunderstandings regarding ADHD and its treatment, in particular, beliefs about side effects and addictiveness of ADHD drugs, despite evidence showing the low risk of such problems and the benefits of drug treatment (Ferrin et al.,

2012; Efron,1998; Ferrin & Taylor,2011). Distrust resulting from such misunderstandings therefore is a major barrier to accessing care. At this point, questions of how to build trust and maintain treatment relationships between child psychiatrists and families of children with ADHD are essential (Lee et al., 2013). Our research team therefore established a hospital-based family support group in central Taiwan to facilitate access to clinical services.

This action research is a pilot program that aims to intervene in the therapeutic relationship with families with ADHD children. Although the importance of family support groups has been highlighted from time to time, there has been little research along these lines (Foy & Earls, 2005; Chacko et al., 2012). Since the idea of patient and family support groups is widely accepted, it has become practical to organize such groups with little impact from social stigma in Taiwan, especially in the field of community mental health (Chou, Liu, & Chu, 2002; Chien & Norman, 2009; Peers for Progress, 2011). However, such efforts or resources directed at ADHD families are very limited. The issue is a critical one for ADHD treatment, because recent studies have shown better results when families, teachers, and health care professionals share information and work in partnership (Zwi et al., 2011; Power et al., 2012; Ostberg & Rydell, 2012; Moldavsky & Sayal, 2013). In other patient groups, behavior therapy related coping strategies have been beneficial to all stakeholders (Lerner et al., 2011; Chacko et al., 2012). Furthermore, it has become clear that patient or family support groups contribute significantly to building trust between members of the health care team and patients' family and social networks (Foy & Earls, 2005; Coletti et al., 2012). With widespread public misconceptions about ADHD and reports of stigma experienced in Taiwan, our action research is meant to serve as an in-time educational intervention as well as an effort to empower these ADHD families.

Objectives

1. To identify coping strategies related to behavior therapy in the ADHD patient group
2. To facilitate the various layers of trust building
3. To encourage the ADHD family support group to act autonomously
4. To enable this family support group to contribute to trust building mechanisms in the therapeutic relationship

Methods

A hospital-based family support group was set up in central Taiwan following the report in a newspaper on 21 August 2008 describing how a teacher tied up a hyperactive fifth grade boy in a chair with string. During breaks between classes, other classmates held one end of the string, like a leash, to accompany and control the boy. One of our major research team members, Dr.Vincent Chin-Hung Chen, had been working as a child psychiatrist at a nearby university-affiliated hospital (Chung Shan Medical Hospital - CSMH). Dr. Chen asked the hospital to hold a press conference the following day to respond to the news story and to introduce the concept of ADHD to the public along with interventions that are available. He then dedicated himself to educating the public in central Taiwan about ADHD, holding a public lecture every three months since then. Around 100 to 200 participants attend these lectures every time; most of them are teachers and parents with ADHD kids. In these lectures, Dr. Chen invites psychologists to share the principles of behavior therapy, special education professors teach parenting skills, and teens with ADHD as well as their parents share their experiences of suffering and growth in facing ADHD. The presentations are recorded as videos and provided to first time patients coming to the department of psychiatry at CSMH. Dr. Chen also conveys fundamental concepts of ADHD through radio, newspapers, and

magazines. He has been invited to more than 20 schools to teach people about ADHD. All principals of schools in the city of Taichung have attended his lectures.

Participatory action research to form an ADHD family support group began in 2008. This research is part of large-scale project supported by the Social Empowerment Alliance and sponsored by the National Science Council, Taiwan. The study was approved by the institutional review board of Chung Shan Medical University Hospital and Taipei Medical University.

