



Foundations for the Future

Exploring Perspectives in the Management of ADHD



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1. Foreword: Why We Need This Report

'Quality of life' is a measure of the impact a particular condition can have on a patients' wellbeing. However, it is an all-encompassing term that means different things to different people. Whilst over the last two decades impairment on quality of life has been an important consideration in managing many conditions in both adults and children, it is only now being viewed as relevant to those with Attention Deficit Hyperactivity Disorder (ADHD).

If the impact of ADHD on quality of life is to be a useful concept then it is essential that the meaning is clear and that terms are well defined. This report endeavours to provide an overview of the subject, a usable definition to describe the impact of ADHD on quality of life and a basis on which to improve it.

This is, to our knowledge, the first report to bring together comprehensive evidence relating to the quality of life of ADHD patients, alongside the opinions and perspectives of those who deal with the condition including healthcare professionals, third party groups, community-based personnel and teaching staff.

The report encourages clinicians to consider the wider impact of ADHD and its treatment on a young person's day-to-day life beyond the school day, including adverse effects on academic performance, peer-to-peer relationships, social skills, family interactions, self-esteem and long-term social outcomes. It also urges all professionals in the area of ADHD to agree a clear definition for quality of life in ADHD and use this when managing the condition.

With these tools it is hoped that we, as professionals, are able to develop more integrated, defined and appropriate management strategies. The ultimate aim is to improve long-term outcomes for children with ADHD and their families.

Professor Harry Zeitlin

*Emeritus Professor of Child and Adolescent Psychiatry, University College London,
Consultant, North Essex Mental Health Trust*

2. Executive Summary

- Attention deficit hyperactivity disorder (ADHD) is associated with impairment in many areas of a child or adolescents' broader functioning, referred to as their 'quality of life' (QOL).
- The QOL of children and adolescents may be impaired both in the short and long-term as a result of their ADHD. Effects can be assessed and measured in distinct domains: emotional wellbeing, physical activity, social and family interaction, academic achievement, level of self-satisfaction and self perception.
- Although the impact of ADHD on QOL has been identified, current management of the condition still focuses on controlling the core symptoms of hyperactivity, impulsiveness and inattention, especially during the school day while the impact of ADHD on QOL, such as social relationships and family interaction, tend to be overlooked in any detail.
- The development of an increasing number of multi-dimensional clinical rating scales and the consideration of patient perception now afford the opportunity to measure the health of children and adolescents with ADHD more comprehensively.
- The current inconsistency in approach towards considering QOL in ADHD also extends beyond the clinical setting. In order to develop a unified approach to improving QOL in ADHD, clinicians must work together with external agencies and third parties to increase long-term clinical and social outcomes for all children and adolescents with ADHD.

3. Contributing Advisers

Phil Anderton

Former Senior Police Officer

Lancashire Police Community Safety Team



Phil Anderton first started working in ADHD as a senior police officer when he was responsible for reducing youth crime in Lancashire. While seeking to undertake this responsibility in a manner that broke new ground, he began working with other agencies involved in the lives of young people with ADHD in an attempt to foster greater understanding and thereby reduce the risk for young people with ADHD. Phil speaks on the subject throughout Europe and the US. Phil currently works as a management consultant with Mott Macdonald who has kindly allowed him to continue his good work in this field.

Andrea Bilbow

Founder and Director

The National Attention Deficit Disorder Information and Support Service (ADDISS)



Andrea Bilbow's younger son was diagnosed with ADHD and Aspergers Syndrome in 1992 at the age of five years. Soon after his diagnosis, Andrea became actively involved in researching and learning about ADHD, which resulted in her setting up a local support group. The acute lack of awareness and expertise among childcare professionals drove her to establish the National Attention Deficit Disorder Information and Support Service (ADDISS). Andrea has since organised seven international three-day conferences and over 19 local one-day training events, bringing together healthcare professionals and those involved in the care of people with ADHD from all over the world in order to raise awareness of the condition and share current information. Professionals and parents in the UK and abroad recognise ADDISS as the leading national advocacy movement in the UK.

