

ADHD

in practice



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Comment

Implementation is key

“Every five to ten years the guidelines for ADHD diagnosis and treatment must be refreshed. This year, The National Institute for Health and Care Excellence (NICE) guidelines are in the process of being updated and will replace the 2008 version.’ The committee have updated or added new recommendations on recognition, information and support, managing ADHD (including non-pharmacological treatment), medication, follow-up and monitoring, adherence, discontinuation and review of medication. This is a huge job, but the evidence found in the big pile of new articles is, like in the former guideline, still not very strong – especially concerning new diagnostics or therapeutic measures. Of course, there are some changes, such as the use of lisdexamphetamine (if available) as first choice medication, then dexamphetamine or methylphenidate, then atomoxetine, which is the only medication that has a UK marketing authorisation for this indication in adults at the time of consultation (September 2017). In children, the order is: long-acting methylphenidate, lisdexamphetamine, atomoxetine or guanfacine (all licensed). The main recommendation is, however: patient-tailored therapy by mutual agreement.

Although the guideline is excellent and up to date, implementation will be the difficult part. It depends on the perception and framing of ADHD in the media and lay people, financial structures, perverse incentives, fear of labelling and inadequate knowledge of school teachers and GPs. What I mentioned in the last edition of *ADHD in practice* is still valid: it is a long march for any individual with ADHD traits to get what he or she is looking for.

Everyone should read up on the struggles of families with a child with a disability. In Valerie Ivens’ article, you feel the anger and hope of a parent. A diagnosis can come as a huge relief, but what comes next? Realising what patients and families have to deal with might provide the incentive to address these issues in your own practice. And don’t forget to embrace the support groups!

Michiel Noordzij’s article is not so much about DSM categorisation, as it is about direct help after measuring concerns about the functioning of the child. The Functioning Profile (FP) is an instrument that consists of a very

down-to-earth needs-based assessment and needs-based support. It does not require labelling and the intervention can come from both skilled and non-skilled people in the different environments of the child. The FP can also be used as pre-diagnosis if the child has no benefit from the intervention. Even in children with an ADHD diagnosis, the FP can aid in decision-making on how best to support the child. It gives a much wider assessment than an ADHD diagnosis and prevents over- and under-diagnosis. If you are interested, Dr Noordzij is ready to install the FP in your practice and to teach you how to use the software and other tools, even in English!

We, as professionals, are aware of risk factors for individuals with ADHD, but their exact mechanisms are not known. It may have to do with impulsivity or inattentiveness or comorbid conditions. In recent years in the Netherlands, for example, there has been a sharp rise in street accidents caused by drivers texting while driving. Around 50% of drivers admitted that they look at their mobile phone occasionally while driving. So, if they are distracted or bored due to their ADHD trait, they should be treated before driving. Texting during driving is as dangerous as drink driving and will be fined in the same way by the police. For the price of one prescription, [ok?] you can treat one patient for one year with long-acting methylphenidate. So, choose your battles! In some countries, the police employ drug tests to detect drivers using illicit drugs, but dexamphetamine also gives a positive result. Normal therapeutic doses are not considered punishable, but some patients need high doses to protect themselves (and others) against bad driving or even road rage, so, according to the current law, they will be fined. An additional problem is self-medication of cannabis which can be detected days or weeks after use.

Nathan Hodson writes about a new phenomenon, the use of memes. Maybe you don’t know what memes are (like me!), which is a good incentive to read this interesting article. Your adolescent patients are almost all dedicated users of social media and will appreciate your knowledge in this field.

Enjoy this issue ”

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Rob Rodrigues Pereira, Editor

■ The Functioning Profile allows the user to measure the progress of the child's current situation in both specialised settings and in low-skilled areas, by youth care professionals, parents and teachers.



ADHD and the Functioning Profile

Attention deficit hyperactivity disorder (ADHD) has multiple manifestations. It is more than a DSM-5¹ classification made in a consulting room, and more than adequate medication and psychoeducation given to the child and its parents. The many manifestations of ADHD that are encountered in schools and youth services need to be considered in decision-making about the next steps for the child. This requires putting the additional knowledge and skills from those who work and interact with the children on a daily basis into practice. This article describes the Functioning Profile (FP),² an instrument that allows a needs-based assessment in the child's everyday environment, taking into account the multiple manifestations of ADHD and specialist knowledge and skills. The outcomes from the FP assessment contribute to organising support for children in youth care, schools and at home, without the risk of early medicalisation.

The complexity of ADHD

ADHD can be considered a complex disorder because of its varied manifestations and its extensive consequences for development. The support of children with ADHD requires insight into the factors that play a role in their current situation. In order to achieve needs-based support, a specific needs-based assessment of the child needs to be

carried out. This requires the organised handling of a multitude of data.

The complexity of ADHD can be described on different levels:

- symptom level
- developmental level
- contextual level
- organisational level.

The symptom level describes the functioning of the child. This level identifies the possible co-morbidities – the regulatory and other behavioural issues that can manifest themselves in the child.

At the level of development, the various developmental areas of the child and the status of maturational delays are described.

The child's contextual level analyses the interactions of the child with his/her environments, including: home, school and leisure. The cultural background of the child, religion, educational and parenting styles, life events, trauma's and unsafe situations are all considered at this level.

The organisational level of ADHD applies to the micro level of treatment, where it is decided how to address the disorder, developmental delays and interactions, in a methodical coherence. An order needs to be arranged in how to treat or support the child at this level. The organisational level also applies to the meso level of regional co-operation: how is 'who does what' determined, and how

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is adequate communication across the child's support system achieved? At macro level, decisions are made about the allocation of resources. This level demonstrates the need of the government and the municipalities to demedicalise. It is about providing support to children in their living environments without sticking with medical labels. It goes hand-in-hand with the need to save on budgets.

The distinctions between the four levels – symptom level, developmental level, contextual level and organisational level – provide a complex approach to ADHD. All play their role in the daily decision-making about how the child should be supported. A diagnosis and evidence-based treatment from a consulting room is no longer enough and is sometimes no longer accepted. In addition, it must be remembered that many children with ADHD never appear, or appear only briefly, in consulting rooms. Therefore, their behaviour and specific needs are shown and best observed in their living environments. The question now is, how can the child be supported with a complex and changing presentation of ADHD if they are unlikely to present in the consulting room? An additional question is, how can the people who are busy with the specific needs shown by this child on a daily basis be supported? To make a start, it is necessary to make this complex and ever-changing set of factors available for making decisions in the workplace.

