



## Original article

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

T. Hirvikoski <sup>a,b,\*</sup>, T. Lindström <sup>a</sup>, J. Carlsson <sup>a</sup>, E. Waaler <sup>a</sup>, J. Jokinen <sup>c,d</sup>, S. Bölte <sup>a,e</sup>

<sup>a</sup> Department of women's and children's health, pediatric neuropsychiatry unit, center for neurodevelopmental disorders Karolinska Institutet (KIND), Karolinska Institutet, Stockholm, Sweden

<sup>b</sup> Habilitation & health, Stockholm county council, Stockholm, Sweden

<sup>c</sup> Department of clinical neuroscience, Karolinska Institutet, Stockholm, Sweden

<sup>d</sup> Department of clinical sciences, psychiatry, Umeå university, Umeå, Sweden

<sup>e</sup> Child and adolescent psychiatry, center for psychiatry research, Stockholm county council, Stockholm, Sweden

## ARTICLE INFO

## Article history:

Received 7 July 2016

Received in revised form 28 February 2017

Accepted 10 April 2017

Available online 9 May 2017

## Keywords:

Attention deficit disorder with hyperactivity

Awareness

Randomized clinical trial (RCT)

Health knowledge

Attitudes

Practice

Pedagogies

## ABSTRACT

**Objective:** To examine the feasibility, efficacy, and effectiveness of PEGASUS, a group-based structured psychoeducation for adults with ADHD and their significant others.

**Method:** A pragmatic parallel group add-on design multicenter randomized controlled trial was conducted, comparing an 8-session treatment with PEGASUS (allocated  $n = 97$ ; 48 with ADHD and 49 with significant others) to treatment as usual (TAU, allocated  $n = 82$ ; 39 with ADHD and 43 significant others). Participants (individuals with ADHD and significant others) were recruited from five psychiatric outpatient departments and block randomized to PEGASUS or TAU. Knowledge about ADHD was measured using the ADHD 20 scale pre- and post-intervention and served as primary outcome.

**Results:** Knowledge about ADHD ( $d = 0.97$  [95% CI: 0.61–1.31]) increased following PEGASUS participation compared to TAU. Improvements were also observed in secondary outcomes e.g. global life satisfaction ( $d = 0.25$  [95% CI: from –0.09 to 0.59]). Overall treatment satisfaction was good. Over 90% of the participants completed the program. Post-intervention data was obtained from  $n = 89$  in PEGASUS group and  $n = 70$  in TAU group and analyses were conducted per protocol. No important adverse effects or side effects were observed.

**Conclusions:** Group-based structured psychoeducation PEGASUS for adults with ADHD and their significant others is a feasible, efficacious, and effective treatment option to increase ADHD knowledge and general life satisfaction in psychiatric outpatient care.

© 2017 The Authors. Published by Elsevier Masson SAS. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

## 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 (Bieder-

man 2004; Fayyad 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

\* Corresponding author at: Corresponding author. Center for Neurodevelopmental Disorders at Karolinska Institutet (KIND), CAP Research Center, Gävlegatan 22B, 11330 Stockholm, Sweden.

E-mail address: [tatja.hirvikoski@ki.se](mailto:tatja.hirvikoski@ki.se) (T. Hirvikoski).

<http://dx.doi.org/10.1016/j.eurpsy.2017.04.005>

0924-9338/© 2017 The Authors. Published by Elsevier Masson SAS. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

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 psychotherapeutic 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 ( $IQ \leq 70$ ); 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

clinical group leader with varying professional background, such as psychologist, nurse, occupational therapist, or social worker. The group leaders included other lecturers from the staff of the clinical department, depending on the topic of the respective sessions. Session topics and contents are summarized in Table 1. For resource saving reasons, PEGASUS groups were relatively large for group training in psychiatric settings and usually included 10–15 adults with ADHD and at least as many significant others. In the current study, 90% of the individuals with ADHD participated with one significant other. The group's composition was diverse regarding educational background, gender, and age. The program was manualized and has been published in the form of a guide for group leaders and a workbook for the participants (in Swedish), and is described in detail elsewhere [25,33,34].

The TAU group continued to receive standard clinical services from their local clinical departments, including both pharmacological and non-pharmacological intervention, which were not individually monitored in this study. The TAU group received PEGASUS during the following semester/term (i.e. they received standard clinical services while on a waiting list for PEGASUS).

### 2.3. Treatment fidelity

The PEGASUS program has a high degree of standardization regarding content and the way of delivery, including the general approach, communication style, and personal contact. Materials, including the ready-made lectures, are provided to the group leaders on a USB memory stick. In the current study, group leaders were regularly invited to supervision meetings to discuss issues related to the group leader's role, the program, and the research procedures. In between the supervision meetings, group leaders could contact the project leader by e-mail or by phone for support

and advice. No significant deviations from the intended psychoeducational program were noted at any of the five sites.

### 2.4. Measures

#### 2.4.1. Demographic data

Case histories and socio-demographic data on participants with ADHD were extracted from their clinical files. Moreover, they completed a questionnaire "Current Life Situation" covering demographic information and current stressors in different areas of life [35]. A modified version of this questionnaire was used to assess the background and demographic data of the significant others.

#### 2.4.2. Outcome measures

Self-report questionnaires were distributed at baseline, i.e., 1–2 weeks before the intervention started, before randomization (T1), at post-treatment, i.e., 1–2 weeks after the last session (T2), and at the 3-month follow-up (T3).

**2.4.2.1. Feasibility and treatment satisfaction.** In relation to the efficacy measures, the feasibility and treatment satisfaction were considered as secondary outcome measures.

Treatment completion was measured as the percentage of individuals allocated to the intervention who attended at least 4 out of the 8 course sessions. However, we also calculated the mean number of attended course sessions for individuals with ADHD and their significant others, respectively.

Treatment satisfaction/acceptability was measured using a modified version of the evaluation questionnaire (Bramham et al., 2009), which was completed anonymously at the end of each course session by all participants. The evaluation questionnaire

**Table 1**

Themes and main focus of PEGASUS sessions, as well as lecturers recruited by the group leader.

Themes and main focus of the eight PEGASUS sessions	Profile of the lecturer
<i>Introduction to ADHD in adulthood</i> Gives the participants a joint, basic understanding of the ADHD diagnosis, as well as of common difficulties (including psychiatric comorbidity) and strengths for individuals with ADHD	The first lecture should preferably be held by the senior group leader
<i>Pharmacological and psychological treatment</i> Introduces and describes available treatment strategies and options	Psychiatrist and psychologist experienced in the treatment of ADHD in adults
<i>Lifestyle factors: sleep, stress, diet, and exercise</i> Focuses on the connection between general lifestyle factors (such as sleep and physical activity) and ADHD symptom severity	Psychologist, occupational therapist, nurse, or other professional experienced in the theme of the lecture
<i>Structure and strategies in everyday life</i> Presents a range of strategies and cognitive aids developed to ease the life of individuals struggling with executive difficulties	Occupational therapist experienced in adult ADHD
<i>Living with ADHD – acceptance and change</i> Focuses on life with ADHD, as experienced and related by an individual having received the diagnosis as an adult	An individual with an ADHD diagnosis
<i>ADHD in relationships</i> Focuses on how ADHD symptoms such as inattention and impulsivity may affect social behaviour and close social relationships. Both positive and negative aspects of ADHD in relationships are discussed from the perspectives of adults with ADHD and significant others	Psychologist, social worker, or other professional experienced in the theme of the lecture
<i>ADHD at work</i> Informs about the various support measures provided by the employment services and about how job assignments/the workplace may be adjusted based on ADHD symptoms	Guest lecturer(s) from local employment services and psychologist, occupational therapist, or other professionals experienced in ADHD in the workplace
<i>Service and support provided by society</i> Informs about the various support measures society may provide for individuals with ADHD <sup>a</sup>	Guest lecturer from local municipality services, social worker, or other experienced professional

<sup>a</sup> A representative from the Swedish interest organization. Attention, informs briefly about their work in conjunction with course session 5 or 8.

consists of five statements rated “0” (do not agree at all) to “4” (totally agree). Three of the statements target the respondent’s appraisal of the contents and gained knowledge of the specific lecture (topic):

- “My knowledge about ADHD has increased”;
- “The contents of the lecture today was useful”;
- “The contents of the lecture today was relevant according to my experiences”;
- The other two items assess the participant’s experience of taking part in group discussions/exchange of experiences;
- “It was helpful to share experiences with other participants”;
- “It was helpful to take part of others’ experiences”.