Dr Saroj Jamdar

Associate Specialist in Child Health

Child & Family Mental Health Service, Wigan, Greater Manchester



Dr Jamdar is a Community Paediatrician with special interest in the area of ADHD. She qualified in India from Jabalpur and completed an MD in paediatrics from the Post Graduate Institute of Medical Education and Research at Chandigarh, India. After moving to the UK, she undertook a diploma in Child Health in Glasgow. Dr Jamdar has participated in various studies which looked at the impact of ADHD on quality of life and presented the resulting data to international audiences in Vienna, San Diego and regionally to paediatric and child psychiatry colleagues. In addition, Dr Jamdar has also written a paper on the management of ADHD for the British Journal of Hospital Medicine and participated in a BBC Horizon programme entitled 'Living with ADHD'.

Lisa Mangle

Specialist ADHD Nurse

Ryegate Children's Hospital, Sheffield, Yorkshire



Lisa Mangle began her career in 1985 when she trained as a Paediatric Nurse at Sheffield Children's Hospital. Over the next 15 years, she gained experience in a variety of specialist areas including surgery, medicine and oncology. In 2000, Lisa graduated with a BSc in Psychology which fuelled her interest in ADHD. For the past five years, she has worked as an ADHD Clinical Nurse Specialist at The Ryegate Children's Centre in Sheffield. In addition, Lisa is currently studying for an MA in Autism and is also an active member of the UK ADHD National Nurse Network (UKANN) Steering Group, which organises annual conferences attended by over 120 specialist ADHD nurses.

Fintan O'Regan

Behaviour Management Consultant

Epsom, Surrey



Fintan O'Regan is a former science teacher and Headmaster of The Centre Academy School, regarded as the first specialist school within the UK for children with ADHD/Oppositional Defiant Disorder (ODD). He is currently an associate lecturer at Leicester University and the Institute of Education as well as an external expert for Worcester University. Fintan is the Honorary Education Director of the ADDISS Charitable Trust and a Behaviour Adviser for Surrey LEA and the National Association of Special Educational Needs (NASEN). In addition, he has written a number of published articles on the subject of behaviour management and Special Educational Needs (SEN). He is author of the Times Educational Supplement (T.E.S.) award winning book, *Educating Children with ADHD* (2000). Other books include *How to Teach and Manage Children with ADHD* (2001), *Surviving and Succeeding in SEN* (2004), *ADHD* (2005), *Challenging Behaviours* (2006) and *Troubleshooting Challenging Behaviours* (2006).

Dr Chris Steer

Consultant Paediatrician

Victoria Hospital, Kirkcaldy, Fife



Dr Steer qualified at Edinburgh University 1971 and has been a Consultant Paediatrician at the Victoria Hospital in Kirkcaldy, Fife since 1984, with dual accreditation in Paediatrics and Paediatric Neurology. He is responsible for a busy Neurodevelopmental, Learning Disability and Paediatric Epilepsy Clinic in Fife. In addition, Dr Steer is a Fellow of the Royal College of Paediatrics Child Health (RCPCH) and Royal College of Physicians (RCPsych) Edinburgh. His clinical and research interests and publications include pharmacotherapy and quality of life in ADHD, Paediatric Epilepsy, Autism and Learning Difficulties. Dr Steer is also a contributor to the SIGN Guidelines on ADHD and Paediatric Epilepsy, a member of the Quality Improvement Scotland (QIS) working group auditing ADHD services across Scotland (ADHDSOS), a member of steering groups for the Scottish Intercollegiate Group on Alcohol (SIGA) and the Scottish Paediatric Epilepsy Network (SPEN).

Professor Harry Zeitlin

**Emeritus Professor of Child and Adolescent Psychiatry, University College London
Consultant, North Essex, Mental Health Trust**

Essex



Professor Harry Zeitlin studied medicine at the London Hospital and initially pursued respiratory medicine. He became interested in the psychological impact of physical disorder and trained in Psychiatry and then Child Psychiatry at the Maudsley Hospital. In 1974, Professor Zeitlin moved to the Westminster Children's Hospital as Senior Lecturer and Regional Tutor, where he strove to improve the teaching of Child Psychiatry in General Medical Training. He became Professor of Child and Adolescent Psychiatry at University College London in 1991 until 2004, when he received then the title of Emeritus Professor. He

has worked over many years as an expert witness to the courts, providing particular focus on the impact of disorder and treatment on quality of life. Professor Zeitlin has published on a range of topics including long term outcome from childhood, child abuse, substance misuse in children and adolescents, child psychiatry and the law, prevalence of Tourette's syndrome and ADHD.