Our research team, led by Dr. Chen, introduced the public to the concept of support groups and interventions for ADHD. After attending lectures or seeking treatment for their children with ADHD at CSMH, some parents and teachers asked to participate in the ADHD support group. In 2011, we organized a family support group named 心動家族: literally, "heart movement family group" (HMFG) (心 means "heart." Here, "heart" refers to the term for inattention in Chinese - 不專心 ("unfocused heart"); 動 meaning "movement" or "activity" relates to 過動 ("excessively active"), the term for hyperactivity in Chinese.) In addition to regular public speaking every three months, Dr. Chen meets the families of ADHD children monthly to respond to their questions about ADHD, including diagnosis, treatment, and parenting. We also applied for funding for public education from pharmaceutical companies like Eli Lily and Janssen. These funds provided a series of training programs for the members of the HMFG, including parental behavior therapy training programs and an Applied Behavior Analysis (ABA) program. An interactive educational website (http://www.tc-adhd.com) was also created. A In 2012 we held a Rubik's cube competition. In 2013, we began to promote a movement called "Caring Angels for ADHD," inviting people concerned about ADHD kids to come together and providing training for them. In addition, some members of the HMFG have recently begun taking the initiative to meet and organize their own activities independently.

By the end of 2012, members of the support group had begun meeting to organize activities independently of research team member involvement. We identified core leaders in the group and adopted an oral history approach (Tsai, 2011) starting in January 2013 to document the experience in order to produce a model that could be used elsewhere. One child psychiatrist, eight family members, and two patients are participating in the ongoing interviews. Five major dimensions are included in the interview project: (1) life histories of narrators, (2) illness narratives from the point of view of receiver or giver of care, (3) experiences taking care of an ADHD child, (4) experience of knowing Dr. Chen and taking part in this family support group, and (5) expectations for the future. Analyzing these narratives, we will first try to identify the most common coping strategies, which may be related to behavior therapy in this patient group. Secondly, we illustrate major family narrative patterns of taking care of more or less severe cases. Finally, we explored the interaction between families with ADHD children, physicians and broader social networks.

Results

By the end of 2012, there were 209 individuals participating in the family support group. The average age of their ADHD children was 9.7 years with a standard deviation of 3.5. Almost 80% of the children were boys. The families' profiles deserve attention, as they have a high level of education with more than 46% of fathers and 57% of mothers having university degrees. Their children also suffer significantly from allergic rhinitis (54.4%), nail biting (30.6%) and sleep problems (25.4%). Various stressors in these children's lives are evident, such as conflict with classmates (45.5%), bullying by classmates (21.1%) and conflict with teachers (21.1%). The most

common sources of information about ADHD available to this group are school teachers (49.8%), books (31.6%) and the Internet (29.7%) (Table 1).

Table 1 : General information of subjects (n=209)

General information		
Children		
Age		9.7±3.5
Gender (boys)		79.90%
Allergic rhinitis		54.50%
Nail biting		30.60%
Sleep problems		25.40%
Stressors	Conflict with classmates	45.50%
	Bullied by classmates	21.10%
	Conflict with teachers	21.1%
Parents		
Parents' marital status	Divorced or single parents	14.80%
Education (university)	Father	46.90%
	Mother	57.40%
Sources of information about	Books	31.60%
ADHD	Lectures	17.70%
	Magazines	12.40%
	Internet	29.70%
	TV	13.40%
	Radio	1.90%
	Newspapers	12%
	Teachers	49.80%
	Relatives and friends	22.00%

Certain kinds of compulsive behavior are evident in many cases. For example, one child (case A) may count steps in his/her mind while taking stairs or climbing ladders; if he/she loses track of the number, he/she has to climb the stairs again. Most parents had not heard of ADHD and tended to blame themselves for their children's misconduct in school. With a test (Continuous Performance Test, CPT) provided by Dr. Chen, some parents even began to realize that they themselves suffer from ADHD. The most common therapeutic effect is greater patience and ability to tolerate inattentive behaviors in their kids. Learning from the oral history approach, we have identified several crucial methods parents use to cope with ADHD symptoms.

Parents stated:

(1) 'We have to help our children find a way to work towards having peaceful minds.' 'It may be breathing exercises to help free them from panic.' Parents also 'assist and guide children to cultivate the habit of taking notes.' Those behavior techniques help.