An overall evaluation score is generated based on the mean rating of all five statements. In this study, the goal was to reach consistently high treatment satisfaction across the course sessions, defined as a mean overall evaluation score of  $\geq 3$ .

Adverse events (AEs), defined as any inconvenience that a participant reported, or serious adverse events (SAEs), defined as anything that required inpatient hospitalization, were recorded in the case report forms.

**2.4.2.2. Efficacy.** Primary efficacy outcome measure was ADHD knowledge, measured in all participants using the ADHD 20 Questions, a knowledge quiz modified for this study (Bramham et al., 2009), with 20 true/false/do not know scaled items, with 1 point given for correct answer and higher total scores reflecting better knowledge about ADHD.

Secondary efficacy outcome measures assessed global life satisfaction, psychological well being, and relationship quality (measured in all participants), as well as burden of care (in significant others) and self-esteem (in individuals with ADHD). Global life satisfaction was measured using the Satisfaction With Life Scale (SWLS) [36]. Its five items are scored on a 1 to 7 scale with “1” indicating high dissatisfaction, “4” a neutral point and “7” high satisfaction with life. The Hospital Anxiety and Depression Scale [37] was used to measure well being on the two subscales Depression and Anxiety containing seven items each, scored on a 0 to 3 Likert-scale (higher scores indicate more symptoms). The Questions About Family Members (QAFM) [38] constitute a dyadic self-report questionnaire, which was used to measure aspects of the quality of the relationship between the co-participants, i.e., the relationship between the adult individual with ADHD and his/her significant other(s). The QAFM comprises four subscales: [1] Critical Remarks (directed at the other person); [2] (the respondent’s) Emotional Over-involvement; [3] Perceived Criticism (from the other person); and [4] (perceived) Emotional Involvement (from the other person in the relationship). The 30 items are scored on a 1 (“almost never”) to 5 (“almost always”) Likert-scale. Low scores on the first three subscales are indicative of a good relationship quality, while on the fourth subscale (Emotional Involvement), high scores indicate the same.

The burden of care experienced by significant others was assessed using the Burden Assessment Scale (BAS) (Reinhard et al., 1994), a scale consisting of 19 items scored on a 4-point Likert-scale from 1 (“Not at all”) to 4 (“A lot”). A potential decrease in self-esteem was investigated using Rosenberg’s Self-Esteem (RSE) Scale (adults with ADHD only) (Rosenberg, 1965), consisting of 10 items scored 0 to 3, with higher scores indicating stronger self-esteem.

## 2.5. Recruitment, enrolment, and randomization

Participants were recruited from the patient base of the five participating psychiatric departments. The first contact with the

ADHD participants was established by sending out study information from each of the five clinics via regular mail. Thereafter, the participants were invited to visit the respective clinical department in smaller groups for further information and evaluation of their individual eligibility for the study. An experienced clinical psychologist conducted individual interviews, collected additional questionnaire data, and studied case files in order to assess inclusion and exclusion criteria.

The group leaders received both oral and written instructions for the randomization procedure. After inclusion and after the baseline measurements at T1, the participants with ADHD were individually randomized to either PEGASUS during the same semester or TAU group who received the PEGASUS during the following semester. The groups were not stratified according to any variable, but block randomization was applied at each of the five sites in order to ensure that they would be of approximately similar size (1:1 ratio). The block sizes (not known by the participants) varied between 12 and 27 participants (with ADHD only). Randomization was created by drawing lots. After determining the block size, which varied as a function of the number of participants who had announced interest in participation, folded opaque information cards in envelopes were created by the project leader and contained information on the result of the randomization. The cards were placed in a container and mixed. The container was placed in such a manner as to make it impossible for the group leader to see the card that he drew for the participant, thus both being blinded. The group leader then informed the participant of the results of the randomization and assigned the participant to intervention or TAU. Thus, the participants were able to follow the randomization process and their reaction to the outcome of the randomization could be responded to immediately.

The participants completed the questionnaires at baseline before they were randomized, and were thus blinded to intervention allocation at T1. The power calculation regarding total sample size was based on moderate effect size (corresponding to 0.5 SD) observed in the ADHD group in the measure used as primary outcome measure in current study. Thus, 0.80 power (at alpha level of .05) required approximately 50 participants with ADHD in each group (Hirvikoski et al., 2015).

## 2.6. Statistical analyses

The main analysis focused on the change from baseline (T1) to post-treatment (T2) on the efficacy measures, while we also analyzed the stability of the results at T2 using a simple contrast with follow-up (T3) as the reference category (for those individuals having T3 data, i.e., per protocol). Measures of efficacy were analyzed using a series of repeated measures mixed-design analyses of variance (rmANOVAs), with group (intervention versus TAU/waiting list) as a between-subjects factor and outcome scores obtained on two (T1–T2) or three (T1–T3) measurement occasions as repeated measures within-subject factors. Effect sizes were expressed as partial eta squared ( $\eta_p^2$ ) and interpreted as 0.01–0.05 = small effect size, 0.06–3 = moderate effect size,  $\geq 14$  = large effect size [39]. For significant results, we also calculated Cohen’s *d* effect sizes (with 95% confidence intervals) and these were interpreted as 0.20–30, a small effect, around 0.50 (half a SD), a moderate effect, and  $\geq 0.80$ , a ‘large’ effect [39]. All statistical analyses were planned a priori and the alpha level was set at  $P = 0.05$ . Outliers were screened within each group (PEGASUS versus TAU), separately for groups of individuals with ADHD versus significant others. Values greater than 1.5 times the interquartile range (IQR) were regarded as outliers and excluded from the analyses using pair-wise exclusion. Outliers were generally few in number.

**3. Results**

A total of 97 individuals with ADHD and 100 significant others were assessed for eligibility (Fig. 1) (n = 197 in total). Of the individuals with ADHD who took part in the enrolment process, 89.7% (n = 87 with ADHD; as well as 92 significant others, in total

n = 179) were included and randomly assigned to either the intervention or TAU group. Five participants in the PEGASUS group (two with ADHD and three significant others) declined participation after randomization and therefore did not undergo the treatment as intended. In total, 92 individuals (46 with ADHD and 46 significant others) participated in one of the five PEGASUS