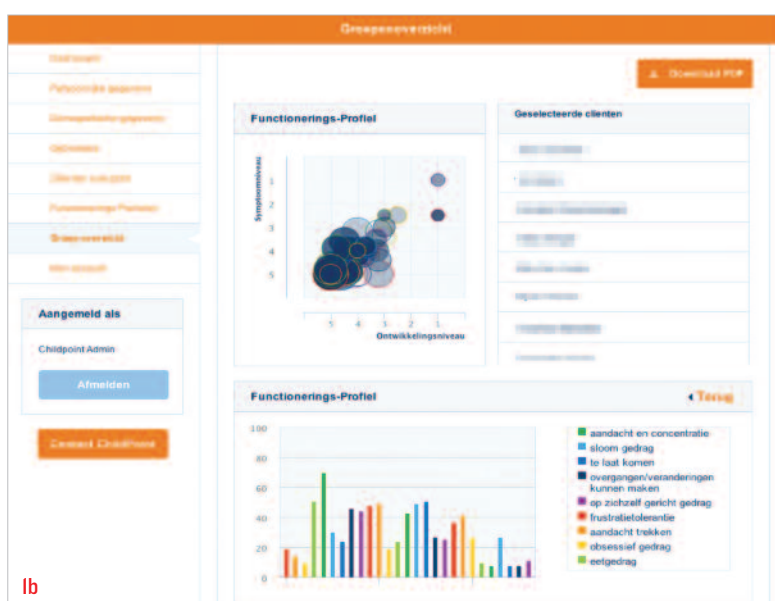
Needs-based assessment and support with the FP

To respond adequately to the different needs at a given time and, therefore, to changing manifestations of symptomatology, development and living conditions of the child, it is necessary to be able to portray these. Based on 25 years of clinical experience, a web-based application was developed that takes a survey of the child's current situation in all the areas mentioned – this is the FP. It captures an image of the filler's concerns about a broad spectrum of functioning, and interaction with the child and of any point of concern could also be a stimulating factor. For example, if a child is showing behavioural problems, the appropriate functioning of his conscience can be a stimulating factor. The identified points of concern will be used as the basis for the support that the child will receive. The FP is used to monitor the results of the support given by simply filling out the FP again. By repeating the FP, it is possible to portray the child's progress, but also to assess and correct the effectiveness of actions taken. The FP shows the graphical display of previous results, so that it is easy to monitor the the child's progress. Any outcome of a repeatedly executed FP says something about the progress of the child and about the outcome of the intervention performed.

Measuring the progress of a child's current situation in multiple places is important. The FP can be used both in specialised settings and in low-skilled areas by youth care professionals, but also by parents and teachers. The child can also participate in completing their FP from about 12 years of age. With different people contributing to the FP



1a



1b

with a complex disorder like ADHD, ideas on the next steps can differ between contributors, but the FP also facilitates discussion with shared reference points. This is useful in situations where both professionals and non-professionals come together and in which decisions must be made.

The FP can be used as a first measurement (pre-diagnosis) for concerns about the functioning of the child. It enables decisions to be made about whether (over-) medicalisation can be prevented, or whether further investigation of the child is appropriate. If there is prolonged suboptimal functioning in the child, unrecognised relapse in functioning, or if the school teacher is concerned about the progress of development or of the effect of measures taken, the FP can be deployed. The FP can be used to make an inventory of the child's specific support needs in special education upon entry and leaving the class. Both in youth care and at school, the FP helps professionals improve their ability to work around the child with the ability to evaluate and revise decisions earlier. This helps to systematise the care process in sometimes complex circumstances.

►► **Figure 1.** Screenshots from the Functioning Profile showing the use of the moving bubble, with the desired situation highlighted in pink and action points to achieve the goal on the right (1a) and an example of a group report (1b)

Information and Communications Technology (ICT) makes it possible to carry out a group analysis of a class or department and of children in a particular district, school or region. A group analysis gives an indication of the complexity of a group problem and helps in designing group interventions. On a larger scale, the group analysis helps allocate resources and assess their impact.

Using the ‘moving bubble’, another feature of the FP (see Figure 1), scenarios can be discussed with those involved with the child. If a bubble in a graphical representation of the results is moved to a more desired location, the programme immediately calculates what prevents the child from functioning at that level. Its use makes it possible to discuss the feasibility of an idea or plan with all concerned.

The FP shows the child’s actual level of functioning, which may be at a high (green), moderate (yellow) or low (red) level. These three levels of functioning each have their own support guidance. For example, at green level a simple consultation is often enough, while adequate support at the red level requires more effort across the child’s whole support system. The results from the advice at red level are difficult to predict, require more involvement from professionals and will be more expensive to obtain.

When the FP indicates areas or points that require support, the level of functioning shows the feasibility of a plan of action. Using the FP, therefore, can play a role both in conducting a needs-based assessment and planning needs-based support. A link is made between a broad inventory of factors and the organisation of the approach to support the child.

The FP and ADHD

If a child has an ADHD diagnosis, it does not mean that there is a clear indication of how support will be provided. Although we have to use DSM-5 to classify ADHD unambiguously,¹ there is no uniform manifestation of the disorder – either with the same child over time or with different children at the same time. The consequence of repeated application of a wide profiling with the FP is that, even in complex ADHD, there are no actions that are not

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Profiling and determining a child’s level of performance is useful in the light of needs-based assessment and needs-based support
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specifically aimed at the needs of the child in his/her context. In addition, the measures taken can be corrected as necessary.

If the child presents his/her ADHD in a series of manifestations, that do not lead to an adequate diagnosis, or if there is no longer adequate care or support, the child, parents and school can be under great pressure. Over time, separate measures can be taken to focus on isolated problems, such as: behavioral, anxiety and mood problems or disadvantages in development and school performance, without the connection with ADHD. This usually does not improve the child’s prognosis.

Group analysis

In a group analysis at a special education school, the FP was used in 15 boys aged 13–17 years old, as the school was concerned about them and asked for advice. Eight of them showed the following combination: attention problems, poor executive functions, learning problems, acting out and acting in and regulatory problems of emotions and aggression. All were not, or no longer, in care and their behaviour posed serious problems to the school. Although it was not possible to get them all to the outpatient clinic for an adequate diagnosis and treatment, it was possible to advise the teachers how to deal with each of them better, based on their own specific FP.

