

Living with symptoms of Attention Deficit-Hyperactivity Disorder (ADHD) in adulthood: a systematic review protocol of qualitative evidence

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Review question/objective

The objective of this systematic review is to identify and synthesize the best available evidence on how adults experience living with Attention Deficit-Hyperactivity Disorder (ADHD).

The review questions are:

- How are adults diagnosed with ADHD characterized?
- What is the experience of adults living with symptoms of ADHD?
- Which protective factors in the milieu do adults living with ADHD find important in order to manage daily life skills?

Background

Attention Deficit-Hyperactivity Disorder (ADHD) is diagnosed according to DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, produced by The American Psychiatric Association) and IDC-10 (International Classification of Diseases, produced by World Health Organization, WHO) criteria that relate to four dimensions of behavior: inattentiveness, restlessness, impulsivity and hyperactivity ¹.

The onset of the disease occurs in childhood. Some children grow out of their ADHD-symptoms during their adolescent years, but it is estimated that 80% of those diagnosed with ADHD in childhood continue to have symptoms throughout their lifespan^{2, 3, 4} and the prevalence of current adult ADHD is estimated at 4.4%.⁵

ADHD is associated with psychiatric comorbidity, psychosocial problems and some children are at risk of developing relatively severe psychiatric syndromes in adulthood such as antisocial personality disorder^{6, 7, 8, 9}. For people diagnosed with ADHD in childhood or young adulthood the symptoms affect multiple areas of daily life functioning such as school adjustment, academic performance and social functioning are impaired, and children with ADHD often have difficulties in social relationships^{10, 11}.

Primary research has mainly focused on the negative effects of ADHD, maybe because individuals with ADHD have, to varying degrees, behavioral characteristics, such as inattention, distractibility and impulsivity, low frustration tolerance, frequently shifting activities, difficulties in organizing and often daydreaming¹², and all of these characteristics can be troublesome and hamper daily life. The ADHD symptoms affect the individuals quality of life so living with ADHD becomes 'a way of life'¹³.

Studies have shown that people with ADHD have difficulties in forming strong friendships, although they are able to manage interpersonal relationships and do have social acquaintances and friendships, it is reported that they have fewer close friends and have trouble with keeping friends than controls¹³. It is reported that people with ADHD have a negative perception of their marital and family life; with problems in relation to communication involvement, roles, problem solving etc.¹³. Adult individuals with ADHD also have a higher incidence of separation and divorce^{14, 15, 16}.

Educational and academic functioning is affected as many sufferers experience difficulties with academic achievement. For example, they may have reading disabilities, be in special educational services, repeat grades and have failed to finish high school and achieve a lower mean grade point average which has a negative impact on access to higher education and employment opportunities^{3, 4, 10, 11, 14, 16}. Individuals occupational functioning is also affected, as adults with ADHD often have an inability to maintain stable employment as they have more frequent employment changes, perform poorly, quit, or are fired from their job, and employers rate the ADHD employees work performance lower than compared to controls^{10, 16, 17, 18}. It has also been demonstrated that individuals with ADHD generally have lower self-esteem and fewer friends than control groups¹⁰.

Although the majority of studies show that ADHD symptoms do hamper daily life for people with the disease and they have deficits in coping they are able to some degree reappraise situations and reframe problems¹⁹. Furthermore people diagnosed with ADHD do not necessary regard themselves to be impaired, as their reported self-image does not reflect the degree of severity or pervasiveness of maladjustment¹¹.

Therefore, according to the literature there appears to be different perspectives regarding how ADHD symptoms influence daily living for people with ADHD. It is therefore relevant to focus on the subject from the perspective of people who are living with ADHD, because in order to support them in managing their daily life skills it is necessary for health care staff to understand how people with ADHD experience and manage their symptoms. It is also important to know which protective factors in the milieu are supportive in relation to their ability to manage daily life. This is necessary in order to develop strategies to help people with ADHD select careers, which match their strengths and weaknesses, and to stay in

touch with social relations, to complete education and to hold down their jobs. Developing such strategies is important as individuals with ADHD are striving to master the chaos due to the ADHD symptoms²⁰.

An initial search in the databases PubMed, CINAHL, JBIConnect+, DARE, PROSPERO, Cochrane Library and PsychINFO indicated that no systematic review on this topic exists, or is currently underway.

This systematic review aims to identify the evidence on which to base support when caring for adults with ADHD in order to evolve strategies to help people with ADHD in managing their daily life.

Keywords

Attention Deficit Hyperactive Disorder; quality of life; family; social support; adaption; psychological; educational; daily life skills; life impairment; social life skills; academic functioning; social adjustment; interpersonal relation; family health; social support; adolescents; 16-18 years; adult; 19-44 years; middle aged; 45-64 years

Inclusion criteria

Types of participants

This review will consider studies that include adults diagnosed with ADHD. For the purposes of this review, adults are defined as both men and women aged 16 years and older.