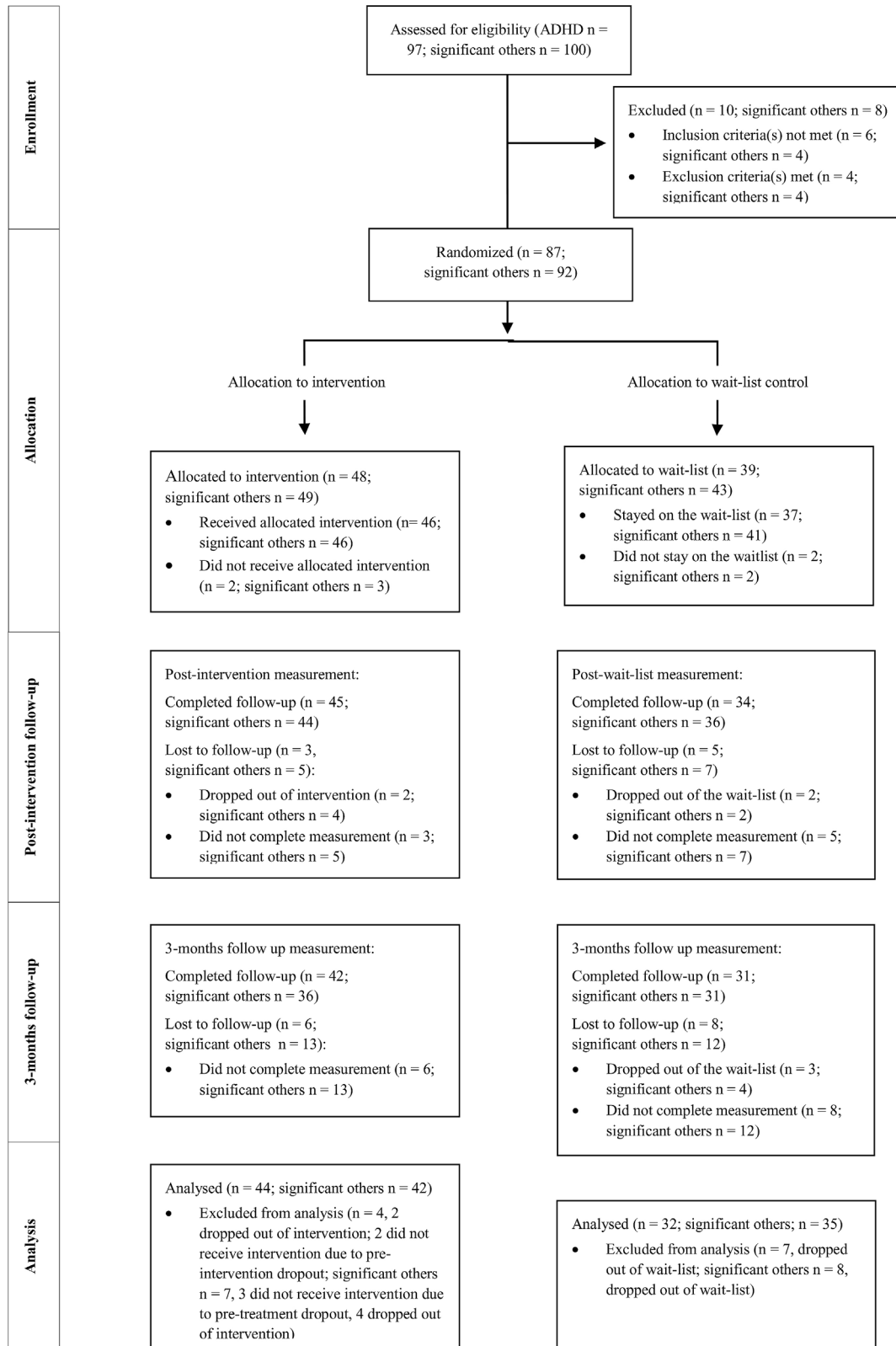


Fig. 1. Flow-chart of the study participants.

**Table 2**  
Sample characteristics: demographic and background data on the participants diagnosed with ADHD.

Participants with ADHD	Intervention group (PEGASUS) n = 48	TAU controls n = 39	t-test/Chi <sup>2</sup> test
Age (years)	M = 38.6, SD = 10.3 Range: 19–59	M = 38.2, SD = 11.4 Range: 20–65	n.s.
Gender (female)	31 (64.6%)	21 (53.8%)	n.s.
ADHD subtype			n.s.
ADHD-C	38 (79.2%)	33 (84.6%)	
ADHD-A	8 (16.7%)	6 (15.4%)	
ADHD-NOS	2 (4.2%)	0 (0%)	
Years since diagnosed with ADHD	M = 1.51, SD = 2.9 (mv = 1)	M = 1.59, SD = 2.2	n.s.
Background of psychiatric care (prior diagnostic assessment)			
None	9 (18.8%)	6 (15.4%)	
Less than 2 years	11 (22.9%)	11 (28.%)	
2–5 years	9 (18.8%)	9 (23.1%)	
More than 5 years	19 (39.6%)	12 (30.8%)	
Current psychological treatment	5 (10.1%; mv = 1)	14 (35.9%; mv = 1)	P = 0.01
Pharmacological treatment of ADHD	31 (64.6%)	23 (59.0%)	n.s.
Any psychoactive medication	38 (79.2%)	28 (71.8%)	n.s.
At least one additional DSM-IV diagnosis	31 (64.6%)	17 (43.6%)	P = 0.05
Employment			n.s.
Full-time work/Full-time studies	36 (75.0%)	26 (66.7%)	
Unemployed	4 (8.3%)	5 (12.8%)	
Long-term sick leave/disability pension	5 (10.4%)	5 (12.8%)	
Other	3 (6.3%)	3 (7.7%)	
Education			n.s.
Academic degree	6 (12.5%)	4 (10.3%)	
Upper secondary school	25 (52.1%)	21 (53.8%)	
Nine years of compulsory school	14 (29.2%)	14 (35.9%)	
Other	3 (6.3%)	0 (0.0%)	

mv: missing observations; ADHD-C: ADHD combined type; ADHD-A: ADHD predominantly inattentive type; ADHD-NOS: ADHD not otherwise specified.

groups. Although a large majority of the participants completed the treatment phase, a substantial minority of both PEGASUS and TAU group members were not reached at the 3-month follow-up; 30% of the data were missing for significant others at T3 (for details, see Fig. 1). Participants who did not show-up at the follow-up assessments also received the questionnaires via mail, but return rate was low. The results regarding measures of efficacy were

analyzed per protocol, i.e. for those individuals for whom data was available at T1–T2 and T1–T3, respectively.

### 3.1. Demographic data

The background and demographic data of the participants are depicted in Table 2 (individuals with ADHD) and Table 3

**Table 3**  
Sample characteristics: demographic and background data on the participating significant others.

Significant others	Intervention group n = 49 (PEGASUS)	TAU controls n = 43	t-test/Chi <sup>2</sup> test
Age (years)	M = 43.3, SD = 13.5 (mv = 2) Range: 19–67	M = 38.6, SD = 11.3 Range: 20–62	n.s.
Gender (female)	32 (65.3%)	27 (62.8%)	n.s.
Employment			n.s.
Full-time work/full-time studies	38 (77.6%)	41 (95.3%)	
Pensioner/senior citizen	2 (4.1%)	0 (0.0%)	
Unemployed	4 (8.2%)	1 (2.3%)	
Long-term sick leave or disability pension	1 (2.0%)	0 (0.0%)	
Other	4 (8.2%)	1 (2.3%)	
Education			n.s.
Academic degree	16 (32.7%)	12 (27.9%)	
Upper secondary school	22 (44.9%)	27 (62.8%)	
Nine years of compulsory school	8 (16.3%)	4 (9.3%)	
Other	3 (6.1%)	0 (0%)	
Relation to the participant with ADHD			n.s.
Partner	27 (55.1%)	24 (55.8%)	
Parent	11 (22.4%)	8 (18.6%)	
Sibling	4 (8.2%)	3 (7.0%)	
Adult offspring	2 (4.1%)	2 (4.7%)	
Friend	5 (10.2%)	3 (7.0%)	
Other	0 (0.0%)	3 (7.0%)	
Living together with the participant with ADHD (Yes)	26 (53.1%)	23 (53.5%)	n.s.
Involved in the diagnostic assessment of the participant with ADHD (Yes)	27 (55.1%)	27 (62.8%)	n.s.

mv: missing observations.

(significant others), separately for each of the two groups (PEGASUS versus TAU).

### 3.2. Feasibility and treatment satisfaction

#### 3.2.1. Treatment completion

Forty-six out of 48 allocated individuals with ADHD (95.8%) completed the intervention. On average, individuals with ADHD attended 86.0% of the sessions, i.e., were absent on one PEGASUS occasion. Forty-five out of 49 allocated significant others (91.8%) completed the intervention. On average, the significant others attended 79.0% of the PEGASUS sessions.