Conclusion

Profiling and determining a child’s level of performance is useful in the light of needs-based assessment and needs-based support. The FP is an ICT tool that gives a broad picture of the current situation of a child or group of children. It illustrates the concerns of one or more fillers about a child, as well as the stimulating factors, in many areas of functioning and interaction. The FP gives handles for making decisions on support at the youth care or school or workplace or home or sports club. This helps in systematising decisions about a child. It can be used as a tool for pre-diagnosis, and it helps to prevent over-diagnosis and unnecessary medicalisation. The FP also helps to prevent missing a diagnosis. If ADHD is established, the FP can provide advice to skilled and non-skilled people involved in the child. With the ‘moving bubble’ technology, scenarios can be made and tested for feasibility. Group analysis enables the evaluation of data on a larger scale ■

Declaration of interest

The author declares that there is no conflict of interest.

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Key points

- ▶ The Functioning Profile (FP) is a web-based application that surveys the child’s current situation to contribute to organising support for children in youth care, at school and at home to avoid early medicalisation.
- ▶ The FP can also be used to track the child’s progression and to ensure the support recommended is having the desired effect.
- ▶ The FP prevents missing a diagnosis as it can be used by professionals the child encounters in their every day situation, and does not rely on the child presenting in clinic.


To access the Functioning Profile website, please go to www.functioneringsprofiel.nl (available in Dutch only). The Functioning Profile is available in English and will soon be available in German. Please contact the helpdesk for information about the possibilities or for further information: info@functioneringsprofiel.nl

The role of support groups

Raising a child with any disability is something that only parents who have experienced it can really understand. That is not said lightly, nor is it intended to diminish the genuinely serious task of parenting in general, but it does add an extra dimension. I have worked with children and young people with a diagnosis of attention deficit hyperactivity disorder (ADHD) and their families for nearly 20 years, and their stress and exhaustion is palpable. ‘Is it my fault?’, ‘Why me?’, ‘I must be a bad parent.’ Add to that the exhaustion of actually raising a child who generally cannot start a task, stay on task, finish a task, fidgets endlessly, zones out, forgets instructions (regardless of countless reminders) is usually late, cannot get up in the morning, loses books and sports kit and is often constantly on the go – if not physically, then mentally and verbally. The self-blame game goes on and on. Typically, up until a formal diagnosis, advice will have been arriving thick and fast from all quarters. As so many of our parents from ADHD Richmond support group testify, everyone has an opinion about their child: ‘Give it time,’ ‘She needs a better routine’, ‘She’s hungry’, ‘She’s thirsty’, ‘She’s hot’, ‘She’s cold’, ‘He’s the eldest’, ‘He’s the youngest’, ‘Well he’s the middle child’, and classically ‘Ah, well, he’s a boy.’ Eventually, a diagnosis can come as a huge relief, but what next?

Experience of special needs and isolation

Despite having a daughter with a chronic and complex medical condition, support groups were not for me. I was lodged firmly in the medical model, believing only the oracles of Great Ormond Street, having been let down by local services who felt they could not cope with her complex needs. I felt isolated, sad and angry and eventually transformed this negative energy into a passionate determination to ensure she would be well supported. I was fortunate

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and strong testimony to the willpower and resilience of those who come through such adversity. My experience encouraged me to ensure that other parents were not alone, and I started work at a local charity for children with special needs. It was there that I came across ADHD and the parents who felt victimised, blamed, stigmatised and that their children were misunderstood. I felt a real need, not only to support these families, but to represent their collective voice to local service providers with the hope of effecting change and greater understanding.

Support groups could play a pivotal role, not only in supporting families through incredibly challenging times but also by forming a common voice for change. My aim in this article, while accepting that support groups are not for all, is to underline the important role they play and the unharnessed potential they possess. Whether it occurs immediately after diagnosis or at a critical point in a child’s life, a shared experience has significant benefits. My aim is to highlight and galvanise the huge potential and passion of parents to make a bigger difference. To me, this latter part is missing in the national ADHD context and I would like to establish a framework that allows support groups around the country to come together towards a common goal of challenging ignorance and raising awareness. Supporting families, studying the condition, working with young people and working with service providers to bring about understanding and change has been my day-to-day mission ever since.

The hidden ADHD story

Both anecdotally and from evidence-based research, there is no doubt that ADHD leads to conflict and poor cohesion within the family¹ and significant depression, anxiety and stress for parents.² Children and young people with ADHD may have a higher

enough to be able to give up my career to help structure and encourage her and inform others about how to best help.

Today, she is a thriving

frequency of behavioural and conduct problems than children without ADHD, leaving a larger than usual burden on families to cope.³ In adolescent follow-up studies of girls, persistent impairments were found in multiple domains, such as peer rejection and academic achievement,⁴ and increased risk for developing other psychopathologies, such as conduct disorder or depression, was evident.⁵ Girls with ADHD are also more likely to be bullied than their peers without ADHD.⁶ These factors impact on young people’s mental health and their ability to manage the school day and make and keep friends. The wider family is also impacted, with friends and relations struggling to understand and support what seems like a very difficult child or teen.

We also know that parents feel stigmatised by social groups, and that the effects on social functioning may impact personal relationships with partners, so all too often family breakdowns occur.

The real ADHD – not just naughty kids?

Anyone who has any solid working knowledge about this neuro-developmental condition will roll their eyes at this overused, inaccurate and frankly insulting anecdote that ADHD is just a way of describing naughty kids – it is wrong and that is a fact. Parents and carers have had enough of being stigmatised by poorly researched newspaper headlines screeching about pharmaceutical company profits without understanding the facts. In the UK, the only way to get a diagnosis of ADHD is to see a trained expert – usually a consultant child and adolescent psychiatrist – and reach a diagnostic threshold over a number of niche determined criteria. ADHD has to be considered a life-changing disability that adds serious and sustained impairment to everyday activity. This is no disability featherweight, but a chronic and serious condition.

The complexity of a diagnosis means that one child is rarely like another, causing late diagnosis, confusion and misunderstanding among professionals. In all the time I have worked alongside families and health and teaching

professionals, I can honestly say no two children have ever been alike in their presentation of ADHD or mix of difficulty.

Diagnosis and next steps

A clear diagnosis of ADHD helps the person and the wider family too. Anecdotally, we hear there is less blame, a willingness to think again about how they interact with their child and a change in attitude towards others once they have a clear understanding of what the diagnosis actually means.

A coffee and a chat – so yesterday?

So what is the role of support groups, and have they moved on from a shared chat over a coffee? Is there still a place for just meeting and talking in an age when everything is available through an online search? Well, I fundamentally believe there is an absolutely critical role for face-to-face contact.