For the purposes of this review, a clinical diagnosis of ADHD will be one based on criteria:

- ADHD: ICD-10: F90 (Diagnostic and Statistical Manual of Mental Disorders, produced by The American Psychiatric Association)²¹
- DSM-IV-TR: 314 (Diagnostic and Statistical Manual of Mental Disorders, produced by The American Psychiatric Association)²²

Phenomena of interest

The phenomena of interest are the experiences of how adults with ADHD experience and manage to live with symptoms of ADHD and links between any protective factors provided by relatives, friends, fellow-students, mentors and colleagues, in order to derive strategies to manage ADHD symptoms.

Types of studies

This review will consider studies that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

In the absence of research studies, other texts such as opinion papers and reports will be considered.

Search strategy

The search strategy aims to find both published and unpublished studies. A three-step search strategy will be utilized in this review. An initial limited search of MEDLINE, CINAHL, Embase and PsychINFO will be undertaken followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe an article. A second search using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference list of all identified reports and articles will be searched for additional studies. Studies published in Danish, English, German, Norwegian and Swedish will be considered for inclusion in this review. Databases will be search from their inception to July 2012.

The databases to be searched include:

MEDLINE, CINAHL, Embase, PsychINFO, Swedmed+ and Scopus.

Initial keywords to be used will be:

Attention Deficit Hyperactive Disorder, quality of life, family, social support, adaption, psychological, educational, daily life skills, life impairment, social life skills, academic functioning, social adjustment, interpersonal relation, family health, social support, adolescents: 16-18 years, adult 19-44 years, middle aged 45-64 years

The search for unpublished studies will include: MedNar, ProQuest Dissertations and Theses

The following homepages will be searched.

www.adhdnorge.no (The Norwegian ADHD Society)

www.attention-riks.se (The Swedish ADHD Society)

www.ADHD.dk (The Danish ADHD Society)

www.adhdeurope.net (ADHD Europe)

www.chadd.org (Children and Adults with Attention Deficit/Hyperactivity Disorder)

www.psych.org (The American Psychiatric Association)

www.europsy.net (The European Psychiatric Association)

www.adhdaustralia.org.au (Australian and New Zealand ADHD Support Groups)

Assessment of methodological quality

Qualitative papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix I). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

In the absence of research studies, papers selected for retrieval will be assessed by two independent reviewers for authenticity prior to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute Narrative, Opinion and Text Assessment and Review

Instrument (JBI-NOTARI) (Appendix I). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

Data collection

Qualitative data will be extracted from papers included in the review using the standardized data extraction tool from JBI-QARI (Appendix II). The data extracted will include specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives.

In the absence of research studies, data will be extracted from papers included in the review using the standardized data extraction tool from JBI-NOTARI (Appendix II). The data extracted will include specific details about the phenomena of interest, populations, study methods and outcomes of significance to the review question and specific objectives.

Data synthesis

Qualitative research findings will, where possible be pooled using JBI-QARI. This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings (Level 1 findings) rated according to their quality, and categorizing these findings on the basis of similarity in meaning (Level 2 findings). These categories will then be subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings (Level 3 findings) that can be used as a basis for evidence-based practice. Where textual pooling is not possible the findings will be presented in narrative form.

In the absence of research studies, textual data will, where possible be pooled using JBI-NOTARI. This will involve the aggregation or synthesis of conclusions to generate a set of statements that represent that aggregation, through assembling and categorizing these conclusions on the basis of similarity in meaning. These categories will then be subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice. Where textual pooling is not possible the conclusions will be presented in narrative form.

Conflicts of interest

None

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Appendix I: Appraisal instruments

QARI Appraisal instrument

JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

Reviewer Date

Author Year Record Number

	Yes	No	Unclear	Not Applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is there congruity between the research methodology and the research question or objectives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Is there congruity between the research methodology and the methods used to collect data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is there congruity between the research methodology and the representation and analysis of data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there congruity between the research methodology and the interpretation of results?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there a statement locating the researcher culturally or theoretically?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the influence of the researcher on the research, and vice-versa, addressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Are participants, and their voices, adequately represented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include Exclude Seek further info.

Comments (Including reason for exclusion)

NOTARI appraisal instrument

**JBI Critical Appraisal Checklist for Narrative,
Expert opinion & text**

Reviewer Date

Author Year Record Number

	Yes	No	Unclear	Not Applicable
1. Is the source of the opinion clearly identified?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Does the source of the opinion have standing in the field of expertise?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Are the interests of patients/clients the central focus of the opinion?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is the opinion's basis in logic/ experience clearly argued?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is the argument developed analytical?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there reference to the extant literature/evidence and any incongruency with it logically defended?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the opinion supported by peers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include Exclude Seek further info

Comments (Including reason for exclusion)

Appendix II: Data extraction instruments

QARI data extraction instrument

JBI QARI Data Extraction Form for Interpretive & Critical Research

Reviewer Date

Author Year

Journal Record Number

Study Description

Methodology

Method

Phenomena of interest

Setting

Geographical

Cultural

Participants

Data analysis

Authors Conclusions

Comments

Complete

Yes

No

NOTARI data extraction instrument

JBI Data Extraction for Narrative, Expert opinion & text

Reviewer Date

Author Year Record Number

Study Description

Type of Text:

Those Represented:

Stated Allegiance/ Position:

Setting

Geographical

Cultural

Logic of Argument

Data analysis

Authors Conclusions

Reviewers Comments

Data Extraction Complete

Yes

No