#### 3.2.2. Treatment satisfaction

The participants reported generally good treatment satisfaction. The goal of an overall evaluation score of at least 3 was reached on 7 out of 8 PEGASUS occasions (Fig. 2). There were no differences in treatment satisfaction between the individuals with ADHD and their significant others ( $t$ -tests, all  $P$  values  $> 0.10$ ). Moreover, a separate analysis of items related to contents/knowledge and exchange of experiences, respectively, revealed generally high satisfaction with both aspects of psychoeducation: “gained knowledge”, ranging from  $M = 2.82$  to  $3.61$  and “usefulness of exchange of experiences”, ranging from  $M = 2.66$  to  $3.43$ .

#### 3.2.3. Adverse events (AEs) and serious adverse events (SAEs)

No adverse events or serious adverse events were judged to be related to the program per se.

### 3.3. Efficacy

In this section, the primary and secondary measures of efficacy are presented. First, we describe the results comparing the entire intervention group (both adults with ADHD and the significant others) to the entire TAU group. Thereafter, results are presented

for adults with ADHD and significant others analyzed and compared separately. Table 4 is organized in the same way and depicts the measures that were administered to all participants, including adults with ADHD and their significant others, pre- and post-intervention (i.e. the main analyses per protocol). Finally, the results at T3 (3-month follow-up) as well as findings from questionnaires only collected in either adults with ADHD or significant others are presented below.

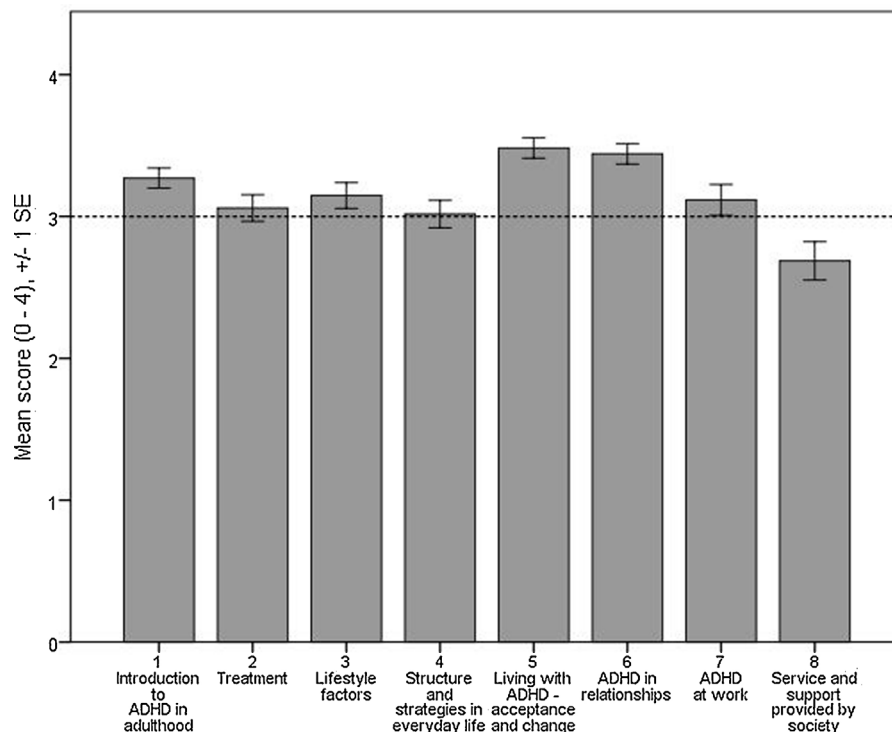
#### 3.3.1. Primary efficacy outcome measure

Knowledge about ADHD increased more in the intervention group than in the TAU group from T1 to T2 (Fig. 3, Table 4). In separate analyses (Table 4), more increased knowledge was observed for both adults with ADHD and their significant for PEGASUS treatment, as compared to TAU group. At T3, the effect was stable as indicated by a nonsignificant change from T2 to T3 (contrast  $P$  value  $< 0.10$ ).

#### 3.3.2. Secondary efficacy outcome measures

Global life satisfaction (SWLS) improved from T1 to T2 in the intervention group as compared to the TAU group (Table 4). The sum scores divided by the number of items improved slightly in the PEGASUS group (ADHD,  $M = 3.21$  pre- to  $3.50$  post-intervention; significant others,  $M = 4.88$  pre- to  $5.13$  post-intervention), but were unchanged in TAU (ADHD,  $M = 3.51$  pre to  $M = 3.40$  post-intervention; significant others,  $M = 4.45$  pre- to  $4.40$  post-intervention). However, in a separate analyses (with less power), the effect for individuals with ADHD and significant others, respectively, only approached, but did not reach, statistical significance (Table 4). There were no significant changes from T2 to T3 (contrast  $P$  value  $< 0.10$ ).

On the measures of well being (Hospital Anxiety and Depression Scale, HADS), a group difference was observed on the HADS anxiety symptoms (Table 4). The separate analyses showed that this difference was only observed in significant



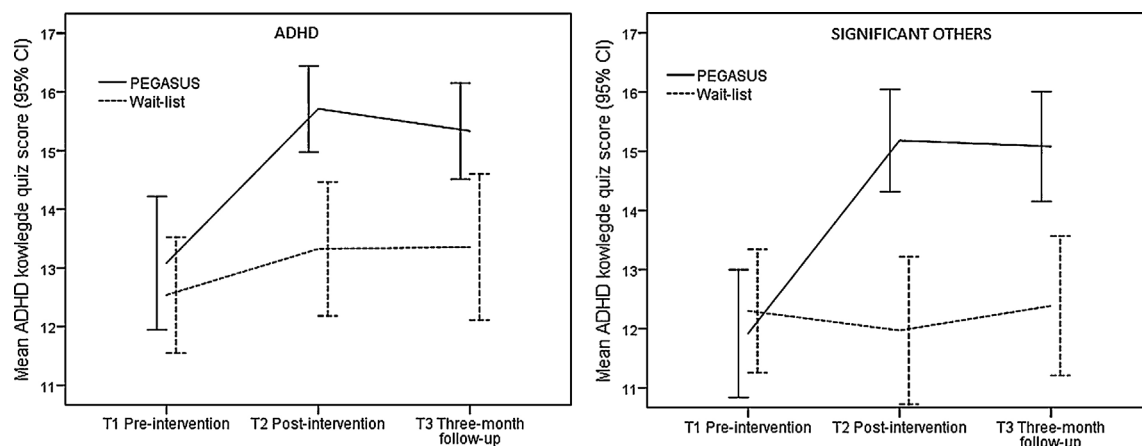
**Fig. 2.** Treatment satisfaction (scored 0–4 for each course session). The goal of a mean score of at least 3 was reached for 7 out of 8 sessions. No differences in treatment satisfaction between the individuals with ADHD and their significant others were observed ( $t$ -tests, all  $P$  values  $> 0.10$ ) and the figure represents combined values from both individuals with ADHD and the significant others.

**Table 4**

Results from baseline to post-intervention in measures for efficacy completed by both the individuals with ADHD and the significant others. The repeated measures ANOVA was calculated separately for the individuals with ADHD and their significant others.

