Female ADHD: An international survey on experiences and health of women with ADHD

Published: 13-10-2023 Last updated: 21-12-2024

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Ethical review Approved WMO **Status** Recruiting

Health condition type Cognitive and attention disorders and disturbances

Study type Observational non invasive

Summary

ID

NL-OMON53638

Source

ToetsingOnline

Brief title

Survey Female ADHD

Condition

Cognitive and attention disorders and disturbances

Synonym

ADHD

Research involving

Human

Sponsors and support

Primary sponsor: Parnassia (Den Haag)

Source(s) of monetary or material Support: Ministerie van OC&W

Intervention

Keyword: ADHD, experiences, health, women

Outcome measures

Primary outcome

The primary parameter is the overall experience and specific experiences of women with ADHD to receive ADHD diagnosis and sources of support.

Second, we want to describe the prevalence of reported health conditions within the following domains; circulatory system, gastrointestinal system, genitourinary system, musculoskeletal system, nervous system, respiratory system, skin, cancer, psychiatric disorders, Covid-19, menstrual cycle, and sleep. Lastly, we ask the women about intimate partner violence.

Secondary outcome

We would like to identify new research topics that women with ADHD would like to have researched.

Study description

Background summary

Attention-Deficit/Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder, characterized by lifetime difficulties in concentration, hyperactivity, and impulsivity (American Psychiatric Association, 2013). The cross-national prevalence of adult ADHD is 3.4% (Fayyad et al., 2017). ADHD has high comorbidity, especially depression and anxiety (Cortese et al., 2016) and has recently been associated with 34 psychiatric comorbidities and somatic disorders (Du Rietz et al., 2021). The gender distribution in adulthood is almost 1:1, but girls and women with ADHD are still underdiagnosed and undertreated (Cortese et al., 2016) .

In clinical practice, we see that ADHD affects women differently than men. It is recognized that females with ADHD show a somewhat modified set of behaviors, symptoms and comorbidities when compared with males with ADHD. It has become clear that a better understanding of ADHD in girls and women is needed if we are to improve their longer-term wellbeing and functional and clinical outcomes (Young et al., 2020).

Therefore, PsyQ Expertise Center Adult ADHD and ADHD Europe collaborated in developing a survey to gain insight in the experiences and general health of women with ADHD.

The field calls for more insight in ADHD in girls and women (Young et al., 2020). So far, little research is done on the experiences and health of women with ADHD. The few studies done often have small sample sizes or are of a qualitative nature. Therefore, the PsyQ Expertise Center Adult ADHD started a collaboration with support network ADHD Europe to develop a survey on the experiences and health of women with ADHD. This survey consists of questionnaires on experiences in retrieving a diagnosis and/or treatment, aims to identify barriers and assisting factors, common health conditions in women with ADHD, and lastly new research topics in women with ADHD.

This survey will be distributed throughout Europe, starting with making it available in English and Dutch. Translations in other languages will be possible. This way, we are able to identify both general experiences of women with ADHD as well as experiences with regard to the local health care system and make comparisons between countries.

This survey is the first to study experiences and health of women with ADHD internationally, and results will provide insights and leads for all involved with diagnosis and treatment of these women.

Study objective

The primary objective is to understand the overall experience of women with ADHD, to identify barriers to diagnosis and sources of support and explore the links between ADHD and other health conditions.

The secondary objective is to identify what needs to be researched further and which interventions are needed.

Study design

Exploratory study following a cross-sectional design.

The survey will be open to fill out from March 2023 to October 2023, and will be available in English, Dutch, Spanish, Italian, French, and German.

The survey is organized into 6 sections, the six sections are:

- (1) Demographic Information;
- (2) ADHD Diagnosis & Symptoms;
- (3) ADHD and Other Health Conditions:

- (4) Menstrual Cycle;
- (5) Sleep;
- (6) Conflict Tactics & Romantic Relationships.

Due to the workload and time investment of the participants, it was decided to offer the survey in 2 parts, part 1 consists of sections 1-3, part 2 consists of sections 4-6. The time investment for completing each of the parts is 25 minutes, bringing the total time investment for the participant to 50 minutes.

Study burden and risks

Risks of participation are considered low. Participants might consider certain questions triggering, but are always free to skip questions and stop the survey.

Contacts

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Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age

Adults (18-64 years)

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Elderly (65 years and older)

Inclusion criteria

Adult women (>18 years) who think they have A(D)HD or are diagnosed with A(D)HD are eligible for participantion

Exclusion criteria

Mensen die niet in staat zijn om de deelnemersinformatie of het toestemmingsformulier te lezen, begrijpen of te tekenen, worden geexcludeerd van deelname.

Study design

Design

Study type: Observational non invasive

Masking: Open (masking not used)

Control: Uncontrolled

Primary purpose: Other

Recruitment

NL

Recruitment status: Recruiting
Start date (anticipated): 20-02-2024

Enrollment: 1000

Type: Actual

Ethics review

Approved WMO

Date: 13-10-2023

Application type: First submission

Review commission: METC Erasmus MC, Universitair Medisch Centrum Rotterdam

(Rotterdam)

Approved WMO

Date: 29-10-2024 Application type: Amendment

Review commission: METC Erasmus MC, Universitair Medisch Centrum Rotterdam

(Rotterdam)

Study registrations

Followed up by the following (possibly more current) registration

No registrations found.

Other (possibly less up-to-date) registrations in this register

No registrations found.

In other registers

Register ID

CCMO NL81142.078.22