Original article

Psychoeducational groups for adults with ADHD and their significant others (PEGASUS): A pragmatic multicenter and randomized controlled trial

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1. Introduction

ADHD is a neurodevelopmental disorder characterized by symptoms of inattention, hyperactivity, and impulsivity causing functional impairment [1]. ADHD persists into adulthood in the majority of cases with a cross-national prevalence rate among adults averaging 3.4% [2]. Disabilities associated with ADHD encompass most major life domains, such as education, work, economy, parenting, social and family life [3–5]. The clinical impact of ADHD is complicated by common psychiatric comorbidities, such as depression, anxiety disorders, and substance use disorders (Biederman 2004; Fayad et al., 2007; Gjervan et al., 2012; Kessler et al., 2006). Adult ADHD is often characterized by emotional dysregulation, which, in turn, is correlated with poor social adjustment to family life and primary relationships [6]. Thus, ADHD typically also affects an individual’s immediate social environment.

Genuine knowledge of ADHD is low in society. Individuals with ADHD and relatives may be stigmatized even by professionals who are supposed to support them, including employees in educational and healthcare systems [7]. It has been suggested that adequate awareness and knowledge proliferate positive attitudes and behaviors toward individuals with neurodevelopmental disorders, and also improve treatment enrolment and adherence [11]. Indeed, increased knowledge about adult ADHD has been found to be associated with lower expressed stigma [12] and, eventually, courtesy stigma [13]. Multimodal treatment, such as a combination of pharmacotherapy and cognitive behavior therapy (CBT) has
been recommended by different clinical guidelines, and should also include psychoeducational elements, that is provide individuals diagnosed with ADHD with comprehensive knowledge about their condition [14–16].

Behavior therapy in groups for adults with ADHD typically includes basic information about the condition, as well as skills training to improve functioning in everyday life [17–22]. However, such a psychotherapeutic approach has been perceived as being too demanding by a considerable percentage of adults with ADHD in a psychiatric outpatient setting, leading to high rates of attrition [18]. Furthermore, structured group-based CBT does not seem to be more effective than ordinary clinical counseling by a psychiatrist [23]. Finally, both CBT with certified clinical psychologists as group trainers and individual clinical counseling by psychiatrists are relatively resource demanding, and do not take into account and advantage of significant others.

Psychoeducation constitutes an approach to intervention providing information about ADHD and presents the opportunity to share experiences with people in a similar life situation, including the perspective of significant others. Importantly, and in contrast to most pharmacological and psychotherapeutical treatments, psychoeducation does not have the primary goal of reducing core symptoms, but aims at improving functional outcomes for the affected individual and to alleviate the burden of care on family members through collaborative management of everyday challenges [24]. Although rarely rigorously studied in adult ADHD [25–27], psychoeducation is deemed a well-established, sufficiently evidence-based intervention for several psychiatric disorders in adulthood [24].

The first four-session psychoeducational program, piloted in 9 individuals with adult ADHD versus 8 controls, yielded promising results with regard to improved organizational skills, on one hand, but also possibly temporary reductions in self-esteem, on the other [27]. Therefore, it is crucial for psychoeducational programs to empower the participants and to avoid psychological harm [28]. In another pilot study [26], an 11-session psychoeducational program (n = 15) was compared with a CBT program with the same length and topics (n = 11). No between-group differences were observed. The effects of both techniques were promising regarding both ADHD symptoms and decreased comorbidity. Nevertheless, this study did not include a non-treatment control group, so unspecific effects of time cannot be excluded. A third study investigated an 8-session psychoeducational group training program for adults with ADHD and their significant others (n = 108; 51 with ADHD and 57 significant others) [25]. The findings supported the usefulness of psychoeducation for increasing knowledge about ADHD without decreasing self-esteem. Nevertheless, the lack of a comparison group strongly limits the generalizability of these results.