A recent study examined what parents of children with disabilities and special needs found helpful about belonging to mutual support groups.⁷ Quantitative data (based on 56 parents from six groups) indicated that members found the groups ‘very helpful’ and were ‘very satisfied’ with the support they received. They also described the groups as high in cohesion, expressiveness, task orientation and self-discovery. An analysis indicated that such support was helpful in three broad areas:

- the sociopolitical, which involved developing a sense of control and agency in the outside world
- the interpersonal, which involved a sense of belonging to a community
- the intra-individual, which involved self-change.

Key benefits were identified as a shared social identity, learning from the experience of others, personal growth (based on confidence and self-esteem), empowerment and psychological health benefits. Studies strongly suggest that parents perceive benefits from peer-support programmes as highly effective, and this is sustained across various types of support and conditions.

Looking at the shared social identity, parents finally found a sense of belonging after other parents had seemed to stigmatise and marginalise them. The story of the cold shoulder at the school gate is a frequent one, as is children not being invited to parties or parents to class

■ For the vast majority of parents and carers, there is a sense of community and belonging which gives them security of knowing that support is at hand, as and when it is needed

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gatherings. Yet the ability to share through a support group helped foster a sense of belonging, support and empowerment. This actually enabled parents to feel able to cope better and experience a reduced sense of isolation, loneliness and guilt.

These are very significant findings that provide evidence to back up the things that parents have consistently told us over the last 20 years.^{8,9}

The joy of the support group ethos is its sense of continuity, to be dipped into and out of throughout a family’s journey. There will always be critical times when parents wish to seek out others who have been through a similar experience, and times when things feel more stable. Typically, key times seem to be school transition periods (primary to secondary, puberty, transition to adulthood and beyond school). On some occasions, it was found to be helpful for parents to create smaller groups meeting outside the main support group forum, typically sharing experiences more closely about topical issues and expanding their social and support networks. In general, and for the vast majority of parents and carers, it is a sense of community and belonging that gives them the security of knowing that support is at hand, as and when it is needed.

The support group offer

The group with which I have worked provides support in many forms. Perhaps

the most important form is an exchange of useful and practical information. Many studies have found that the exchange of useful and practical information is an important element of support, and many parents also described learning from the experience and knowledge of other parents.^{10–13} Add to this the chance to just share experiences with other parents on the same journey and a handful of very experienced professionals covering law, education and coaching, and the value of the group cannot be overstated. In a setting in which parents have access to each other and to knowledgeable experts – either as regular speakers or as the group’s support network – a self-confidence and reassurance starts to develop, empowering them in their conversations with those interacting with their children.

Reports underline the critical importance of social identity – that this sharing fostered a sense of belonging, support and empowerment, and that carers were better able to cope.^{11,14} Parent mentors give further support by drawing on their own experiences to help other parents gain confidence and offer reassurance.

This support allows parents to gain strength and feel empowered as well as helping them to develop new skills and feel more motivated, affirming their experiences as parents.

Perhaps more importantly, belonging to



and sharing these experiences within a group helps parents and carers feel more confident and in control and less alone and depressed, and this in turn brought about an improved relationship with their child.⁸ With a disability that has challenging behaviour and labile emotions at the centre, such a positive finding cannot be overstated.

Support for each other – is there more?

Perhaps my main driver for writing this article is because I see so much more potential for these parent voices and passions. There are no greater advocates for children and young people with disabilities than their parents, regardless of the disability. We have seen over the past 5–10 years a huge awareness campaign for autism and the very real need for a greater understanding of the condition, culminating in the Autism Act, which has paved the way for teacher training, earlier

identification and interventions. I strongly believe that ADHD, increasingly free from its poor press and with brain scanning images confirming the brain development differences, will receive the same national awareness afforded to autism within the next five years. The results would be catalytic in supporting these vulnerable children through school and adolescence, when things can so easily go wrong. The cost to society of a young adolescent routed down a negative path, frequently known to police and the criminal justice system, is huge. The cost of awareness of ADHD and early intervention is a fraction of this and could reduce the amount spent on the criminal justice system in the long run. So yes, this is a rallying call to all of those support groups out there who would like to see a national movement for change. And it won't be a moment too soon.

There is a strong motivation among support group members to offer others

what they have received themselves. Just imagine that operating at a national level ■

Declaration of interest

The author declares that there is no conflict of interest.

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Key points

- ▶▶ Key benefits of support groups are a shared social identity, learning from the experience of others, personal growth, empowerment and psychological health benefits.
- ▶▶ Sharing experiences within a group helps parents and carers to feel more confident, in control and less alone and depressed.
- ▶▶ Support groups have a strong motivation to offer others what they have received themselves.

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ADHD and unintentional injury risk

Attention deficit hyperactivity disorder (ADHD) symptoms have been linked to the risk of unintentional injury for decades, dating to at least the 1939 assertion by Dunbar and colleagues¹ that hypothesised factors such as an ‘urge to activity’ and ‘impulsivity’ might lead to the repeated fracture injuries that the authors observed in select adult industrial workers.

In contemporary epidemiological research, repeated studies indicate that children, adolescents and adults with ADHD have an increased risk of unintentional physical injury. A recent meta analysis reported that effect sizes for the relationship generally hover in the 2.0 range, indicating that individuals with ADHD have roughly twice the risk of injury compared to healthy individuals.² This relation has been reported in large-scale cohort studies (such as Merrill and colleagues³), in studies of risk-taking in simulated environments (such as Stavrinou and colleagues⁴), and matched case-control studies (such as Shilon and colleagues⁵), and seems robust to child development, culture, injury causes and types and changes over time.

Almost all research identifying links between ADHD and injury risk relies on correlational data, however, the causal factors underlying the association remain unknown. Most experts agree that there may be multiple underlying factors that co-occur to increase the likelihood of injury among individuals with ADHD. Below, several of the causal factors hypothesised to be the most relevant are outlined.