4. What is Quality of Life (QOL) in Relation to Attention Deficit Hyperactivity Disorder (ADHD)?

4.1 Attention Deficit Hyperactivity Disorder

Attention Deficit Hyperactivity Disorder (ADHD) is known to be the most common childhood-onset neurodevelopmental condition and one of the most prevalent chronic health conditions affecting school-aged children.^{1,2} Approximately 3-5% of children in the UK currently suffer from the disorder.^{3,4}

Children and adolescents with ADHD often have one or more co-existing conditions or comorbidities. These can make it more difficult to diagnose as many of the symptoms of ADHD can also be symptoms of other disorders. Conditions often linked with ADHD include Oppositional Defiant Disorder (ODD), Conduct Disorder (CD), depression, Tourettes syndrome, anxiety, learning disabilities, language or hearing difficulties and dyslexia.

Characteristic symptoms of ADHD include inattention, hyperactivity and impulsiveness which are displayed to a greater extent than in other children of the same age and development level.⁴ In addition, the effects of ADHD extend far beyond these core symptoms, exhibiting wide-ranging and debilitating effects on the patient's wellbeing.

“Matthew, when trying to justify why his impulsivity had got the better of him, explained that ‘the bad side of my body is stronger than the good side’.”⁵ Parent of Matthew*, age 12

4.2 What do we mean by QOL in relation to ADHD?

It has long been understood that children with ADHD can experience emotional and social problems that can result in an exacerbation of their condition. This ‘quality of life’ effect (or ‘QOL’) is not a new concept, although only recently have researchers begun investigating it in relation to ADHD.

Some clinicians agree that QOL is a measure of the perception of an individual's personal functioning.¹ However, the term encompasses many parameters including the patient's physical, mental and social wellbeing.⁶

Guidance on ADHD issued in 2006 by the National Institute for Health and Clinical Excellence (NICE) specifically mentions that children with severe ADHD can often have low self-esteem, develop emotional and social problems and frequently underachieve at school.³

“Quality of life isn't there for us to find; we need to define what we mean by the term.”

Professor Harry Zeitlin, Emeritus Professor of Child and Adolescent Psychiatry

4.3 How is QOL impaired in children with ADHD?

Since there is no one commonly used definition of QOL in ADHD, it is more pertinent to describe it in terms of the day-to-day effect on the child or adolescent.

The effects of ADHD on a child's QOL fall into three key areas: the child's relationships at home, their friendships and academic achievement at school, and areas that fall outside of these spheres within the external environment (see Figure 1). All these areas interlink and cannot be considered in isolation. For example, a stressful family environment caused by the symptoms of the child's ADHD may impact their performance at school, potentially leading to truancy and ultimately contact with the criminal justice system. Alternatively, prejudice from other parents may lead to social exclusion by peers which may lower the child's self-esteem and damage relationships with family and friends. Therefore, when considering the effect of ADHD on a child's QOL, all three areas must be taken into account with equal weight.

“Sleep deprivation is a specific area of concern in ADHD; the long-term implications of sleep deprivation can compromise a child's emotional and educational development. Finding ways to reduce the negative impact of sleep disturbances should become a routine part of managing ADHD.”

Dr Chris Steer, Consultant Paediatrician

“Although school is important for children and adolescents with ADHD, children actually only spend less than a fifth of their time in school during the course of the year.”