PEGASUS (Hirvikoski et al., 2013) is a psychoeducational group training program for adults with ADHD and their (adult) significant others designed as a first-line treatment, preferably conducted shortly after an established diagnosis and as a complement to pharmacological treatment. By putting psychoeducation first and conveying knowledge about ADHD and available treatment and support options, as well as common care pathways, PEGASUS aims at facilitating the participant’s active involvement in his/her future treatment and case management. The objective of the current study was to further evaluate the PEGASUS program by means of a pragmatic multicenter randomized controlled study conducted in a naturalistic outpatient psychiatric setting.

### 2. Methods

We conducted a pragmatic parallel group design multicenter randomized controlled trial using an add-on design (i.e. the studied intervention added to the ongoing treatment as usual [TAU], and compared to ongoing TAU without additional intervention). The trial was approved by the Regional Ethics Committee of Stockholm in 2012 (2012/422-31/3), and all participants had given their informed consent. Data was collected between March 2012 and December 2013. Detailed information on this trial is provided using the CONSORT 2010 checklist. In addition, information on external validity aspects of the study is detailed using a checklist published by [29] (see supplementary material).

#### 2.1. Participants and settings

The study was conducted as part of the clinical routine at two outpatient tertiary psychiatric clinics specialized in the assessment and treatment of adults with neurodevelopmental disorders (Neuropsychiatric unit Karolinska, psychiatry northwest, and neuropsychiatric unit, psychiatry southwest) and three outpatient psychiatric clinics (Huddinge outpatient psychiatric clinic and Liljeholmen outpatient psychiatric clinic, psychiatry southwest; and Farsta Skarpnäck outpatient psychiatric clinic, psychiatry south) all located in Stockholm county, Sweden.

#### 2.1.1. Inclusion and exclusion criteria

In order to include a sample reflecting the natural composition and heterogeneity of the adult ADHD population treated in an outpatient psychiatric context, the inclusion criteria for the study were broad: ADHD as the primary (neurodevelopmental) diagnosis; age of 18 years or older; and possibility to participate with at least one adult significant other. The exclusion criteria were: current substance abuse (3 months prior to participation); intellectual disability (IQ < 70); organic brain injury; autism spectrum disorder; suicidality; any other severe psychiatric disorders (e.g., psychosis), or adverse psychosocial circumstances (e.g., being homeless), thus making successful participation unlikely or impossible. Ongoing pharmacological treatment or any other psychosocial intervention was not a reason for exclusion, i.e. the PEGASUS program was “added-on” ongoing treatment.

#### 2.1.2. Diagnostic assessment

The diagnostic assessment for ADHD was implemented before the participants were enrolled in the study and followed regular clinical practice in Stockholm County Council clinics [30]. Multiple sources of information were combined to constitute a best clinical estimate consensus diagnosis among the involved clinicians. A clinical interview based on DSM-IV-TR criteria (American Psychiatric Association, 2000), most often the D.I.V.A. 2.0 interview (http://www.divacenter.eu/DIVA.aspx), was conducted to corroborate the diagnosis. For the majority of participants, information from self-rating questionnaires was available, such as from the Wender Utah Rating Scale (WURS-25: PEGASUS M = 53.8, SD = 17.6; TAU M = 52.7, SD = 17.7) [31]; or the Adult ADHD Self-Report Scale (ASRS, PEGASUS M = 51.6, SD = 12.3; TAU M = 50.1, SD = 12.52) [32]. Additional information was routinely obtained from significant others, previous case files, neuropsychological testing and urine drug screening.

#### 2.2. Interventions

The PEGASUS program is an 8-session psychoeducational intervention that includes adults with ADHD and their significant others in all elements of the program. The program is based on general principles taken from CBT, neuropsychology, and good cross-disciplinary clinical practice pertaining to ADHD. The overarching goal of the intervention is to increase the participants’ knowledge of ADHD, including available support and treatment strategies in order to facilitate optimal self-management of ADHD in daily live. Groups were closed and conducted weekly by a senior
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