

A common link between clinical practice and research: the ADHD model for Central Taiwan

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Abstract

This study aimed to describe a research model regarding the Attention Deficit Hyperactive Disorder (ADHD) in Central Taiwan based on the strategy of routine data collection from clinical practice. Therefore, a prospective study with naturalistic observation was used. Modeling study was developed in clinical evaluation and treating for the ADHD children at Department of Psychiatry, Chung Shan Medical University Hospital in Central Taiwan. For all new patients, their first visit information were collected, including socio-demography, ADHD symptom scale, family support, academic performance, enuresis, severity of disability, mother depression, blood pressure (BP), heart rate (HR), weight, height, help-seeking behavior. After the clinical interview, patients were arranged to be assessed by the Neuropsychological test such as Continuous Performance Test (CPT). During the follow-up period, many variables (messages for the side effects, BP, HR, Weight, Height, CPT, ADHD symptom scale) were recorded. Finally, the ADHD clinical-based research model was contributed using all variables into many studies such as the ADHD comorbidity study, family study, sleep study, assessment tool development and treatment outcome study. The results had shown a several ADHD

related papers have been published from this model. New treatment strategies emerged from the findings of studies. This is a feasible model for combining clinical practice with research to produce international publications. Clinical benefits of this model include creating culture-specific knowledge from the clinicians' own clinical practice, focusing essential processes on cost-effective patient retreatment, and maintaining ongoing relationships with patients. In conclusions, our experience shows the clinical practice based longitudinal study is feasible and the results can nurture the quality of clinical practice vice versa.

Keywords : ADHD model, attention, family, hyperactive, longitudinal study

Introduction

Process of clinical practice includes assessment (diagnosis), intervention (treatment), evaluation of outcome (including side effects of intervention), and follow-up. The process is the same as that of research. Researchers need to record the baseline characteristics of subjects, measure the target problems and try to deal with these problems and evaluate the results of interventions. Specifically, the characteristics of

clinical practice for psychiatrists is similar to that of cohort study, encompassing: 1) from here and now to the future; 2) multiple exposures and multiple outcomes and 3) long term observation period. Clinical practice raises idea and provides target subjects for research. Consequently, the findings of studies can nurture the quality of clinical practice. Although the level of evidence-base is inferior for cohort study compared to randomized control trial (RCT), it is unethical to carry out any RCT in real world medical practice. Attention-deficit-hyperactivity disorder (ADHD) is estimated at 5.3% according to a review of 102 studies from seven regions (Polanczyk, de Lima, Horta, Biederman, & Rohde, 2007). ADHD is increasingly recognized as a common neuropsychiatric disorder that impairs social, academic, and occupational functioning in children, adolescents, and adults (Barkley, Fischer, Smallish, & Fletcher, 2006; Pliszka, 2007). ADHD patients continue to have problems in adult life, such as interpersonal difficulties and dismissal from employment, and they are at higher risk for drug and substance abuse and dependence (Harpin, 2005). Longitudinal studies of outcomes of childhood ADHD in young adults show lower academic and occupational achievement and higher rates of incarceration, mental health problems, and divorce compared with control groups (Barkley et al., 2006; Pliszka, 2007). Since ADHD has such a long term effect, it also causes the burden of parents. Mothers of children with ADHD reported greater psychological distress and perceived less support from their families than did mothers of controls (S. S. Gau, 2007). Scahill et al. reported that families of children with ADHD had lower socioeconomic status (SES), more often had psychiatrically ill parents, and exhibited more familial dysfunction (Scahill et al., 1999). Several studies have established that ADHD is associated with significantly increased parenting stress (Anastopoulos, Guevremont, Shelton, & DuPaul,

1992; Podolski & Nigg, 2001). Disruptive parent-child interaction in children with ADHD has been observed across different age ranges, from preschool to adolescence.