Core symptoms

ADHD is hallmarked by three behavioral patterns – inattention, impulsivity and hyperactivity – and each has been hypothesised to play a role in risk of injury among people with ADHD. Inattention incorporates behaviours such as failing to attend to details, sustain attention during tasks, attend to and follow instruction and stay organised. Maintaining one’s physical safety may require such skills. As an example, research in computer-simulated virtual pedestrian environments suggests that children and adolescents with ADHD exhibit riskier street-crossing behaviours than children without ADHD do, perhaps because they attend less carefully to the traffic environments that they encounter.^{4,6} Similar observations are reported in reviews of how ADHD diagnoses influence driving safety.⁷

Impulsive behaviours associated with ADHD include patterns of interrupting others, experiencing difficulty in

waiting and intruding into others’ activities. Such behaviours may also increase the risk of injury. For example, in case reviews of paediatric burn injuries, scholars ascribe a substantial portion of unintentional burn injuries to children’s impulsive behaviours, including playing with fire and flammable liquids/aerosols and pulling pots with hot liquids onto themselves.^{8,9} Others have approached links between ADHD-associated impulsivity and injury risk from a neurobiological perspective. They argue that executive function deficits, such as poor inhibitory control, may lead individuals with ADHD to make dangerous, disinhibited or impulsive decisions in injury–risk situations, such as while driving.⁷ Still others have approached the question from a behavioural perspective, discovering that boys with ADHD, perhaps due to impulsive behaviour patterns, were

less likely to anticipate risk or personal harm when encountering hazardous situations, and were also less apt or able to consider prevention strategies, therefore, leading to increased risk of injury.¹⁰

Individuals with ADHD may also display hyperactive behaviour patterns, which include difficulty sitting still, fidgeting, leaving one’s seat inappropriately and running and

climbing in situations when one should not. Although on the surface hyperactive behaviour patterns might appear to be related to injury risk, scientific results linking the two are not well-established. One can imagine proscribed situations in which hyperactivity may result in injury – fidgeting in heights where fall injuries are plausible or climbing unstable structures – but research-based links between attentional deficits and injury, and between impulsivity/disinhibition deficits and injury, are more established than links between hyperactivity and injury.

Behavioural choices

Increased risk for injury among individuals with ADHD may not occur entirely through direct pathways, but also through more frequent exposure to situations that might cause injury to anyone. In other words, individuals with ADHD may choose to engage in activities that expose them to higher injury risk, and the higher exposure rate leads to higher injury rates. There is evidence, for example, that children with ADHD choose to play on team sports more than individual sports or other leisure activities.¹¹ Such engagement may lead to more frequent sports-related injuries, risk that is amplified by evidence that children

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... individuals with
ADHD may choose to
engage in activities
that expose them to
higher injury risk ...
”

■ Children with ADHD prefer to play on sports teams over individual sports or other leisure activities. Such engagement may lead to more frequent sports-related injuries – an effect amplified by evidence that children with ADHD engage in more aggressive and illegal play during team sport competitions than comparison groups do



with ADHD engage in more aggressive and illegal play during team sport competitions than comparison groups do.¹¹ Links between ADHD and selection of injury–risk situations probably continue throughout the lifespan. Among adolescents, there are associations between ADHD and substance use, which may lead to increased injury risk through falls, intoxicated driving and other mechanisms.¹² It is unclear if adults with ADHD drive more often than adults without ADHD, but there are established links between adult ADHD and risky and reckless driving behaviour.¹³

Comorbid conditions

ADHD frequently co-occurs with other mental health conditions, including oppositional and conduct disorders. Symptoms from comorbid conditions may contribute to increased injury risk among individuals with ADHD. For example, oppositional defiant disorder co-occurs in about one-third to half of children with ADHD and includes symptoms of defiance and disobedience against rules.¹⁴ When rules are present to ensure safety and are defied, injuries may occur. Similarly, conduct disorder co-occurs frequently with ADHD and includes symptoms of fighting, truancy and fire-setting that may be associated with injury risk. One relevant study found that pre-schoolers diagnosed with oppositional defiant disorder (ODD), and followed for two years, had more injuries than demographically matched controls, but that comorbid ADHD did not contribute additional risk beyond the ODD diagnoses.¹⁵ Some have proposed that oppositionality may be particularly relevant for young children with ADHD, as young children with hyperactive and impulsive behaviour patterns may be protected from injury by adult supervisors, especially if comorbid oppositional behaviour patterns are absent. Older children and adolescents, who make many decisions about their safety independent of adult influence, may be more influenced by impulsive or inattentive behaviour patterns.¹⁶

'Reverse' causality: can injuries cause ADHD symptoms?

The general consensus among scholars is that ADHD symptoms might lead to increased injury risk, but a 'reverse' hypothesis has emerged in the field proposing that injuries might sometimes cause ADHD. Severe head trauma injuries, in particular, can lead to ADHD symptoms and lead to ADHD diagnoses. Patients who experience traumatic brain injuries most dramatically display deficits in inhibition that closely mimic ADHD symptoms, sometimes called 'secondary ADHD'.¹⁷ Symptom changes are sometimes temporary, but there is also evidence of long-term changes in functioning relevant to ADHD symptoms and diagnoses, especially following severe brain injuries.¹⁸

“
Severe head trauma injuries, in particular, can lead to ADHD symptoms and even to ADHD diagnoses. Patients who experience traumatic brain injuries most dramatically display deficits in inhibition that closely mimic ADHD symptoms, sometimes called 'secondary ADHD'
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Implications for treatment and prevention

Injury scholars often cite an adage, 'injuries are not accidental'. In fact, there are a number of strategies that can be used to prevent injuries from occurring, including injuries to individuals with ADHD.

From an injury prevention perspective, the same strategies used to prevent injuries for the general population are likely to be effective for individuals with ADHD. Children with ADHD must be supervised by qualified and attentive adults, as those adults can provide the impulse control and attentional capacity required to keep children safe in potentially dangerous environments. Adolescent and adult drivers with ADHD will experience reduced risk if they avoid driving while distracted, fatigued or intoxicated. Sports injuries can be prevented through judicious refereeing, and workplace injuries through adherence to occupational safety guidelines and policies. Broad injury prevention guidelines specific to particular age groups, environments and situations are available from multiple government, non-profit and scholarly sources. From the perspective of treating ADHD, to state the obvious, it would be expected that amelioration of symptoms

Key points

- ▶▶ ADHD symptoms and diagnoses are associated with increased risk of unintentional physical injury.
- ▶▶ The risk transcends age, human development, culture, geography and time.
- ▶▶ Causality of the link between ADHD and injury risk is unknown and likely multifaceted, but hypothesised factors include: the inattentive and impulsive traits associated with ADHD; behavioural choices that expose individuals with ADHD to higher injury risk; comorbid conditions (including oppositionality) and possibly 'reverse causality,' whereby traumatic brain injuries cause ADHD symptoms and diagnoses.
- ▶▶ Treatment of ADHD should reduce injury risk, and injury prevention efforts should reduce risk for all individuals.

associated with ADHD – and especially symptoms associated with inattention and impulse control – might reduce the risk of injury for those individuals with ADHD. There is some published evidence that pharmacological treatment might reduce risk of injury.¹⁹

Conclusion

ADHD is associated with increased risk of unintentional injury. Research supports this association through lifespan development, across cultures and across time. The causality of the relation is less established, although data support the hypothesis that the core symptoms of ADHD – especially inattention and impulsivity, as well as comorbid symptoms from disorders such as ODD and behavioural choices made by individuals with ADHD – contribute to the association. There is also some evidence that traumatic brain injuries may create ADHD symptoms and diagnoses. Further research is needed to continue to analyse the relationship, but we must simultaneously work to prevent injuries among individuals with ADHD, both through empirically supported injury-prevention strategies and through empirically supported behavioural and pharmacological treatment of ADHD ■

Declaration of interest

The author declares that there is no conflict of interest.