Fintan O'Regan, Behaviour Management Consultant

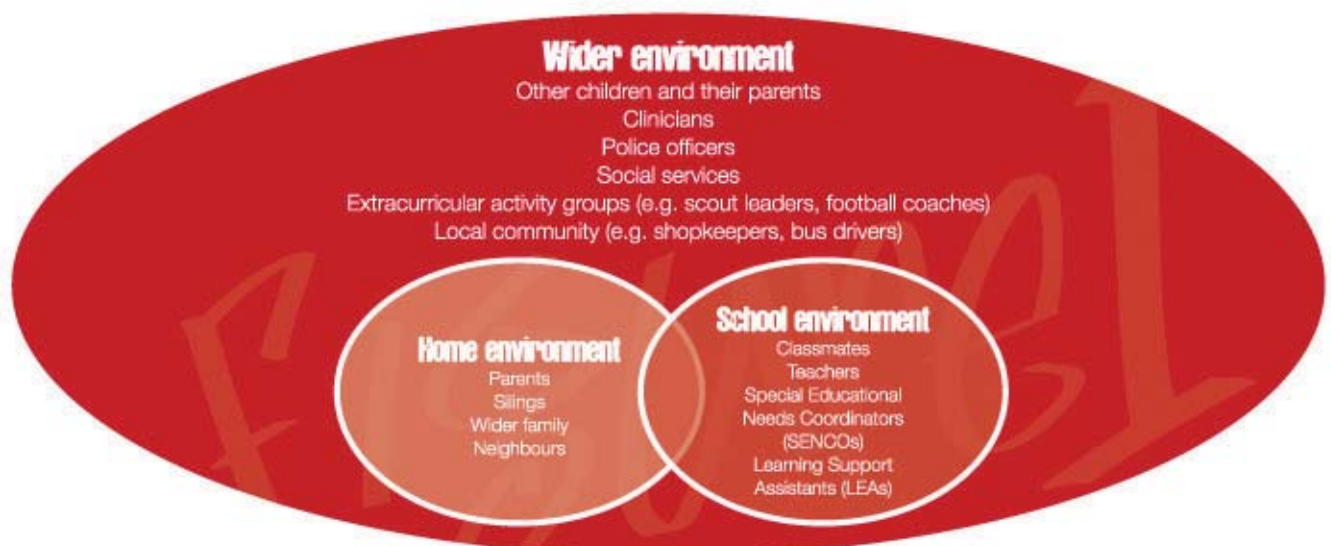


Figure 1. Areas for interaction for a child with ADHD

| | |
|-----------------------------------|---|
| Self-esteem | 80% of parents feel that their child has a lower self-esteem compared with their peers. ⁷ |
| Academic performance | In 92% of cases, parents feel that their child's ability to achieve at school is affected by their ADHD. ⁷ |
| Peer-to-peer relationships | Almost 65% of UK children with ADHD are unable to maintain lasting friendships with their peers. ⁸ |
| Self perception | Children with ADHD feel that they have a lower self-esteem than peers who don't suffer from the condition. ⁹ |
| Social acceptability | 39% of children with ADHD have been excluded from school as a result of their condition. ⁷ |
| Social functioning | 53% of children with ADHD spend the majority of their free time alone. ⁸ |
| Family relationships | Almost one half of families report a significant negative impact as a result of their child's ADHD. ⁹ |

Figure 2. Specific examples of the wider areas in which ADHD can have a wider impact on the wellbeing of children and adolescents.

4.4 Current clinical focus: The school day

ADHD has a significant impact on the academic achievement of the child or adolescent. A recent study has shown that the majority of children with ADHD were rated as performing below the expected level for their age and cognitive functioning.¹⁰ In addition, due to the restless and impulsive symptoms of ADHD, children with the condition can often display disruptive behaviour in the classroom which can effect the quality of learning of all the other children in the class.

In order to combat the impact that ADHD can have on the child's life at school, many clinical management strategies currently focus purely on controlling the child's symptoms throughout the school day. However, in reality children can sometimes only spend just four hours on lessons or working during a weekday.¹¹ It is the unstructured time at home and in the outside world that is harder to manage.

“As every class is likely to have one or more child with ADHD, it could be argued that as this child is taking up a lot of the teacher's time, the quality of learning of the other children is being affected. Therefore, every child in every classroom is affected to some degree, either directly or indirectly, by ADHD.”

Fintan O'Regan, Behaviour Management Consultant

Around 40% of children with ADHD have received a Statement of Educational Needs, demonstrating the severity of the condition in relation to achieving in the classroom.⁷

“I drift off for a few minutes... when I come back round, everyone is two pages ahead of me.”¹² Claire*, aged 13

*Real name substituted to protect identity

“The important factors in a school environment are academic achievement and social interaction. If you are not succeeding in these, you are not going to be a happy child.”