In Taiwan, the prevalence of ADHD was estimated at 7.5% (S. S. F. Gau, Chong, Chen, & Cheng, 2005). According to analysis of the National Health Insurance dataset, the rate of seeking medical help for ADHD is as low as 20% in Taiwan (Chien, Lin, Chou, & Chou, 2012). The main obstacles for 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). 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). To address this situation, as an extension of treating ADHD patients at a major medical center in central Taiwan we established a hospital-based ADHD family support group beginning in 2008 (Vincent Chin-Hung Chen & Tsai, 2013). Simultaneous with establishment of the family support group, we constructed a naturalistic, prospective follow-up study of an inception cohort of patients with ADHD.

Objectives

In this report, we describe how our ADHD treatment model supports a clinically based naturalistic research program and discuss its feasibility. Success with international publications demonstrates international recognition of this research model and the clinical significance of its findings

Methods

Participants and procedures

Along with the clinical procedure of treating ADHD, a naturalistic, prospective follow-up study for ADHD was established (Fig. 1). The sample comprised ADHD patients and their parents recruited at a child psychiatric outpatient clinic at Chung Shan Medical University Hospital in Taichung City in Middle Taiwan. On the first day of visiting, all participants (N=600) (ADHD adolescents by themselves; ADHD children by parents) completed a set of self-reported questionnaires including the baseline information checklist, The Swanson, Nolan, and Pelham rating scale version IV (SNAP-IV), The World Health Organization Quality of Life - BREF (WHOQOL-BREF), Adult ADHD Self-report Scale

(ASRS) and The Center for Epidemiologic Studies Depression Scale (CES-D) administered by a psychiatric nurse. The participants were explained how to fill the questionnaires and if they have any question, they can request us for an interpretation. Basic physical data such as height, weight, blood pressure (BP), heart rate (HR) were collected. After interviewed by the psychiatrist (Dr. Chen), a series of test were arranged, including EKG, blood test for zinc and ferritin, polysomnography (PSG), Continuous Performance Test (via the Gordon Diagnostic System, GDS), IQ, Heart Rate Variability (HRV), aciwatch and auditory attention test. If the patients begun to use the drugs, side effect checklist, SNAP-IV, height, weight, BP, HR, aciwatch, and CPT were assessed regularly.