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In this regular column we feature a collection of abstracts that highlight some of the new research in the field of attention deficit hyperactivity disorder (ADHD). Research in this field is diverse and rapidly expanding, and we will endeavour to give you a sample of new findings and trends.

Biological markers, group visits, social deficits and consent

Welcome to this edition's 'Abstract watch'. Given the quest for biological markers of ADHD, Wainstein *et al* make an interesting observation. We explore Bauer *et al*'s novel use of group attendance at ADHD clinics. Obioha *et al*'s study on social skills deficits raises an interesting observation that is typically associated more with ASD than ADHD. Finally, Naenen-Hernani *et al* explore the use of informed consent in minimising treatment drop out.

Pupil Size Tracks Attentional Performance In Attention-Deficit/Hyperactivity Disorder

Wainstein G, Rojas-Libano D, Crossley NA *et al*. *Sci Rep* 2017; 7: 8228. <http://dx.doi.org/10.1038/s41598-017-08246-w>

Pupil size serves as a promising marker of cognitive states as they reflect the activity of an 'arousal' network. Pupil size from ADHD and control subjects was monitored during a visuo-spatial working memory task. A sub group of children with ADHD performed the task twice, with and without methylphenidate. A decreased pupil diameter was shown in off-medication patients and was no longer present when patients took their medication. A correlation was found with pupil size and the subjects' performance and reaction time variability and this effect was modulated by medication. The results indicate that pupil size could serve as a biomarker in ADHD.

Acceptability of Group Visits for Attention-Deficit Hyperactivity Disorder in Pediatric Clinics

Bauer NS, Azer N, Sullivan PD *et al*. *J Dev Behav Pediatr* 2017; 38: 565–572. <http://dx.doi.org/10.1097/DBP.0000000000000492>

This study investigates the views of caregivers, child participants and facilitators on the acceptability of ADHD group visits in busy paediatric clinics. A total of 34 caregivers, 41 children and 9 facilitators offered feedback. The feedback received indicated that caregivers enjoyed the 'support group' aspect and learning new things from others. An improved understanding of ADHD was also reported by caregivers, and the group visits enabled positive changes between parents and their child. The



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majority of families and facilitators highlighted a variety of benefits of the use of a group visit model for ADHD care. Despite systems-level barriers to implementation, families and facilitators felt the benefits outweighed the challenges.

Decreased Faux Pas Recognition and Parental Underestimation of Social Deficits in ADHD Children: A Pilot Study

Obioha O, Papaioannou H, Mendoza M and Milanaik RL. *Res J of Clin Pediatr* 2017, 1: 2.

This study aimed to assess social deficits in 50 children with ADHD (aged 7 to 17 years old) using Faux Pas Recognition tests and the accuracy of their parents' predictions of their performance. Children with ADHD performed worse on the 'absence of faux pas' condition than children without ADHD did. Children with ADHD also performed significantly worse on Faux Pas Recognition testing, indicating children with ADHD may have substantial difficulties evaluating social situations. A large discrepancy was noted between subject's Faux Pas Recognition scores and their parents' predictions, prompting concerns as to whether parents of ADHD children appropriately anticipate their children's social needs.

Influence of Written Informed Consent for Methylphenidate on Medicine Persistence Rates in Children with Attention-Deficit Hyperactivity Disorder

Naenen-Hernani K, Palazón-Bru A, Colomina-Climent F, Gil-Guillén VF; GAIPNA (Alicante Research Group in Child and Adolescent Psychiatry). *J Dev Behav Pediatr* 2017; 38: 603–610. <http://dx.doi.org/10.1097/DBP.0000000000000495>

A cohort study of 141 children with ADHD was undertaken to assess the influence of written informed consent on nonpersistence with methylphenidate treatment. Two groups were analysed with and without written informed consent. To assess the influence of consent on nonpersistence, bootstrapping was used to determine relative risk reduction (RRR) and number needed to treat (NNT). The use of written informed consent yielded higher persistence rates. Further studies are needed to determine whether we can use this procedure routinely in clinical practice ■

■ Internet memes provide a quick and engaging means of entertainment and self-expression for young people with ADHD



Internet memes: what professionals need to know



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People with attention deficit hyperactivity disorder (ADHD) spend large amounts of time online, and researchers are increasingly asking about how this interacts with their condition. Internet ‘memes’ are one medium through which people share and broadcast their thoughts and feelings online. For young people with ADHD, internet memes provide a quick and engaging means of entertainment and self-expression. This article explores the messages

that people with ADHD share and receive online, particularly with respect to treatment decisions and bridging the gap between professionals and the world of memes.

The association between ADHD and problematic internet use is well researched. People with ADHD use the internet for longer periods of time than the general population;¹ in fact, the symptomatology of ADHD is thought to overlap with internet addiction² and, in particular, problematic

internet gaming.³ These behaviours result in reduced sleep among people with ADHD, exacerbating their symptoms.¹ A systematic review by Wang *et al*⁴ found that internet use was associated with more severe ADHD, leading to the authors' recommendation that family and professionals should monitor internet use among people with ADHD closely.

On the other hand, internet use can also be empowering. People with ADHD and their families frequently go online for information about the diagnosis of ADHD,⁵ although they generally prefer to receive information from health professionals.⁶ Montoya *et al*⁷ worked with health professionals and parents to investigate the quality of online information about ADHD, and found its quality was 'generally poor'. This is particularly problematic because inaccurate online information can create tension between professionals and families regarding the appropriateness of diagnosis.⁸ It is, therefore, essential that healthcare professionals are aware of the information that people with ADHD are receiving online.