(2) 'While watching the kids absorbed in things that interest them, we are very much moved by the various ways they try to overcome their

inner obstacles.'

(3) 'Everybody has to find their own way of getting through life. Happiness and self-sufficiency will follow. I will do my best to accompany my children in their process of searching.' These kinds of reflective statements are commonly seen as positive therapeutic effects of the support group process.

(4) 'A capable schoolteacher is able to identify the strengths of different children and provide appropriate guidance, encouragement and support.' 'Case B is a reliable child, the only thing we need to do is to give him/her proper guidance.' 'The teacher gives case C responsibility and recognition of his/her achievements. These kids behave in totally different ways to achieve superb performance."

Child psychologists in the support group said the following:

(5) 'Learning the proper way of communicating is crucial for ADHD children. It is recognized that people with features of ADHD do not easily receive external messages, especially when they are experiencing tension or under stress. Formerly, when faced with frustrating situations, these kids tended to do mental simulations beforehand. However, they confined themselves too much to their own preconceptions. As a result, they were not able to anticipate responses they did not expect. They then try to react to the communication relying on their own preconceptions. This is the main reason for communication barriers.'

In addition to these common strategies for coping with ADHD learned through behavior therapy, severe cases should receive appropriate medication. Usually taking medication for one year will yield significant progress that can be documented from an academic perspective. However, interpersonal communication skills remain a major challenge for patients of this kind. Some common themes identifiable in family narratives follow:

(1) 'It is crucial to provide role models in daily life when parenting children with severe ADHD. Regular daily activities, nurturing with love, and approaching life as a game are essential.'

(2) 'Parents have to work together. We find we are in the same boat. My husband has very actively searched out the most up-to-date information about ADHD. We support each other to help our child.'

(3) 'We appreciate the sensitivity of the schoolteacher. This teacher is able to understand my child's difficulty and provide special assistance to help him understand. Although he kicked another child, there was no physical punishment. Instead, our kid was told to write "I should not kick anyone" on two sheets of paper. One for us, the other for the victim. This is an important strategy to provide a supportive environment for our child.'

(4) 'When we bring our child to play with other ADHD children, we learn how much we have in common and encourage each other with the thought that although our children are getting a slow start on their life journeys, they will not be losers in the end. We know how to make things work out and support each other.'

(5) 'While being patient and tolerating difficulties, we also know we may keep high expectations for our ADHD children. However, delaying and denying treatment is the most pernicious problem.'

While oral history interviews with the participants in the ADHD family support group reveal high satisfaction levels, building trust between patients and doctors is crucial. The following common themes related to trust building in the treatment process appeared in interviews:

(1) 'My first reaction to the doctor's instruction to put my child on medication was to do Internet searches for information with scientific merit. Evaluating scientific merit helped me to exclude those voices advocating non-compliance.

I am ready to assist my child for ten years or more to cope with the ADHD symptoms.' Helping a child deal with ADHD is part of a parent's way of giving their blessing to their child.

(2) 'We need to help our children understand medication in words they can understand. Once I told my child that "there is a bug in your brain, and the medication will help you drive it out."

(3) 'We should take the initiative to communicate with our child's schoolteachers and friends. We have to inform teachers of our child's situation. We may also encourage our child to inform his/her friends that, "because I am like a runaway sports car without brakes, I do not manage my own behavior well. I hope you can help me together. I cannot stop. Please help..." If I see any ADHD-related stories in the newspaper, I will make a copy for my kid's schoolteacher.'

(4) 'Building a communication channel solely between you and your kids. It is important to guide your child on how to express emotions, manage interpersonal relations properly and to negotiate in a way that is acceptable. You might have to be like a tape recorder patiently reminding your child again and again in order to help him/her develop proper behavior patterns.'

