Pilot study of the efficacy of empowering patients through coaching as a complementary therapy in attention deficit hyperactivity disorder

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Received 22 January 2015; accepted 15 June 2015
Available online 2 February 2016

Abstract

Introduction: Attention deficit hyperactivity disorder (ADHD) is the most frequent neurodevelopmental disorder and must be considered a public health priority because of its functional repercussions in school, family, and social settings. Health empowerment is an innovative model of care for patients with chronic diseases based on self-management education. Our goal is to evaluate the effectiveness of empowerment using coaching within a multimodal treatment plan in paediatric patients with ADHD.

Material and methods: Descriptive open prospective study. We included children between 6 and 12 years old belonging to patient association in a suburban area of the Region of Madrid. We evaluated the situation before and after 5 cost-free coaching sessions using the Conners Questionnaire, Dundee difficult times of day scale, and satisfaction scales.

Results: We included 49 patients (73.5% males) with an average age of 8.5 years. The ADHD hyperactive-impulsive subtype was present in 63.3% and 77.6% had some type of comorbidity. All were treated with methylphenidate and their clinical course was poor. Clinical improvements were observed in 79.6% with a 34.6% mean reduction in symptoms (SD 11.1), and improvements remained stable at 6 months follow-up after coaching. We reached a satisfaction level of 7.8 out of 10 (SD 1.7), and 93.9% of the participants recommended this treatment to other families.
Conclusions: Our results provide information on the potential benefits of coaching as complementary treatment for ADHD.
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PALABRAS CLAVE
Empoderar;
Coaching;
Trastorno por déficit de atención e hiperactividad;
Hiperactividad;
Déficit de atención;
Psicoestimulantes

Estudio piloto de la eficacia de empoderar a pacientes mediante coaching como tratamiento asociado en el trastorno por déficit de atención e hiperactividad

Resumen
Introducción: El trastorno por déficit de atención e hiperactividad (TDAH) es el trastorno del neurodesarrollo más frecuente y debe ser considerado un problema de primer orden de salud pública por sus repercusiones funcionales a nivel escolar, familiar y social. Empoderar en salud es un modelo innovador en el cuidado de pacientes con enfermedades crónicas, basado en la educación de automanejo. Nuestro objetivo es valorar la eficacia de empoderar mediante coaching, dentro de un plan de tratamiento multimodal en pacientes pediátricos con TDAH.
Material y métodos: estudio descriptivo, abierto y prospectivo. Incluimos a niños de entre 6 y 12 años pertenecientes a una asociación de pacientes de un área suburbana de Madrid. Valoramos la situación previa y posterior a 5 sesiones gratuitas de coaching mediante el Cuestionario de conducta de Conners de dificultades a lo largo del día (D-DTODS) y escalas de satisfacción.
Resultados: Incluimos a 49 pacientes, el 73,5% varones, con una edad media de 8,5 años. El 63,3% tenía TDAH subtipo hiperactivo/impulsivo y el 77,6% algún tipo de comorbilidad. Todos tratados con metilfenidato y mala evolución clínica. El 79,6% mejoró clínicamente, con una reducción media ± DT de los síntomas del 34,6 ± 11,1% y mantenida en el 79,6% tras 6 meses de seguimiento post coaching. Alcanzamos un nivel de satisfacción de 7,8 ± 1,7 sobre 10 y el 95,9% recomendó el tratamiento a otras familias.
Conclusiones: Nuestros resultados aportan información sobre los posibles beneficios del coaching como tratamiento asociado en el TDAH.
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Introduction
Attention deficit hyperactivity disorder (ADHD) is the most frequent neurodevelopmental disorder in childhood. Its estimated prevalence ranges between 5% and 8% depending on the diagnostic criteria, assessment method, sources of information, and social and cultural characteristics of the analysed population.1-3 It is more frequent in boys than in girls (3:1) and its peak prevalence occurs between the ages of 6 and 9, although it has also been reported in preschool children and adults. Therefore, it should be considered a lifetime disorder.4