Figure 1

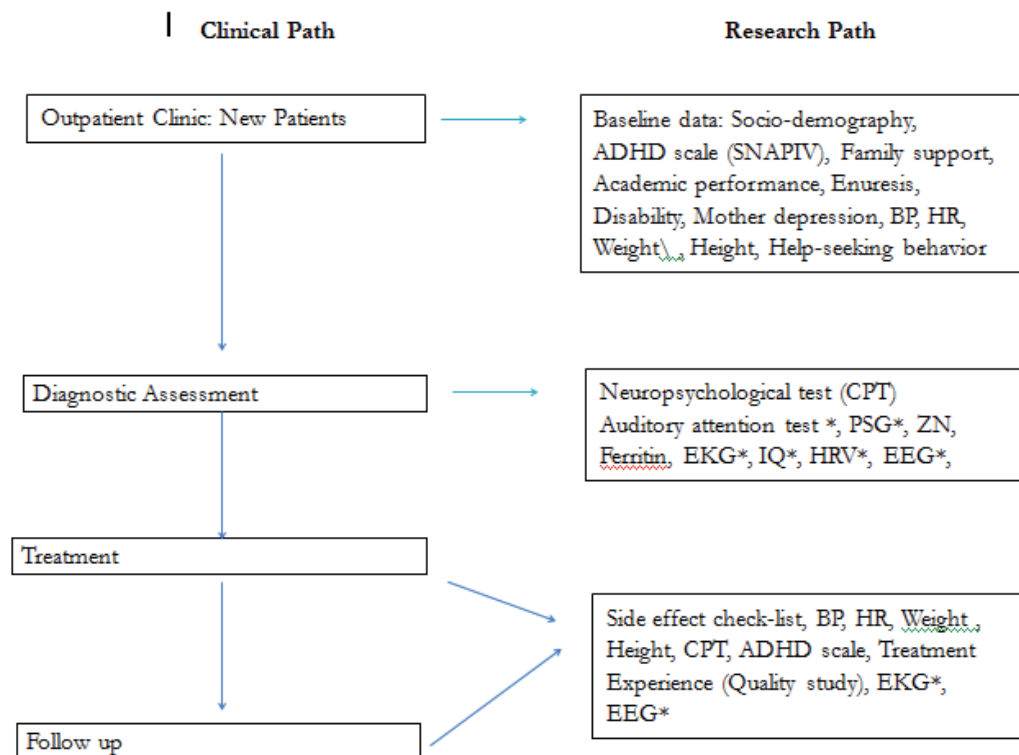


Figure 1: diagram showing the clinical procedure of treating ADHD, a naturalistic, prospective follow-up study for ADHD

Measurement

The content of base-line information checklist encompassed demographic data, psychosocial information for parents, history of physical problems before treatment: preterm, seizure, head injury, birth weight, heart disorder, allergy rhinitis, biting nail, sleep problem, and enuresis.

The Swanson, Nolan, and Pelham rating scale version IV (SNAP-IV)

The 26-item SNAP-IV consists of the core symptoms of ADHD, including 9 items for inattention (IA), 9 items for hyperactivity/impulsivity (HI), and 8 items for oppositional symptoms (OP). The SNAP-IV has been found to have good psychometric properties in Taiwan, including test-retest reliability (intra-class correlation = 0.59-0.72), and internal consistency (alpha = 0.88-0.90)(S. S. F. Gau et al., 2008).

World Health Organization Quality of Life-Short Form:

The World Health Organization Quality of Life (WHOQOL) is a cross-cultural comparable assessment instrument for QoL that measures four broad domains: physical health, psychological health, social relationships, and environment, measuring 28 items on a 5-point scale (1-5). The questionnaire comprised two items for general assessment, seven items for physical health, six items for psychological domain, four items for social domain, and nine items for environment domain, and has been used as an outcome-measurement tool in patients receiving MMT. The WHOQOL-BREF has also been adapted to Taiwan Chinese and Taiwanese versions. Three of the four domain scores demonstrated internal consistency (Cronbach's alpha) coefficients ranging from 0.70 to 0.77 and content validity coefficients of 0.53 to 0.78 for item-domain correlations (McCance-Katz, Rainey, Jatlow, & Friedland, 1998).

Adult ADHD Self-Report Scale Chinese Version (ASRS)

The World Health Organization developed Adult ADHD Self-Report Scale (ASRS) in 2005 with the revision of WHO Composite International Diagnostic Interview (CIDI). The ASRS comprised 18 questions reflecting the DSM-IV criteria A symptoms of ADHD. The wording of questions provided a context which is more suitable for adults. The 18 items were split into two parts which part A is for inattentive type ADHD whereas part B for hyperactive/impulsive type. The scale of each question ranged from 0 to 4 (from never to very often). In the Chinese version, the score of 17 or higher in either part A or B means the patient is likely having ADHD and 24 or higher means highly likely (Yeh, Gau, Kessler, & Wu, 2008). ASRS was used in epidemiology studies and also showed good validity among SUD patients. The psychometric properties of the Chinese version of the ASRS had been valid in Taiwan with good concordance and internal consistency (Yeh et al., 2008).

Family Adaptability, Partnership, Growth, Affection, and Resolve Scale (APGAR):

Developed by Smilkstein (1978), Family APGAR is a reliable, validated, and utilitarian instrument for evaluating subject satisfaction with five components of family function (Bell, 2010). Higher scores summed from the 5-point response scales indicate poorer family support in this study. The internal consistency, construct validity, and differential validity are moderate. The family APGAR was translated into Chinese by Chau et al. Studies for validity and reliability have also been conducted in Taiwan. (Wang et al., 2011).