	Baseline (T1)		Follow-up (T2)		rmANOVA statistics $F(df)$ (interaction effect)	Effect size expressed as $\eta_p^2$ and $d$ (95%CI) when significant	P value
	Intervention $M$ (SD)	Waiting list $M$ (SD)	Intervention $M$ (SD)	Waiting list $M$ (SD)			
<b>ADHD knowledge</b>							
All participants	12.74 (3.54) $n=82$	12.65 (3.20) $n=63$	15.65 (2.44) $n=82$	12.81 (3.49) $n=63$	$F(1,143)=41.89$	$\eta_p^2=0.23$ $d=.97$ (.61–1.31)	$P<0.001$
Adults with ADHD	13.38 (3.39) $n=42$	12.55 (3.36) $n=31$	15.76 (2.31) $n=42$	13.65 (3.10) $n=31$	$F(1,71)=5.86$	$\eta_p^2=0.08$ $d=.79$ (.30–1.26)	$P=0.018$
Significant others	12.08 (3.61) $n=40$	12.75 (3.10) $n=32$	15.52 (2.58) $n=40$	12.00 (3.69) $n=32$	$F(1,71)=45.55$	$\eta_p^2=0.39$ $d=1.13$ (.62–1.62)	$P<0.001$
<b>Global life satisfaction (SWLS)</b>							
All participants	20.05 (6.60) $n=75$	20.05 (7.22) $n=60$	21.41 (6.62) $n=75$	19.78 (6.48) $n=60$	$F(1,133)=5.23$	$\eta_p^2=0.04$ $d=.25$ (-.09-.59)	$P=0.024$
Adults with ADHD	16.05 (5.73) $n=39$	17.54 (6.96) $n=28$	17.49 (5.96) $n=39$	17.00 (5.25) $n=28$	$F(1,65)=3.47$	$\eta_p^2=0.05$	$P=0.067$
Significant others	24.39 (4.40) $n=36$	22.25 (6.81) $n=32$	25.67 (4.28) $n=36$	22.22 (6.53) $n=32$	$F(1,66)=1.65$	$\eta_p^2=0.02$	$P=0.204$
<b>Well being: anxiety (HADS)</b>							
All participants	8.72 (4.38) $n=82$	9.27 (4.83) $n=60$	8.56 (4.42) $n=82$	10.25 (5.38) $n=60$	$F(1,140)=3.90$	$\eta_p^2=0.03$ $d=.35$ (.01-.68)	$P=0.05$
Adults with ADHD	10.81 (3.63) $n=43$	12.57 (2.44) $n=28$	10.56 (4.03) $n=43$	12.68 (3.85) $n=28$	$F(1,69)=0.18$	$\eta_p^2=0.003$	$P=0.677$
Significant others	6.41 (3.98) $n=39$	6.38 (4.55) $n=32$	6.36 (3.78) $n=39$	8.13 (5.67) $n=32$	$F(1,69)=5.59$	$\eta_p^2=0.075$ $d=.37$ (-.10-.84)	$P=0.021$
<b>Well being: depression (HADS)</b>							
All participants	5.73 (3.50) $n=82$	5.32 (3.40) $n=62$	5.66 (4.11) $n=82$	5.97 (4.35) $n=62$	$F(1,142)=1.93$	$\eta_p^2=0.13$	$P=0.167$
Adults with ADHD	6.95 (3.44) $n=43$	6.10 (3.43) $n=31$	7.16 (4.31) $n=43$	6.90 (4.61) $n=31$	$F(1,72)=0.54$	$\eta_p^2=0.007$	$P=0.465$
Significant others	4.38 (3.09) $n=39$	4.55 (3.24) $n=31$	4.00 (3.19) $n=39$	5.03 (3.91) $n=31$	$F(1,68)=1.87$	$\eta_p^2=0.03$	$P=0.177$
<b>QAFM – critical remarks</b>							
All participants	21.56 (7.12) $n=77$	22.29 (6.94) $n=56$	20.74 (6.93) $n=77$	21.86 (6.81) $n=56$	$F(1,131)=0.18$	$\eta_p^2=0.001$	$P=0.68$
Adults with ADHD	21.80 (8.30) $n=41$	22.39 (6.98) $n=28$	22.17 (8.30) $n=41$	21.71 (7.08) $n=28$	$F(1,67)=0.51$	$\eta_p^2=0.007$	$P=0.480$
Significant others	21.28 (5.59) $n=36$	22.18 (7.03) $n=28$	19.11 (4.52) $n=36$	22.00 (6.66) $n=28$	$F(1,62)=4.67$	$\eta_p^2=0.07$ $d=.52$ (.01–1.02)	$P=0.035$
<b>QAFM – perceived criticism</b>							
All participants	14.66 (5.00) $n=80$	13.07 (4.61) $n=56$	13.99 (4.90) $n=80$	13.04 (4.57) $n=56$	$F(1,134)=0.93$	$\eta_p^2=0.007$	$P=0.336$
Adults with ADHD	15.27 (5.00) $n=41$	12.89 (4.68) $n=26$	14.44 (5.16) $n=41$	12.00 (3.88) $n=26$	$F(1,65)=0.20$	$\eta_p^2=0.00$	$P=0.888$
Significant others	14.03 (4.98) $n=39$	13.40 (4.61) $n=30$	13.51 (4.63) $n=39$	13.93 (4.99) $n=30$	$F(1,65)=1.33$	$\eta_p^2=0.19$	$P=0.253$
<b>QAFM – emotional over-involvement</b>							
All participants	20.35 (6.04) $n=79$	20.50 (5.32) $n=56$	19.63 (5.79) $n=79$	20.04 (5.14) $n=56$	$F(1,133)=0.14$	$\eta_p^2=0.001$	$P=0.714$
Adults with ADHD	19.73 (6.67) $n=41$	20.25 (4.79) $n=28$	20.02 (6.66) $n=41$	19.54 (4.61) $n=28$	$F(1,67)=1.10$	$\eta_p^2=0.016$	$P=0.297$
Significant others	21.03 (5.28) $n=38$	20.75 (5.88) $n=28$	19.21 (4.75) $n=38$	20.54 (5.67) $n=28$	$F(1,64)=2.57$	$\eta_p^2=0.039$	$P=0.114$
<b>QAFM – emotional involvement</b>							
All participants	13.72 (2.70) $n=75$	14.66 (3.01) $n=59$	13.75 (2.40) $n=75$	14.49 (3.10) $n=59$	$F(1,132)=0.23$	$\eta_p^2=0.002$	$P=0.633$
Adults with ADHD	14.76 (2.71) $n=38$	15.38 (2.58) $n=29$	14.58 (2.49) $n=38$	14.72 (2.87) $n=29$	$F(1,65)=0.66$	$\eta_p^2=0.010$	$P=0.419$
Significant others	12.65 (2.26) $n=37$	13.97 (3.20) $n=30$	12.89 (2.00) $n=37$	14.27 (3.35) $n=30$	$F(1,65)=0.10$	$\eta_p^2=0.00$	$P=0.922$

SWLS: Satisfaction with Life Scale; HADS: Hospital Anxiety and Depression Scale; QAFM: Questions about Family Member.



**Fig. 3.** Knowledge of ADHD, including available treatment and support, increased from pre- to post-intervention (and was stable up to the three-month follow-up in the individuals having the follow-up data), in both adults with ADHD and their significant others, as compared to the TAU comparison group.



others. Among those in the TAU group, the anxiety symptoms increased from T1 to T2, while no changes were observed in the significant others in the PEGASUS group. The results were stable from T2 to T3 (contrast  $P$  value  $< 0.10$ ). There were no changes in HADS-depression symptoms (all  $P$  values  $< 0.10$ ).

In the measures of relationship quality (QAFM), the overall analyses of all participants were nonsignificant (all  $P$  values  $< 0.10$ ) and no effects were observed among adults with ADHD (all  $P$  values  $< 0.10$ ). However, positive changes were observed among significant others after the intervention. Regarding QAFM-critical remarks, significant others reported that they expressed fewer critical remarks to the individual with ADHD (Table 4). On the remaining three subscales, the decrease in emotional over-involvement and perceived criticism approached but did not reach statistical significance (emotional over-involvement analyzed from T1 to T2,  $P = 0.11$ , and perceived criticism analyzed from T1 to T3,  $P = 0.14$ ). There were no significant changes from post-intervention to follow-up (T2–T3) (contrast  $P$  values  $< 0.10$ ).

The burden of care, as experienced by the significant others, was generally decreased during the study period [PEGASUS group T1,  $M = 13.55$  ( $SD = 8.88$ ) and T2,  $M = 11.68$  ( $SD = 8.95$ ); TAU group T1,  $M = 16.48$  ( $SD = 12.84$ ) and T2,  $M = 14.55$  ( $SD = 11.12$ );  $F(1,65) = 4.10$ ,  $P = 0.047$ ,  $\eta_p^2 = 0.06$ ], while there was no interaction effect.