Fintan O'Regan, Behaviour Management Consultant

4.5 Social interaction & self-esteem

Developing the ability to make and maintain friendships during childhood and adolescence is key to successful development and self-esteem. Unfortunately, young people with ADHD have difficulty cultivating these relationships and developing social skills. The symptoms of impulsivity, inattention and hyperactivity often cause children to be excluded from social activities from a very young age. Without appropriate treatment, social exclusion can become even more disabling as the child gets older and they can have difficulty creating and maintaining friendships, thus lowering their self-confidence.¹³

Young people with ADHD are often bullied by their peers for acting differently or displaying unusual behaviour. More than half of children with ADHD have been shown to get picked on by other children often or most of the time, compared with children without the condition.⁸ Children with ADHD can be perceived as irritating, immature and offensive by their peers and adults alike.

As a result of the disrupted and poor development of social skills, older children often display “anti-social” behaviour and commonly find themselves outside the law and almost 20% of adolescents with ADHD have been in trouble with the police.⁷

53% of children with ADHD play alone most of the time, compared to only 12% of children without the condition.⁸

“Not everyone likes me at school but at least my teacher is nice to me.”¹² Alex*, age 9

4.6 Long-term social outcomes

Evidence suggests that up to seven in 10 children continue to show symptoms of ADHD into adolescence and adulthood.¹⁴ As a result, these adolescents are at an increased risk of poor long-term outcomes such as lower educational and employment achievements, antisocial behaviour, smoking and may even begin taking harder drugs at a younger age compared with peers.^{15,16} Teenagers with ADHD are more likely to fail at school and get lower status jobs than their peers.¹⁷ It is thought that poor long-term outcomes are due to the low self-esteem acquired during childhood which can persist into adolescence.

Young people with ADHD often live on the edge of society; young adults who have been diagnosed with ADHD in childhood have been found to have a greater involvement with drug use, the courts and police than their peers.¹⁸ The Criminal Justice Report, authored by the Audit Commission in 2004, found that there has been a significant increase in mental health problems among young people in contact with the criminal justice system in recent times, including ADHD.¹⁹ The condition is particularly high amongst young offenders; studies have found that between 25-45% of young male prisoners have ADHD.^{20,21}

Associated comorbidities can also increase the risk of negative long-term outcomes independently of ADHD; data indicates that ADHD with associated conduct disorder (CD), related yet different disorders, confers a risk of adult illegal behavior or arrest in later life.²² CD has around a 50% comorbidity with ADHD and can therefore exacerbate the risk of long-term dysfunction.²³

*Real name substituted to protect identity

"ADHD has a huge effect on long-term social outcomes. People with poorly managed or misdiagnosed ADHD are more likely to enter the criminal justice system which, in turn, frustrates their opportunities in life." Phil Anderton, Former Senior Police Officer

"My son became extremely paranoid and was angry at the world because of what his ADHD had done to him and the lack of support he received. He is now in prison. If his problems were tackled when he was much younger then his story could have been very different." Parent of Andrew*, aged 23



4.7 How do other childhood conditions affect QOL?

It is widely accepted that many other chronic childhood diseases adversely affect QOL. For example, evidence shows that atopic dermatitis, the most common inflammatory skin disease in children, has psychosocial effects including behavioural problems, excessive dependency and fearfulness.²⁴ In addition to the impact on the child, the condition has a social, emotional and financial impact on the family; mothers of children with the condition report a decrease in employment outside the home as well as difficulty with discipline.²⁵

With regards to school-aged children, intensive diabetes treatment has a documented psychosocial impact on the patient. Parents also have great emotional and physical demands placed upon them at the time of diagnosis which may be problematic because the psychosocial adjustment of parents has been linked to similar difficulties in their children.^{26,27}

Tourette's syndrome, which is now acknowledged to be far more common than once thought, affecting up to 1% of 13-14 year olds in the UK,²⁸ also has a profound effect on the schooling, social and work functioning of those affected by the condition. In addition, some patients also have comorbidities including ADHD.