The Center for Epidemiological Studies Depression Scale (CES-D):

The CES-D is a self-administered scale assessing the depression quotient in the preceding

week (Radloff, 1977). The 20-item questionnaire describes the self-reported depression scale. For each item associated with depressive symptoms, the scores range from 0 to 3 (never or rarely to always), and the total scores range from 0 to 60. A score equal to or above 16 indicates apparent depression, and higher scores correlate with a higher level of depressive symptoms. The validity, reliability, internal consistency, and test-retest repeatability has been verified (Cronbach's alpha = 0.90, intraclass correlation reliability = 0.93); (Cheung & Bagley, 1998). The CES-D has also been translated into Chinese, and has been applied in numerous epidemiology studies of depression in the general population (Yang, Soong, Kuo, Chang, & Chen, 2004).

Ethical approval

The study was approved by the institutional review board of the Chung Shan Medical University. All subjects provided written informed consent before participation.

Results

From the ADHD clinical practice based research model, we could carry out several studies as following:

- ADHD Comorbidity Study: enuresis, preterm, biting nails, allergy, and ODD.
- ADHD Family Study: parents' ADHD (rated by ASRS), depression (rated by CES-D), quality of life and help seeking behavior (including qualitative study).
- ADHD New Assessment Tools Study: auditory attention, test, actiwatch.
- ADHD Sleep Study.
- ADHD Treatment Outcome Study: long term effects and side effects of treatment.

Some papers have been already published from these studies. Most of them linked to parent-child interaction. A meta-analysis of behavioral parent training for children with ADHD was reported and

we found the majority of outcome categories were associated with a moderate effect size at post-treatment that decreased to a small effect size at follow-up. Parenting competence was the only outcome that had a large effect, which decreased to moderate at follow-up (Lee et al., 2013).

Another related report was regarding parent-child interaction of mothers with depression and their children with ADHD (Lee et al., 2013). The study participants comprised 39 mother-son dyads including children with ADHD and mothers with depression, children with ADHD and mothers without depression, and children without ADHD and mothers without depression. It was suggested that children with ADHD whose mothers were depressed were less positive in their parent-child interaction compared with children in the other groups. Maternal depression may play an important role in the affective presentation of dyads of children with ADHD and mothers with depression.

Recently, a new paper to introduction our experience to organize the family support group entitled "ADHD Family Support Group: A Hospital-based Model in Taiwan." Has been published. This family support group has demonstrated high motivation and efficiency in addressing its members' concerns, as well as convincing therapeutic benefits. In addition to above papers, we have been preparing several reports encompassing findings from Polysomnography, auditory attention test, Continuous Performance Test, Heart Rate Variability, mothers' quality of life, and ADHD comorbidity.

Discussion

From the experience of ADHD clinical practice based research model, in Central Taiwan, we can find a common path between clinical practice and research. We also find the model is feasible. The best benefit from this model is to

create the culture specific knowledge from the clinicians' own clinical practice. Another benefit is that most of the steps are cost-effective since most of them are essential process to treat patients and extra cost is not necessary. Lastly, clinicians can obtain more information and better compliance from patients if they can maintain a good relationship with them. Combining clinical practice and research in this way rewards clinicians' willingness to pay more attention to patients in their clinical work.

Based on the findings that depressed mothers had poor interaction with ADHD children, we have

been carrying out a new project, a parent-child interaction group therapy program, to help the depressed mothers with ADHD children. This was a 12-session group therapy based on waiting control design. We will evaluate the impact of the program on mother's depressive symptoms, quality of life and interaction with their children. We also will assess the impact on the children's ADHD symptoms and other behavior performances. The project was initiated from our findings of clinical practice and can echo our suggestion that clinical based study and clinical practice can nurture each other.

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