No negative effects on self-esteem were observed on the Rosenberg self-esteem scale. Both overall and interaction effects for analyses from pre- to post-intervention yielded  $P$  values  $< 0.10$ . In contrast, a general increase (without interaction effect) in self-esteem was reported from T1 to T3 in those individuals for whom T3 data were available ( $F(2,128) = 3.61$ ,  $P = 0.03$ ,  $\eta_p^2 = 0.05$ ).

#### 4. Discussion

In this pragmatic multicenter randomized controlled trial of group-based psychoeducation (PEGASUS program) we observed good feasibility, high treatment satisfaction, and large effects on knowledge of ADHD, available support and treatment options in adults with ADHD and their significant others following treatment. The trial was conducted in a clinical outpatient psychiatric setting with experienced clinicians as group leaders and recruitment of the participants from the patient base of the five psychiatric clinics involved in the study.

An explicit goal of the study was to recruit participants who were representative of the heterogeneity of the adult ADHD population in a naturalistic adult outpatient psychiatric context. The clinical characteristics of the cohort were comparable to those of previous study samples of adults with ADHD from similar settings, i.e. psychiatric outpatient context [18,35,40,41]. The same applies for their significant others [25]. As expected, the significant others had higher levels of education and more often full-time employment than the individuals with ADHD. The demographic characteristics of our sample were also close to the corresponding figures for the entire Swedish general population (Statistics Sweden, <http://www.scb.se/en/>). Accordingly, the significant others scored, on average, within the non-clinical range at baseline on measures of psychological well being, i.e., under the mean score 7 on both depression and anxiety scales of the HADS [42] and global life satisfaction, i.e., a mean item score on the SWLS above the neutral point of 4 [43]. These relatively low scores at baseline may affect the possibility of capturing treatment effects, given the narrow scope for change.

In most cases, the significant others were partners or parents of the individuals with ADHD, but also included siblings, friends, and adult offspring. It was not possible to analyse the association between the type of the relationship in the participating dyad and

treatment effects in our relatively small sample. This is, however, definitely an interesting topic for future research. About 20% of the participating significant others were parents of young adults with ADHD, which may reflect the ongoing role of parents as information seekers and coordinators for their children, a responsibility that continues when the offspring reaches adulthood [44]. Given the complexity of its clinical presentation, ADHD frequently leads to functional impairments in several contexts, [3,45,46], which inevitably lead to contacts with healthcare providers and societal authorities. Thus, families living with ADHD face high demands regarding awareness of possible sources of support and of municipality, county, state, and other relevant authorities, as well as coordination of various contacts [44]. Previous research [45] has shown that individuals diagnosed with ADHD, as children were dependent on their parents as young adults to a much higher degree than individuals who were not diagnosed with ADHD.

While in the current study, the majority of the participants with ADHD had  $\geq 2$  years of ongoing contacts with psychiatric service providers and were diagnosed, on average, 1.5 years before being invited to participate in the project, the PEGASUS program is preferably offered to newly diagnosed adults with ADHD and their significant others. Before coming to terms with (i.e., accepting) the established ADHD diagnosis, it is quite common to encounter emotional turmoil and confusion characterized by negative thoughts and rumination (Young et al., 2008). Not much is known about family members' reaction to the diagnostic assessment and establishment of the ADHD diagnosis in an individual close to them. The PEGASUS program is intended to create a setting for processing and accepting the diagnosis while avoiding depressive rumination. Moreover, some aspects of the information covered in the PEGASUS program should be most helpful early on in the clinical management, i.e., in parallel with the planning of pharmacological treatment and other clinical efforts. In our study sample, the individuals undergoing pharmacological treatment (slightly more than 60% of those with ADHD) were, in most cases, already on stable psychopharmacological treatment, and those without medication had in many cases ceased pharmacotherapy due to side or default effects. Despite the observed good treatment satisfaction and positive effects in present study groups, we still consider the PEGASUS program to be best suited for implementation shortly after establishment of an ADHD diagnosis in adult individuals.

In the open pilot study on the PEGASUS program [25], the participants reported good treatment satisfaction with the program as a whole. In the present study, we observed good treatment satisfaction regarding the two investigated aspects of psychoeducation (contents/knowledge and exchange of experiences, respectively) for each of the eight PEGASUS sessions, as reported by both individuals with ADHD and their significant others. Therefore, the goal of maintaining a consistently good standard concerning the chosen topics and prepared material throughout the program was deemed to be accomplished.

Since the PEGASUS groups are relatively large, preferably 10 to 15 individuals with ADHD and at least equally many significant others (although one of the sites in the current project included a smaller group) and therefore necessitate considerable administrative resources, it is important to provide the group leaders with the necessary organizational support. In an outpatient psychiatric context, scarce resources (such as sufficient time) may hamper the implementation of new methods. Thus, the [group leader materials](#), including ready-made session items (including Power Point® presentation), as well as information folders, invitational letters, checklists, etc., are provided on a USB memory stick following the workbook for the group leader. The goal of these materials is to facilitate the implementation, as well as to create

coherent professional materials for the different phases of preparing, recruiting, delivering, and following-up. According to the feedback from the group leaders, these materials significantly reduced the administrative burden and increased treatment fidelity.

Today, many individuals with ADHD remain untreated, because both pharmacological and psychosocial treatment services are still underdeveloped [47]. The PEGASUS program seeks to complement pharmacotherapy by including a large proportion of adults with ADHD early on in psychiatric care pathways. In a previous study, the program was judged to be a suitable treatment option for > 90% of individuals diagnosed with a primary diagnosis of ADHD in an outpatient psychiatric context [25]. In the current study, > 90% of the included individuals completed the program and, on average, individuals with ADHD were present at 7 out of 8 sessions and significant others 6 to 7 out of 8 sessions, which indicates good to excellent feasibility in a clinical setting.

The primary outcome measure in the current study was increased knowledge of ADHD, including available support and treatment options, as measured by a 20-item ADHD quiz. Previous research has indicated that providing educational information increases knowledge and positive attitudes and behaviors toward children with neurodevelopmental disorders, while provision of a diagnostic label alone is insufficient to achieve such an effect [11]. ADHD in adulthood has been suggested to be even more likely than ADHD in childhood to be associated with misperceptions, confusion, and an increased number of laypeople and professionals lacking ADHD-related knowledge [48]. Variables identified as being associated with stigma in ADHD are the general public's uncertainty concerning the validity of ADHD diagnoses, perceived dangerousness of individuals with ADHD, stigmatization of ADHD treatment, disclosure of diagnostic and/or medication status, as well as different socio-demographic factors [7]. Consequently, individuals with ADHD risk self-stigma with similar biases, while significant others may be afflicted by courtesy stigma. Therefore, it is of paramount importance to provide professionals (who deliver the information to the patients) with educational information materials that are based on evidence-based practices, i.e., those combining the best available knowledge acquired from science, professional practice, and the clients' experiences, values, and needs. Furthermore, the psychoeducational program must be delivered in a way that does not cause harm. In a previous study [27], in addition to positive effects, a reduction in self-esteem was also observed, probably owing to an increased awareness of the functional impairments and the effort needed to manage everyday life associated with ADHD. In the current study, we observed increased knowledge in both adults with ADHD and their significant others, without any observed negative effects on self-esteem (measured in adults with ADHD only). The significant others reported a reduction in critical remarks directed to the individual with ADHD (as well as a trend toward decreased emotional over-involvement), and improved psychological well being. However, the between-group difference in psychological well being was also due to decreased well being in those in the TAU group. It is a common experience both from clinical practice and research (Young et al., 2008) that receiving a diagnosis without adequate support may lead to a period of poor psychological well being in adults with ADHD and this may also be true in significant others.