5. The Current Evidence Base

As outlined in section 4, ADHD can impair many areas of a child's development including academic performance, social development, behaviour in school, peer-to-peer relationships and family functioning. However, in line with a more traditional approach, the majority of pharmacological studies have been carried out on the basis of measuring core symptoms rather than QOL.

5.1 What do we currently know?

The concept of QOL (with and without disease association) began to be studied in the US in the late 1980s, focusing on the importance of reviewing a persons' overall functioning. Research has shown that global functioning is affected by the presence of symptoms and its effect on daily activity levels, psychological wellbeing and social interaction.^{29,30}

There are only a few studies that specifically measure the broader effects of ADHD in children. Most recently, Klassen *et al* found that:³⁰

- ADHD has a significant impact on multiple areas of QOL for children and adolescents in comparison to normative data
- Children with ADHD have raised levels of parent-reported problems in terms of behaviour, mental health and self-esteem in relation to symptom severity and comorbidity compared to normative data

“Children with ADHD demonstrated poorer health-related QOL for all domains of psychosocial health and family activities than normative data.”³⁰

Other studies have looked at:

- Evaluating a new parent-completed questionnaire measuring the effect of ADHD on the QOL of patients and their families³¹
- Investigating a new ADHD treatment and its impact on QOL³²
- Comparisons of QOL across different mental health disorders^{33,34}

Notably, Sawyer *et al* found that, after controlling for age, gender and family structure, children with mental health disorders including ADHD were reported to have a significantly worse QOL in several areas compared to children without the disorder. In addition, in many areas they were reported to have a worse QOL than children with physical disorders.³⁴

“Parents reported that the problems of children with mental disorders interfered significantly with the daily lives of children, parents and families.”³⁴

A study by Ralston *et al* in 2004 provided an insight into the sample characteristics, clinical diversity and effects of ADHD on academic achievement and social activities. The aim of the study was to assess all patients with ADHD, regardless of comorbidities:¹⁰

- Sleeping problems were relatively common (48%) with nearly half of the affected children experiencing significant interference in well-being as a result
- Academic achievement and social activities were negatively affected in a sizeable proportion of the sample; only 48% were considered to be manageable in the classroom environment whereas 28% experienced some exclusion from school lessons
- 17% of children with ADHD were in a special education programme, 4% were requested to change to a special needs school and 5% were suspended from school altogether

"Only 48% of children with ADHD were considered to be manageable in the classroom environment." ¹⁰

To date, the largest paediatric UK pharmacological trial investigating QOL as a primary outcome measure has been performed by Prasad *et al.*¹⁹

- Child and parent-rated effects of ADHD on QOL showed that the condition has a significant negative impact on all areas of QOL
- A significant improvement was seen in the QOL benefits of ADHD medications in the area of social acceptance when rated by the child

"The QOL of children and adolescents with ADHD was extremely compromised at baseline, measured using the Child Health and Illness Profile-Child Edition (CHIP-CE) scale, and improved with medication over the 10-week study." ¹³

The study was the first in the UK to evaluate QOL in ADHD and use the measure of child perception (which is discussed in more detail in section 7.3).¹⁹

5.2 What more do we need to find out?

A limitation of the majority of studies involving patients with ADHD is that the child or adolescent's point of view is rarely taken into consideration. The collection of self-perception data should be an important component in QOL studies and is an area which needs to be explored further. The few studies on the impact of ADHD on QOL to date have focused on identifying the effects in terms of specific, individual areas. New studies are beginning to investigate the consideration of broader quality of life outcomes in management decisions, including both pharmacological and behavioural strategies.^{13,26}

If we are to begin to measure QOL, we need to ensure that we strengthen the evidence base moving into the future.

"By improving quality of life, you are putting children with ADHD on the same playing field as everyone else and giving them an equal chance in life." Andrea Bilbow, Founder and Director of ADDISS

DEFINE

6. How Do We Define Parameters of Quality of Life in ADHD?

There are several controversial factors in the overall consideration of quality of life. It could be argued that the concept of a persons' QOL has arisen as a result of modern, developed society. Furthermore, an individual's QOL is subjective and its use as a comparable measure between patients could be questioned.