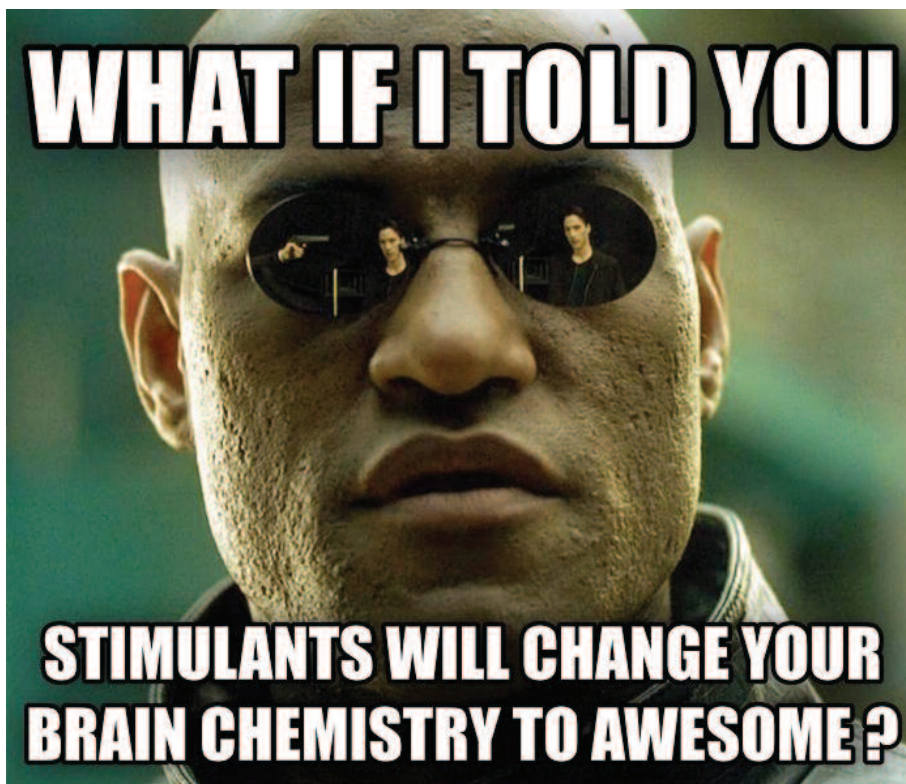
What are 'internet memes'?

The term 'meme' originates from Richard Dawkins' *The Selfish Gene*. Drawing a comparison with genes – the units of genetic transmission – Dawkins coined the term 'meme' to denote units of cultural transmission. Internet jokes became known as memes because they are easily shared across message boards and social media.

The memes being discussed here are usually images with simple captions. Other people can change the image or the caption to create new jokes. Background images are normally available online as clipart graphics or as stock photos, but sometimes memes build upon references from popular culture. Morpheus, a character from the Matrix movies, is famous for making profound comments. Many memes depict Morpheus with the superimposed text 'What if I told you' before a comment or piece of advice, as if to suggest that it would change the way the viewer saw the world. Figure 1 uses this formula to share their positive experience of pharmacotherapy for ADHD.

Memes and ADHD

For this analysis, 202 memes related to ADHD or Ritalin[®] were obtained by



■ **Figure 1.** Morpheus 'what if I told you' meme which the creator uses alongside a comment or piece of advice that it would change the way the viewer saw the world.

searching eight major public meme websites, along with Tumblr, Google Images, a public Facebook page dedicated to ADHD memes and two subreddits. All memes were in the public domain, having been posted on open webpages. Given the

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Memes are likely to be attractive to people with high levels of inattentiveness because they are immediately engaging and rapidly stimulating
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association between ADHD and high levels of internet use, we would expect there to be a lot of memes about ADHD.

There are several factors explaining why people with ADHD are particularly interested in internet memes. First, the captions attached to the graphics or pictures create attractive in-jokes. Memes are simple to make, blurring the distinction between audience and producer. This engenders a feeling of belonging to a

community, an experience particularly important to people who are struggling socially or educationally. This is an example of the link between ADHD, social skill deficits and internet use.⁹

High levels of internet use are particularly associated with inattentive symptoms in ADHD.¹⁰ Memes are likely to be attractive to people with high levels of inattentiveness because they are immediately engaging and rapidly stimulating. Similarly, although people with ADHD are often perceived as witty, many experience social cognition impairments,¹¹ which the structured format of meme-based humour may help to overcome.

The public nature of memes means that they have the potential to help professionals understand patients' feelings on a different level as people will feel more comfortable expressing themselves online compared with being in a consulting room. Memes are used in interaction with other individuals and as a medium of broadcast across larger online communities. As memes are simple to create, they are useful for people without the resources to create online videos, blogs or podcasts. Therefore, memes democratise discourse, allowing more voices to participate. It is this group



■ **Figure 2.** A 'victory kid' meme which the creator uses to indicate that events have worked out better than expected.

of voices that is represented in the following analysis of online memes.

What do memes tell us about ADHD?

People with ADHD use memes to express themselves anonymously in public forums. These messages offer an insight into the experience of having ADHD. Encouragingly, many memes show the positive role that stimulants can play within the management of ADHD. Figure 2 celebrates the beneficial effects of methylphenidate using a popular background image known as 'victory kid'.

This background indicates that events have worked out better than expected. In this case, the creator expresses the view that Ritalin really has helped them to overcome adversity, portraying it as a small but significant victory.

Memes not only help us understand how people with ADHD feel about aspects of their condition, such as treatment, they also affect other people with ADHD. People with ADHD who use memes to share positive messages about ADHD treatment provide a kind of peer support. People with ADHD who see these messages are encouraged to persist with engagement.

People with ADHD who use memes to share positive messages receive a kind of peer support. Those viewing these messages are encouraged to persist with adherence to treatment.

The element of peer support is also present in memes in which people share the issues they have with treatment. Figure 3 uses an image well known to meme users as 'first-world problems', superimposed with the text, 'I need to refill my Adderall but I keep forgetting'. This ironical comment emphasises the challenges of partially managed ADHD. The 'first-world problems' background image is commonly

used by people complaining about relatively insignificant difficulties, so in this meme it creates humour through self-awareness and self-deprecation. This meme is a reminder that people with ADHD often struggle with medication adherence, reflecting the argument by Cutler and Mattingly¹² that one responsibility of professionals is to optimise delivery in order to facilitate medication adherence.