The PEGASUS program is not aiming at reducing core ADHD symptoms, although indirect symptom relief might be achieved through increasing patient involvement, knowledge, and motivation for further treatment. Pharmacotherapy and, possibly, behavior therapy seek to accomplish ADHD symptom reduction; however, it is not certain that group behavior therapy is more effective than psychoeducation [26]. Moreover, a recent large

randomized controlled trial [23] indicated that diagnosis-specific group behavior therapy was not more effective than individual supportive counseling with a psychiatrist. Both psychosocial treatments were inferior to pharmacotherapy. Based on the current scientific literature, psychosocial interventions should not be regarded as a substitute, but as a complement to pharmacological treatment [49], as well as being likely to be effective for individuals on pharmacological treatment and with residual ADHD symptoms [17–22]. Hopefully, psychosocial treatments will improve the long-term quality of life for individuals with ADHD and their significant others. In the present study, we observed a small but positive effect on global life satisfaction in the PEGASUS participants, as compared to TAU group.

#### 4.1. Limitations

The present study has several limitations. Firstly, the sample was relatively small, especially since a large portion of the participants was lost to the three-month follow-up. We were also unable to compute subgroup analysis, for instance the effect of treatment on different types of significant others (e.g. parents versus partners). Secondly, self-rating scales, and not clinician ratings, were used to measure effects. However, the primary outcome (knowledge) is preferably measured using a self-rated knowledge quiz. Moreover, the PEGASUS program has indirect goals of reducing stigmatization and increasing acceptance of the ADHD diagnosis. These parameters were not measured, however, in the present study. In addition, the control group received TAU, why only T1 measurements were blinded (at T2 and T3 participants were aware of treatment or TAU). It may be argued that any kind of intervention added to TAU would be beneficial as compared to a TAU alone. However, our previous experience of loosely structured discussion groups as control groups [18] indicate that this is surely not the case for adult ADHD. A further limitation was the large proportion of missing data at 3-month follow-up (T3), probably owing to a lack of incitement for participating in the follow-up assessment. Regardless of the reason, missing data limited our possibility to analyze data T1–T3, and the main analyses were conducted per protocol T1–T2. Finally, this study was conducted in a naturalistic outpatient psychiatry context, why our results may not easily generalize to other settings such as forensic psychiatry context.

Bearing these limitations in mind, the current results suggest that psychoeducation is a feasible intervention that adults with ADHD and their significant others benefit from in an outpatient psychiatric setting.

#### Role of funding source

Funding for the study was provided by the center for neurodevelopmental disorders at Center for Neurodevelopmental Disorders at Karolinska Institutet (KIND), the Center for Psychiatry Research (CPF), and the Swedish research council (Project numbers: K2009-61P-21304-04-4; K2009-61X-21305-01-1; 523-2009-7054). Further financial support was provided through the Regional Agreement on Medical Training and Clinical Research (ALF/PPG) between the Stockholm county council and Karolinska Institutet. The funding sources had no role regarding study design; in the collection, analysis and interpretation of data; in the writing of the report; and in the decision to submit the article for publication.

#### Contributions

T.H. initiated and designed the study with the aid of several clinicians. T.H., J.C., T.L., and E.W. developed the content of the

PEGASUS material with the aid of several clinicians and individuals with ADHD. T.L. entered the data into a database. T.H. designed and conducted the statistical analysis and wrote the first draft. T.L. and T.H. drew the figures. All authors read and commented on the final manuscript.

### Disclosure of interest

Four of the authors are also authors of the published treatment manual and the course book and receive royalties from Hogrefe (T.H., T.L., J.C., and E.W.). S.B. declares that he has no competing interest. S.B. discloses that he has in the last 5 years acted as an author, consultant or lecturer for Shire, Medice, Roche, Eli Lilly, Prima Psychiatry, GLGroup, System Analytic, Kompetento, Expo Medica, and Prophase. He receives royalties for textbooks and diagnostic tools from Huber/Hogrefe, Kohlhammer and UTB.

J.J. declares that he has no competing interest.

### Acknowledgements

We are indebted to all participants in the projects. We also wish to express our gratitude to the group leaders, Kristina Harsanyi, Emilie Mori, Katarina Granath, Daniel Wallhed Finn, and Annika Jones Grées, as well as assisting group leaders and assistants, Julie Meldahl, Johan Edbacken, Malin Larsson, Phoebe Mattson, Erika von Heijne, and Malin Bygård. We also want to thank the professionals and individuals from the interest organization, Attention, as well as the individuals with ADHD who gave lectures at the different PEGASUS group sessions. The clinical part of the study was conducted as part of the clinical work at Psychiatry northwest, psychiatry southwest, and psychiatry south, Stockholm county council, and we would like to thank operation managers, Maria Starrsjö, Nils Lindefors, and Gabriel Cizinsky.

### Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.eurpsy.2017.04.005>.