Discussion

Through a participatory research project in central Taiwan, we have established an ADHD non-governmental organization. This family support group has demonstrated high motivation and efficiency in addressing their concerns and has produced convincing therapeutic benefits. The narrative findings from oral interviews are consistent with the results of clinically based cohort studies. This research found that the main problems support group members experienced were due to inadequate or inaccurate understanding of ADHD and its treatment.

Throughout the process of forming this family support group, it was crucial that caregivers employ a supportive manner. However, patients do not respond only to the caregivers' compassion and supportive manner. Rather, genuinely enhanced family and social support networks are developed through the group process. The therapeutic effect on the children's ADHD does not result from only collective effort or from objective scientific knowledge. A more tight-knit community is needed, as the intimate sphere reflects the uniqueness of each ADHD case. Building an exclusive communication channel between parents and their kids is extremely important (Lerner 2005; Zwi et al., 2011). Nevertheless, such intimacy cannot sustain itself alone. This intimate sphere is actually encouraged, maintained, and protected by a sense of belonging to an authentic community in which there is little place for a therapist.

Within this support group, people learned from each other on a practical level, for example parents showed each other how 'to help our children understand the medication with words they can understand.' With the support of this community, parents may become more involved, as one observed, 'taking the initiative in communicating with school teachers and friends of our child.' There is much need for pragmatic action in the real world, which cannot be satisfied by purely scientific or therapeutic public discourse (Foy & Earls, 2005; Ostberg & Rydell, 2012). This explains why the autonomous activity of this family support group is helpful, as it was shaped according to their own needs, and helped to foster a new sense of identity.

Conclusion

We observed that the family support group significantly contributed to establishing trust in the therapeutic relationship. In the first stage, behavior therapy coping strategies helped ADHD children find a way to calm their minds and become absorbed in things that interest them, improving their ability to pay attention. In addition,

it facilitated ADHD children's search for their own life meaning. It also helped teachers and parents to sympathetically understand their difficulties and communicate with them appropriately, as well as to identify the strengths of different children in order to provide appropriate guidance, encouragement and support.

Later, the group trust building process helps by developing the parents' trust in their own children. After that, role models for daily life with ADHD kids are crucial for parents. Likewise, trust building efforts help to bind the whole family together, and to extend support networks, first to schoolteachers, and then to include the children's classmates. It is clear that support group members can design and appreciate a supportive environment for ADHD children. Finally, the family support group is valuable for the practical mutual support and assistance it provides.

Recommendations

Building family support system/networks should be a first priority in developing sufficient treatment plans for families with ADHD. It should be the foundation of all treatment plans, wherein therapists should play a role of empowering patients and their families. This kind of social care will provide a crucial complement to clinical care. However, although we propose behavioral training for parents as an effective intervention for children with ADHD, sustaining the effects over time may prove rather challenging (Lee et al., 2013). Study designs that incorporate the support group's cooperation may help us explore this problem more closely. Moreover, a research design based on cooperation from the family support group may be useful for resolving broader issues/symptoms related to ADHD. For example, Dr. Chen's research team has already shown that maternal depression may play an important role in the affective presentation of dyads of children with ADHD and mothers with depression (Lee, at al., 2012). Long-term follow up may help us further address the causality embedded in this dyad. In addition to enabling psychiatric discoveries with scientific merit, the program has started an ADHD non-governmental organization in central Taiwan. Moreover, a series of books to record the experiences of ADHD children and their families will be published. Further research efforts may aim to explore the subjective meanings of ADHD for those who experience it, as well as to develop objective tools that may be used in diagnosis and for investigating outcomes of ADHD treatment, with the ultimate goal of assessing the long-term impact of the disorder and its treatment on families in Taiwan.

Acknowledgements

We thank all the participants for generously sharing their experiences in this research. We received support in the form of a grant (NSC 100-2511-S-038-003) from the National Science Council and support for oral history technique and experience in observing and organizing social networks from the Social Empowerment Alliance. Anonymous reviewers' comments significantly enriched this paper. Public education funding provided by pharmaceutical companies, Eli Lily and Janssen, for this family support group are greatly appreciated and deserve recognition as well.

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