Many other memes reflect on the challenges of using stimulant medication, whether commenting on adherence, adverse effects or stigma. When other people with ADHD view these memes, their own feelings about side effects are validated and normalised, helping them accept their overall experience of psychopharmacology. This is particularly valuable given the stigma facing people with ADHD, which can also impact upon their prospects.^{13,14}

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The management of ADHD is affected by cultural factors, including television and newspapers, but also the internet.

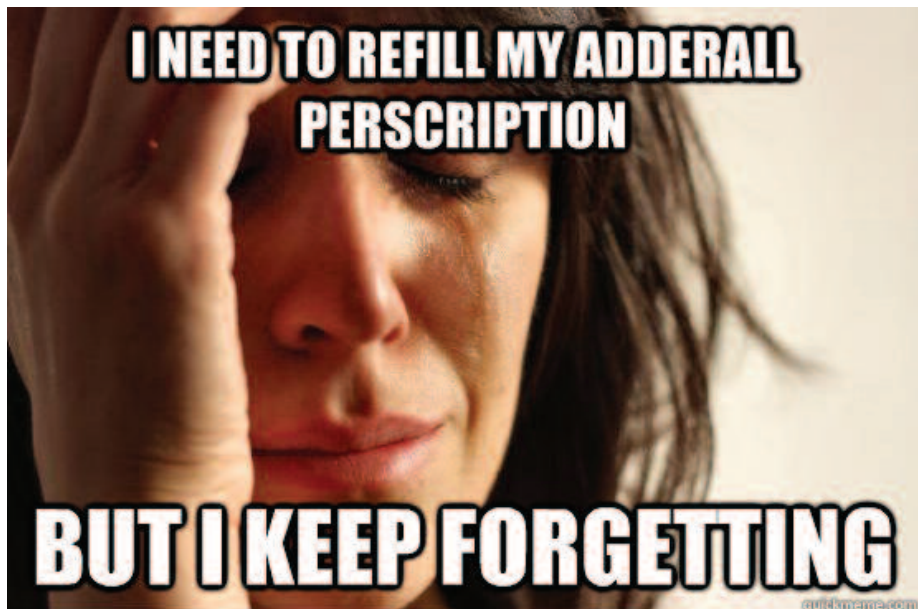
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Harmful messages

However, the messages shared online are not always positive. In this analysis, one third of memes about ADHD treatment made negative or potentially hurtful comments. These memes do not appear to have been created by people with ADHD and betray a lack of understanding of the condition.

One meme uses a ‘condescending Wonka’ image to sarcastically dismiss a person using prescribed ADHD medication: ‘You must have such bad ADD.’ Exposure to messaging that undermines or queries the need for treatment is harmful to people who have been prescribed medication by a doctor. It is known that people who are uncertain about the necessity of medication are at greater risk of intentional non-adherence.¹⁵

Other memes are directed at the self-esteem of people living with ADHD. They



■ **Figure 3.** First-world problems meme the creator uses this image to communicate that the compliant is relatively insignificant and creates humour through self-awareness and self-deprecation.



■ **Figure 4.** The original ADHD treatment meme that demonstrates that messages online are not always positive regarding the treatment of and that there is a lack of understanding about the condition.

Box 1. Action points

- Ask people with ADHD what they are looking at online
- Discuss messages about ADHD that people with ADHD have seen online
- Facilitate self-expression and creativity among people with ADHD
- Encourage participation in positive online forums

often describe people with ADHD as unintelligent – a further impediment to educational achievement. Alternatively, they make a moral judgment about the person with ADHD. This reinforces the

approach described as ‘internalising personal responsibility through moral self-condemnation’ experienced by many people with ADHD.¹⁶ They are epitomised in the many memes describing corporal

punishment as 'the original ADHD treatment', of which Figure 4 is one example.

Harmful messages spread through memes have been challenged by The ADHD Homestead blog,¹⁷ which points out that negative memes made by people without ADHD delegitimise the experience of people who are adhering to medication and experiencing the benefits. The daily challenges of ADHD often affect self-esteem, and this is only compounded by malign misinformation online. This problem is not unique to internet memes; an analysis of newspaper stories found that ADHD was represented particularly harshly there too,¹⁸ but awareness of this group of memes provides additional context for professionals and supporters of people with ADHD.

Learning from memes

The management of ADHD is affected by cultural factors, including television and newspapers, but also the internet. Previous research into stigmatising representations in the media is mirrored in internet meme culture. Professionals caring for people with ADHD benefit from an awareness of these influences and of the self-expression of people with ADHD (see Box 1 for further practical steps). People with ADHD creating and viewing memes online are exposed to many potentially harmful attitudes to ADHD therapy. However, most memes provide an outlet for frustrations, developing community and camaraderie through normalising and validating the experiences of people with ADHD ■

Declaration of interest

The author declares that there is no conflict of interest.

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Key points

- ▶▶ Internet 'memes' provide young people with ADHD with a medium in which to broadcast their thoughts and feelings and provide a quick and engaging means of entertainment and self-expression.
- ▶▶ Memes are of interest to people with ADHD as the captions attached to the graphics or pictures create attractive in-jokes, they are simple to make and it gives people with ADHD a feeling of belonging to a community.
- ▶▶ Memes have the potential to help professionals understand their patients' feelings.
- ▶▶ Exposure to memes that undermine or query the need for ADHD treatment is harmful to people who have been prescribed medication because people who are uncertain about the need for medication are at greater risk of intentional non-adherence.

DIARY DATES

12–14th January 2018

The American Professional Society of ADHD and Related Disorders 2017 Annual Meeting

Washington D.C., USA

The American Professional Society of ADHD and Related Disorders

- info@apsard.org
- <https://apsard.org/meetings/2018-meeting>

3rd–6th March 2018

26th European Congress of Psychiatry

Nice, France

Kenes International

Organizers of Congresses

- www.epa-congress.org

24–31st March 2018

CADDRA presents ADHD 2018 – Exploring the Horizons

Cruise ports of call: Miami, USA;

Key West, USA; Costa Maya,

Mexico; Cozumel, Mexico;

George Town, Grand Cayman

Canadian ADHD Resource Alliance (CADDRA)

- <https://goo.gl/jKdMzZ>

25–27th

April 2018

Royal College of Psychiatrists Faculty of Medical Psychotherapy Annual Conference 2018

Cardiff, UK

Royal College of Psychiatrists

- emma.george@rcpsych.ac.uk
- <https://goo.gl/luSRQo>



25–28th April 2019

7th World Congress on ADHD

Lisbon, Portugal

World Federation of ADHD

- www.adhd-congress.org

ADVERT