### References

- [1] American Psychiatric Association. Diagnostic and statistical manual of mental disorders, Fifth ed., Arlington, VA: American Psychiatric Association; 2013.
- [2] Fayyad J, De Graaf R, Kessler R, Alonso J, Angermeyer M, Demyttenaere K, et al. Cross-national prevalence and correlates of adult attention-deficit hyperactivity disorder. *Br J Psychiatry* 2007;190:402–9.
- [3] Barkley RA. Major life activity and health outcomes associated with attention-deficit/hyperactivity disorder. *J Clin Psychiatry* 2002;63(12):10–5.
- [4] Brod M, Johnston J, Able S, Swindle R. Validation of the adult attention-deficit/hyperactivity disorder quality-of-life Scale (AAQoL): a disease-specific quality-of-life measure. *Qual Life Res* 2006;15(1):117–29.
- [5] de Schipper E, Lundequist A, Wilteus AL, Coghill D, de Vries PJ, Granlund M, et al. A comprehensive scoping review of ability and disability in ADHD using the international classification of functioning, disability and health-children and youth version (ICF-CY). *Eur Child Adolesc Psychiatry* 2015;24(8):859–72.
- [6] Surman CB, Biederman J, Spencer T, Miller CA, McDermott KM, Faraone SV. Understanding deficient emotional self-regulation in adults with attention deficit hyperactivity disorder: a controlled study. *Atten Deficit Hyperactivity Disord* 2013;5(3):273–81.
- [7] Mueller AK, Fuermaier AB, Koerts J, Tucha L. Stigma in attention deficit hyperactivity disorder. *Atten Deficit Hyperactivity Disord* 2012;4(3):101–14.
- [11] Nussey C, Pistrang N, Murphy T. How does psychoeducation help? A review of the effects of providing information about Tourette syndrome and attention-deficit/hyperactivity disorder. *Child Care Health Dev* 2013;39(5):617–27.
- [12] Fuermaier AB, Tucha L, Mueller AK, Koerts J, Hauser J, Lange KW, et al. Stigmatization in teachers towards adults with attention deficit hyperactivity disorder, 3. SpringerPlus; 2014. p. 26.
- [13] Norvilitis JM, Scime M, Lee JS. Courtesy stigma in mothers of children with attention deficit/hyperactivity disorder: a preliminary investigation. *J Atten Disord* 2002;6(2):61–8.
- [14] CADDRA. Canadian ADHD Practice Guidelines. In: CAP-Guidelines Third ed., Canada: The Canadian Attention deficit hyperactivity disorder Resource Alliance; 2011. <http://www.caddra.ca>.
- [15] N.I.C.E.. Attention deficit hyperactivity disorder The NICE guideline on diagnosis and management of ADHD in children, young people and adults. National Institute for Health & Clinical Excellence/The British Psychological Society and The Royal College of Psychiatrists; 2009.
- [16] The Swedish National Board of Health. Wellfare Stöd till barn, ungdomar och vuxna med ADHD (Services for children, adolescents and adults with ADHD); 2014.
- [17] Emilsson B, Gudjonsson G, Sigurdsson JF, Baldursson G, Einarsson E, Olafsdottir H, et al. Cognitive behaviour therapy in medication-treated adults with ADHD and persistent symptoms: a randomized controlled trial. *BMC Psychiatry* 2011;11:116.
- [18] Hirvikoski T, Waaler E, Alfredsson J, Pihlgren C, Holmstrom A, Johnson A, et al. Reduced ADHD symptoms in adults with ADHD after structured skills training group: results from a randomized controlled trial. *Behav Res Ther* 2011;49:175–85.
- [19] Safren SA, Sprich S, Mimiaga MJ, Surman C, Knouse L, Groves M, et al. Cognitive behavioral therapy vs relaxation with educational support for medication-treated adults with ADHD and persistent symptoms: a randomized controlled trial. *JAMA* 2010;304(8):875–80.
- [20] Solanto MV, Marks DJ, Wasserstein J, Mitchell K, Abikoff H, Alvir JM, et al. Efficacy of meta-cognitive therapy for adult ADHD. *Am J Psychiatry* 2010;167(8):958–68.
- [21] Stevenson CS, Whitmont S, Bornholt L, Livesey D, Stevenson RJ. A cognitive remediation programme for adults with attention deficit hyperactivity disorder. *Aust N Z J Psychiatry* 2002;36(5):610–6.
- [22] Weiss M, Murray C, Wasdell M, Greenfield B, Giles L, Hechtman L. A randomized controlled trial of CBT therapy for adults with ADHD with and without medication. *BMC Psychiatry* 2012;12:30.
- [23] Philipsen A, Jans T, Graf E, Matthies S, Borel P, Colla M, et al. Effects of group psychotherapy, individual counseling, methylphenidate, and placebo in the treatment of adult attention-deficit/hyperactivity disorder: a randomized clinical trial. *JAMA psychiatry* 2015;72(12):1199–210.
- [24] Dixon L, McFarlane WR, Lefley H, Lucksted A, Cohen M, Falloon I, et al. Evidence-based practices for services to families of people with psychiatric disabilities. *Psychiatr Serv* 2001;52(7):903–10.
- [25] Hirvikoski T, Waaler E, Lindstrom T, Bölte S, Jokinen J. Cognitive behavior therapy-based psychoeducational groups for adults with ADHD and their significant others (PEGASUS): an open clinical feasibility trial. *Atten Deficit Hyperactivity Disord* 2015;7(1):89–99.
- [26] Vidal R, Bosch R, Nogueira M, Gomez-Barros N, Valero S, Palomar G, et al. Psychoeducation for adults with attention deficit hyperactivity disorder vs. cognitive behavioral group therapy: a randomized controlled pilot study. *J Nerv Ment Dis* 2013;201(10):894–900.
- [27] Wiggins D, Singh K, Getz HG, Hutchins DE. Effects of brief group interventions for adults with attention deficit/hyperactivity disorder. *J Ment Health Couns* 1999;21:82–92.
- [28] Lilienfeld SO. Psychological treatments that cause harm. *Perspect Psychol Sci* 2007;2:53–70.
- [29] Jonsson U, Choque Olsson N, Bölte S. Can findings from randomized controlled trials of social skills training in autism spectrum disorder be generalized? The neglected dimension of external validity. *Autism* 2016;20(3):295–305.
- [30] Stockholm County Council. Regionalt vårdprogram ADHD, lindrig utvecklingsstörning och autismspektrumtillstånd hos barn, ungdomar och vuxna [Regional Clinical Guideline ADHD, mild intellectual disability and autism spectrum disorder in children, adolescents and adults (in Swedish)]; 2010. [https://www.1177.se/Dokument/Stockholms\\_lan/Regionala%20vardprogram/RV\\_ADHD\\_webbversion.pdf](https://www.1177.se/Dokument/Stockholms_lan/Regionala%20vardprogram/RV_ADHD_webbversion.pdf).
- [31] Ward MF, Wender PH, Reimherr FW. The Wender Utah rating scale: an aid in the retrospective diagnosis of childhood attention deficit hyperactivity disorder. *Am J Psychiatry* 1993;150(6):885–90.
- [32] Adler LA, Spencer T, Faraone SV, Kessler RC, Howes MJ, Biederman J, et al. Validity of pilot Adult ADHD Self-Report Scale (ASRS) to rate adult ADHD symptoms. *Ann Clin Psychiatry* 2006;18(3):145–8.
- [33] Hirvikoski T, Waaler E, Carlsson J, Helldén G, Lindström T. PEGASUS Kurs för vuxna med ADHD och deras närstående. Arbetsbok för kursansvariga [PEGASUS course for adults with ADHD and their significant others. A workbook for course coordinators]. Stockholm: Hogrefe Psykologiförlaget; 2013.
- [34] Hirvikoski T, Waaler E, Carlsson J, Helldén G, Lindström T. PEGASUS Kurs för vuxna med ADHD och deras närstående. Kursbok [Course for adults with ADHD and their significant others. A course book]. Stockholm: Hogrefe Psykologiförlaget; 2013.
- [35] Hirvikoski T, Lindholm T, Nordenstrom A, Nordstrom AL, Lajic S. High self-perceived stress and many stressors, but normal diurnal cortisol rhythm, in adults with ADHD (attention-deficit/hyperactivity disorder). *Horm Behav* 2009;55(3):418–24.
- [36] Diener E, Emmons RA, Larsen RJ, Griffin S. The satisfaction with life scale. *J Pers Assess* 1985;49(1):71–5.
- [37] Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;67(6):361–70.
- [38] Hansson K, Jarbin H. A new self-rating questionnaire in Swedish for measuring expressed emotion. *Nord J Psychiatry* 1997;51(4):289–97.
- [39] Cohen J. Statistical power analysis for the behavioral sciences, second edition, New York: Psychology Press; 1988.

- [40] Hirvikoski T, Olsson EM, Nordenstrom A, Lindholm T, Nordstrom AL, Lajic S. Deficient cardiovascular stress reactivity predicts poor executive functions in adults with attention-deficit/hyperactivity disorder. *J Clin Exp Neuropsychol* 2011;33(1):63–73.
- [41] Morgensterns E, Alfredsson J, Hirvikoski T. Structured skills training for adults with ADHD in an outpatient psychiatric context: an open feasibility trial. *Atten Deficit Hyperactivity Disord* 2015.
- [42] Zigmond AS, Snaith RP. The hospital anxiety and depression scale with the irritability depression-anxiety scale and the leeds situational anxiety scale manual. London: GL Assessment Ltd; 1994.
- [43] Pavot W, Diener E, Colvin CR, Sandvik E. Further validation of the satisfaction with life scale: evidence for the cross-method convergence of well being measures. *J Pers Assess* 1991;57(1):149–61.
- [44] Nyttell C, Backman A, Ekstrand C, Hirvikoski T. Mothers navigating the complex landscape of ADHD-services – an analysis of calls to an ADHD-helpline. [submitted].
- [45] Biederman J, Petty CR, Woodworth KY, Lomedico A, Hyder LL, Faraone SV. Adult outcome of attention-deficit/hyperactivity disorder: a controlled 16-year follow-up study. *J Clin Psychiatry* 2012;73(7):941–50.
- [46] Wender PH, Wolf LE, Wasserstein J. Adults with ADHD. An overview. *Ann N Y Acad Sci* 2001;931:1–16.
- [47] Ginsberg Y, Beusterien KM, Amos K, Jousselein C, Asherson P. The unmet needs of all adults with ADHD are not the same: a focus on Europe. *Expert Rev Neurother* 2014;14(7):799–812.
- [48] Burch RJ. Attention deficit/hyperactivity disorder: a disorder of self-awareness. In: Nair J, editor. *Self-awareness deficits in psychiatric patients: neurobiology, assessment and treatment*. New York: W.W. Norton & Co; 2004. p. 229–54.
- [49] Ferrin M, Moreno-Granados JM, Salcedo-Marin MD, Ruiz-Veguilla M, Perez-Ayala V, Taylor E. Evaluation of a psychoeducation programme for parents of children and adolescents with ADHD: immediate and long-term effects using a blind randomized controlled trial. *Eur Child Adolesc Psychiatry* 2014;23(8):637–47.