ADHD is a concept that includes a series of cognitive and behavioural alterations manifesting with a heterogeneous yet identifiable clinical pattern; it has well-defined core symptoms (inattention, hyperactivity, and impulsiveness) and a functional impact in school, family, and social settings. Treatment must be personalised and depends on needs, dysfunction, consequences, comorbidities, and even preferences of patients or their carers. Several clinical guidelines, such as those published by the American Academy of Pediatrics5 and the National Institute for Health and Clinical Excellence,6 recommend pharmacological treatment with psychostimulants as the first therapeutic option for children older than 6 years, with or without psychosocial interventions, parent training, or other therapies. Multimodal treatment, which combines pharmacological treatment (psychostimulants or non-psychostimulants) and non-pharmacological treatment (metacognitive, cognitive-behavioural, and psychoeducational therapy, cognitive rehabilitation programmes), has been proved the most effective in adolescents and adults with ADHD and in patients with comorbid symptoms of anxiety, depression, and oppositional defiant disorder.5-9

Health empowerment is a process by which people gain more control over actions and decisions affecting their health. This innovative approach to chronic patient care is based on training patients to manage themselves; this way, the healthcare professional transmits his or her knowledge of the disease to actively involve patients in treatment and the development of strategies allowing them to lead as productive and satisfactory a life as possible. Empowerment interventions are heterogeneous and range from health training interventions to teaching patients to be experts in their chronic disease.

Recent years have seen the development of a new and less paternalistic approach to patient empowerment: health coaching. Coaching is a technique in which a coach or trainer teaches and/or trains one or more people to reach a goal or develop a specific ability. Coaches never give advice,
answers, or instructions; rather, they ask guiding questions and encourage patients to reach their goals by using their imagination and own resources. Coaching is based on 5 dimensions: listening, intuition, curiosity, promoting action, and deepening knowledge.

Kubik was the first researcher to assess the effectiveness of empowering adult patients with ADHD through coaching. Since then, several studies have evaluated the effectiveness of this technique in different age groups, yielding promising results that suggest that coaching may improve some core symptoms of ADHD (inattention or impulsiveness) as well as other ADHD-related problems.

The purpose of our study is to assess the effectiveness of coaching as part of a multimodal treatment plan for paediatric patients with ADHD and poor clinical progress.

Material and methods

We designed an open prospective descriptive study to assess the effectiveness of empowering patients through coaching as a complement to pharmacological treatment. Our study included patients with ADHD belonging to the AFAN TDAH patient association located in a suburb of Madrid.

1. Inclusion criteria: children aged between 6 and 12 who were members of the patient association and whose parents were willing to participate in group coaching sessions from October 2012 to February 2013. Patients had to meet the following requirements:
   - Diagnosis of ADHD according to the diagnostic criteria established by the Diagnostic and Statistical Manual of Mental Disorders, 4th revised edition (DSM-IV-TR)
   - Treatment with methylphenidate in any of its pharmaceutical formulations at normal doses (0.8–1.5 mg/kg/day), with good compliance.
   - Poor outcomes despite medication: functional impairment affecting at least 2 areas of life (family, school, interpersonal relationships, self-esteem, etc.).
   - Neuropsychological assessment showing normal IQ scores but impaired attention and/or executive function; this was measured using standardised and age-appropriate tests.
2. Exclusion criteria: preschool children, adolescents, patients receiving non-psychostimulants (atomoxetine), and patients showing good clinical progress.
3. Intervention: we conducted 5 free group coaching sessions, one per month. Sessions were led by a coach officially qualified for and specialised in health coaching, but not a health professional.

We structured each session based on the 5 steps of the personal empowerment model developed by Anderson and Funnell:

1. Analysing knowledge of oneself and the situation. We conducted a structured motivational individual interview with each family. Interviews were designed to identify the main problem, the feelings it evoked in the patient and his or her family, and its impact on every aspect of daily life. We also negotiated the rules to be followed every day in the family setting in order to redirect the situation.
2. A brainstorming session aimed to determine the factors potentially responsible for poor results and list the available options. We tried to have all family members commit to listing potential goals and any routines to be used as motors of change.
3. We established an action plan that was realistic, convenient, achievable, and quantifiable, so that patients could reach previously established goals little by little. Changes in perspective made use of the senses, for example, by changing the decoration or the colour of the walls at home, in order to keep children alert and remind them to internalise routine changes.
4. In each case, we presented a challenge that was specific, measurable, responsible, far-reaching, and exciting. Patients were challenged to try to improve their focus, concentration, and organisational abilities, their self-esteem, motivation, and confidence in their ability to succeed.
5. Empathy and self-assessment of achievements. We asked questions to make participants think (‘What do I want?’, ‘What can I tolerate?’; ‘What are the differences between desires and achievements?’) to promote empathy between children and their parents. Feedback was positive and participants made lists of values and routines to be respected.

