Top 10 research priorities relating to treatments for ADHD

Background

SBU compiles scientific uncertainties in healthcare. The aim is to draw attention to questions which require further research. For certain conditions, such as ADHD, there are many uncertainties [1]. In such cases, it may be important to list in order of priority those uncertainties which are most urgent to investigate.

The aim of this project was to highlight the perspectives of consumers and healthcare personnel, as to which treatments warrant most urgent investigation. Thirteen people were selected by SBU to agree on the most important ten uncertainties. The uncertainties which were prioritized were listed in SBU's report on ADHD [1]. The method for prioritizing was inspired by the James Lind Alliance [2].

The ten most important[1] uncertainties

1.	Is there a risk that medication with methylphenidate during childhood will lead to the development of drug dependence later in life?
2.	What are the positive and negative effects of teacher support?
3.	What are the positive and negative effects of multimodal therapy?
4.	Which of the two pharmaceuticals, atomoxetin or methyldiphenidate, is most effective, with the least side effects?
5.	What are the positive and negative effects of methyldiphenidate medication in substance abusers?
6.	What are the positive and negative effects of parental support programmes?
7.	What are the positive and negative effects of supported conversation?
8.	What are the positive and negative effects of computer-aided working memory training?
9.	What are the positive and negative effects of psychoeducative treatment?
10.	What are the positive and negative effects of treatment of sleep disorders with melatonin?

In this context, a positive effect refers to improvement in core symptoms of ADHD (inattention, hyperactivity and impulsiveness)

[1] *1=highest priority.*

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The working group considered that the highest priority was to determine whether treatment of ADHD with methylphenidate during childhood increased the risk of drug dependence later in life. The reason for the urgency was that this is a highly controversial issue, which has been the subject of heated debate. Not only do healthcare personnel require an answer: this question can also be of concern to parents. Another urgent topic was the influence of teacher support, because the school has such a pronounced influence on the child's future. Multimodal therapy is widely used and comprises many different forms of treatment (for example, cognitive behavioural therapy, stress management groups, family therapy and aggression replacement training): it was therefore deemed important to determine whether these forms of treatment are effective. Another important topic prioritized among the top ten was the effect of methylphenidate in cases of substance abuse, because there is lack of consenus as to whether those who suffer from substance abuse should be treated with CNS stimulants.

What is a scientific uncertainty?

A scientific uncertainty means that on the basis of the evidence currently available, it is not possible to determine whether the treatment in question is effective or

not. The gap may be due to unreliable or inconsistent research results, underpowered studies, or there may be no published research at all on the topic.

Why are there so many gaps in our knowledge about this topic?

For many of the treatments included in the ten top list, there are a few studies, but because the studies are flawed by poor quality or lack of transferability[2] of the results, no definite conclusions can be drawn about the effects on core symptoms. For some of the treatments, no studies met the inclusion criteria in SBU's report (teacher support, supported conversation and psyschoeducative treatment).

What is required to bridge uncertainties?

Randomized controlled studies are required, of high quality and adequate blinding[3]. The study population should have a clinically verified ADHD diagnosis, according to established diagnostic criteria. For some research questions, long-term follow-up is important, for example to determine whether medication with methyldiphenidate during childhood increases the risk of subsequently developing substance abuse. These uncertainties could be bridged by well-conducted observational or register studies.

Method

The working group formed to prioritize uncertainties was composed of six people with ADHD and close relatives, along with seven representatives of the health, education and correctional services (psychologists, psychiatrist, primary care physician, corrective services officer, school counsellor and specialist pedagogue). The working group was not required to consider the feasibility of conducting research, for example, issues such as resources, research ethics, or methodology were not taken into account.

Each member of the working group independently selected his/her ten most important uncertainties from the total of 39 listed in the SBU report. The 20 items with the highest rankings were compiled for a workshop. The workshop was conducted in two stages. The initial stage consisted of group discussion in smaller groups, comprising half consumers and half healthcare and school personnel. Each group compiled its own top-ten list. This was followed by a general discussion, in which the entire working group participated, to reach consensus on a final top ten list.

Ethical considerations

In preparation for the workshop, the working group received a modified version of SBU's ethical guidelines [3]. Among topics discussed were equality of access to treatment (for example, who is offered a parental support programme, teacher support and computer-aided working memory training). The issue of third-party influence was also discussed, particularly the availability of different parental support programmes, which can have varying consequences for the parents. The influence of special interest groups, who oppose or support certain treatments, was also discussed, e.g. methylphendiate medication for children or those with substance abuse problems.

Target groups

Researchers within the field of ADHD, research funders, people with ADHD and their close families, health and school personnel, healthcare decision-makers.

Working group

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References

1. http://www.sbu.se/adhd_2013e
2. http://www.jla.nihr.ac.uk/
3. A framework for systematic identification of ethical aspects of health care technologies – the SBU approach. Heintz E, Lintamo L, Hultcrantz M, Jacobsen S, Levi R, Munthe C, Tranaeus S, Östlund P, Sandman L. Submitted.

[2] *Whether or not the study results can be generalized to apply to national conditions, or whether the study sample is representative of the population in general.*

[3] *If possible, the participants, the assisting research personnel and the clinical examiner/assessor should all be blinded as to which treatment is being administered.*