Evaluating effectiveness

We assessed the situation of all patients and their parents before starting the coaching sessions, after 5 sessions, and 6 months after the coaching programme using the following scales:

- Dundee Difficult Times of the Day Scale (D-DTODS; Dr Coghill, University of Dundee) to assess the impact of ADHD on families.
- Short version of the Revised Conners’ Parent Rating Scale (CPRS-R) and Revised Conners Teacher Rating Scale (CTRS-R) to evaluate changes in ADHD symptoms at home and at school as a consequence of coaching. A decrease of 5 or more points on the scale was regarded as an improvement.
- Satisfaction questionnaire: participants evaluated coaching on a scale from 0 (lowest degree of satisfaction) to 10 (highest degree of satisfaction) according to their experiences with the treatment. They also answered the following yes/no question: Would you recommend coaching as a complementary treatment for ADHD?

Statistical analysis

The descriptive statistics used were means ± SD for quantitative variables and percentages for qualitative variables. Comparisons between groups were performed using either the t-test for paired samples (pre-test vs post-test scores) or the chi-square test (and Fisher’s exact test) to compare proportions.
Table 1 Epidemiological characteristics of the sample.

<table>
<thead>
<tr>
<th>N = 49</th>
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</thead>
<tbody>
<tr>
<td>Age</td>
</tr>
<tr>
<td>Sex</td>
</tr>
<tr>
<td>ADHD subtype</td>
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<tr>
<td>Comorbidity</td>
</tr>
<tr>
<td>1. Behaviour disorders: 65.7% (25 patients)</td>
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<tr>
<td>Externalising (ODD, DBD): 60%</td>
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<tr>
<td>Internalising: 40%</td>
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<td>(a) Low self-esteem: 9</td>
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<tr>
<td>(b) Mood disorders: 2</td>
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<tr>
<td>(c) Anxiety: 1</td>
</tr>
<tr>
<td>2. Learning disorders: 34.3% (13 patients)</td>
</tr>
<tr>
<td>3. Other: epilepsy, MR, tics, ASD, SLI</td>
</tr>
<tr>
<td>Treatment</td>
</tr>
</tbody>
</table>

MR: mental retardation; DBD: disruptive behaviour disorder; ADHD-HI: hyperactive-impulsive type of attention deficit hyperactivity disorder; ASD: autism spectrum disorders; SLI: specific language impairment; ODD: oppositional defiant disorder.

The mean difference in Conners scale scores before and after coaching was 6.2 ± 3.9 points, expressed in absolute values, representing a mean decrease of 34.6% ± 11.1%.

Analysis of data by groups revealed that patients for whom coaching was most effective were boys (effective in 83.3% vs 69.2% girls; P = .422), those with combined type ADHD (87.9% vs 62.5% with predominantly inattentive ADHD; P = .060), and patients with comorbidities, especially behaviour disorders (82.1% vs 70.0% in the group without comorbidities; P = .405). However, none of these differences reached statistical significance.

Regarding difficulties throughout the day, improvements were reported for 60% of the patients and 30% felt that their situation had become normal. Among parents, 60% perceived an improvement in quality of life after coaching. Mean satisfaction scores were 7.8 ± 1.7 out of 10.

The group of patients for whom treatment was effective gave coaching a score of 8.1 vs 6.9 in the group of patients who did not consider the intervention effective according to the criteria established previously; 95.9% stated that they would recommend coaching to other families.

Six months after the intervention, 79.6% of the patients for whom coaching had been effective retained the improvements they had achieved.

Results

The study included 49 families of Spanish citizens; each family had a mean of 2.1 children, including one with ADHD. Our sample therefore included 49 patients diagnosed with ADHD according to the criteria listed above. Patients’ ages ranged from 6 to 12 (mean age, 8.5); 73.5% were boys. Patients with the predominantly hyperactive-impulsive subtype accounted for 63.3%; 77.6% of patients presented comorbidities. All patients were receiving methylphenidate at doses ranging from 0.8 to 1.3 mg/kg/day and had poor results. Table 1 lists patients’ epidemiological characteristics.

In the assessment conducted before coaching sessions started, clinical progression of ADHD was poor despite pharmacological treatment, as stated by parents and teachers; patients scored a mean of 18.3 ± 4.5 points on the short version of Conners scale and displayed substantial difficulties throughout the day as shown by the D-DTODS. According to 90% of parents and children, the first and last hours of the day were the most difficult, and 100% felt that their situation at home or at school affected their quality of life. The children’s main problems and concerns, as they themselves reported, were frequent outbursts of temper, low self-esteem, and ‘mental block’ and inability to concentrate when doing homework. Parents reported difficulties understanding their child’s disorder; stress, relationship conflicts, and irritability were the factors with the greatest effect on their quality of life.

After 5 coaching sessions, 79.6% of families (parents/children) noticed improvements (a decrease of at least 5 points on the Conners scale compared to baseline scores). The mean final score in this group was 12.0 ± 3.9; differences between baseline and final scores were statistically significant (P < .001).

Discussion

Emerging healthcare models suggest that patients may benefit from participating in their own management. However, few studies have described the approaches used to prepare patients for self-management.

Health empowerment for patients with chronic diseases is an innovative healthcare model based on self-management training. In this process, patients receive thorough training in and information about their disease, and they participate actively in decision-making, taking joint responsibility for their health decisions. This creates synergy between doctors, patients, families, and carers. The aim is to promote the independence of the patient/carer unit, and improve patient care and safety and treatment adherence.

Coaching makes patients more motivated and changes their attitudes towards the disorder, making adherence easier. Patients work on their needs and problems in a dynamic and personalised way that creates a strong link between coaches and patients, promoting change.

Some clinical references, such as the Clinical Practice Guidelines for Children and Adolescents with ADHD published by the Spanish Ministry of Health, Social Policy, and Equality in 2010 and the NICE guidelines published in 2009, recommend training for the parents of children diagnosed with ADHD and comorbid behaviour disorders.

Of all psychological or psychopedagogical treatments for ADHD (metacognitive therapy, cognitive-behavioural therapy, cognitive rehabilitation, or a combination of the above), cognitive-behavioural therapy demonstrates the greatest effectiveness as a non-pharmacological treatment, especially in adults and in ADHD patients with comorbid symptoms of anxiety and depression.
As occurs with coaching, these interventions address motivation and self-esteem; however, none of them engage patients in decision-making as they simply set rules and give advice according to a predetermined plan.

Our results suggest that coaching may be an effective complementary treatment for ADHD. Symptoms in most of our patients decreased by more than 35%, and the quality of life of patients and their families improved. Improvements were observed even after the initial sessions mainly due to changes in parents’ attitude towards and relationship with the disease. These changes fostered bonding between children and their families and encouraged them to participate in ADHD training and treatment. Coaching promotes a virtuous circle in which changes in the parents’ coping strategies help children commit more fully to routines and treatment adherence. Sessions not only increased quality of life and reduced difficulties throughout the day, but also improved core symptoms and academic performance. In addition, the positive effects of coaching remained apparent in the families that maintained the acquired habits and incorporated new ones.

The degree of satisfaction was also high; most families recommended coaching to other patients, even those families in which the intervention was not considered effective.

The present study has several limitations as an open study with a small sample size (n = 49) in which both assessments and interventions were open. However, we feel that our series is quite homogeneous and representative of normal clinical practice since it was drawn from a population displaying very similar socioeconomic and cultural characteristics, and similar symptoms and dysfunctions caused by the disease.

Our data should be analysed with caution. Voluntary and active participation of parents in treatment, their motivation to change, and the bonds they created with their children after therapy may make them more likely to rate changes in their children’s behaviour as positive, which could lead to biased results.

Our results provide information on the potential benefits of coaching as complementary therapy for patients with ADHD and coincide with previous studies in which coaching had a positive impact on other chronic diseases. The present study describes one way of structuring this process and describes its effectiveness according to the areas affected by symptoms.

We conclude that coaching is aimed at helping patients help themselves by creating a setting based on motivation, confidence, and commitment. Interventions are intended to make patients aware that they need to cooperate with treatment and become committed to change. However, we need further quality studies with greater sample sizes, possibly with a randomised controlled design, before we will be able to recommend coaching as a complementary treatment for children with ADHD with a stronger level of evidence.

Conflicts of interest

The authors have no conflicts of interest to declare.

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