Geographical location and social context can increase or decrease the societal 'norm' for QOL. However, as a model, the core symptoms of ADHD result in a decreased QOL for children and adolescents with ADHD and this effect is seen across patient populations and age groups.¹⁸ The effects of ADHD on QOL should be quantified as effects specifically on health-related QOL (or 'HRQOL').

Considering the evidence outlined in this report, clinicians must look to the effects of ADHD on a patient's overall functional and emotional wellbeing in terms of specific domains in order to measure QOL as a whole:

- Emotional wellbeing
- Physical activity
- Social and family interaction
- Academic achievement
- Level of self-satisfaction
- Self-perception

By using functional measures and child perception, QOL can be measured and, in combination with standard clinical measures, provide guidance for a more holistic approach to the management of ADHD.

“How do you look at quality of life? How do you really know that one person is talking about the same thing as another?”

Professor Harry Zeitlin, Emeritus Professor of Child and Adolescent Psychiatry

“Quality of life may be relative to society but if you have poor health then you have an impaired quality of life, regardless of where you live or who you are.” **Andrea Bilbow, Founder and Director of ADDISS**

PARAMETERS

7. How Do We Measure the Effect of ADHD on Quality of Life?

7.1 How is ADHD currently managed?

There is no single measure, blood test, brain scan or computer task that can make an ADHD diagnosis or guide management of the condition.³⁶ However, some of these can help to support the findings of extensive assessment interviews with the child, parent and teacher.

The Diagnostic & Statistical Manual for Mental Disorders (DSM-IV) provides specific criteria for diagnosing ADHD using the domains of inattention, impulsivity and hyperactivity.⁴ However, these domains focus solely on recognising the core symptoms of ADHD. In line with these criteria, many experts have traditionally advocated the use of strategies that primarily address the core symptoms of ADHD. However, another view is emerging that considers improving quality of life as a management goal in its own right.

As discussed in section 4, ADHD is commonly associated with comorbidities and these should be taken into consideration. Research indicates that between 60% and 80% of ADHD patients, both in childhood, adolescence and adulthood, are likely to have at least one other disorder besides ADHD and over 30% are likely to have at least two other disorders in addition to ADHD.³⁷ Associated comorbidity may or not be initially apparent and the symptoms may be similar to those of ADHD. Clinicians should therefore take comorbid conditions into account, especially when considering QOL factors.

“The main objective of ADHD management is to ensure that the child is functioning at the same level as most of the children in our society. It is imperative to ensure that the child’s core symptoms and quality of life are balanced as the two go hand in hand.”

Dr Chris Steer, Consultant Paediatrician

7.2 The evolution of clinical rating scales

Clinical rating scales have been used since the 1970s and, alongside clinical assessment, aid the diagnosis and assessment of ADHD.³⁸

ADHD and associated comorbidities are often evaluated using standardised behavioural clinical rating scales because they offer many advantages:

- Rating scales are easy to use and cost relatively little.
- Rating scales facilitate systematic comparison of differing informant perspectives. Depending on the scale, the views of the parent, teacher and patient can be observed and compared.
- Rating scales are usually reliable, offering a consistent approach to patient assessment and have been used successfully in a wide range of clinical research on ADHD.

However, the majority of rating scales focus purely on measuring symptom reduction, with no consideration for the effects of ADHD on other aspects of the child’s wellbeing. Although rating scales are valuable tools for diagnosing ADHD and assessing symptoms, there is currently no universally accepted scale for measuring QOL or a scale that specifically measures QOL outcomes in ADHD.



MEASURING

For example, the SNAP-IV rating scale encompasses a broad range of measures, consisting of 26 criteria (2000), the Conner's Index Questionnaire (1968), the IOWA Conner's Questionnaire Rating Scale (1998). The Revised Conner's Rating Scales also cover a broad range of observed comorbidities and enable a more holistic approach to assessment by including questions about skills and participation in leisure activities. Both scales are closely aligned to the DSM-IV criteria. Other commonly used clinical rating scales in the UK can be found in Appendix 1, although please note that

An increasing number of clinical rating scales are being developed to help identify and define ADHD, but also assist clinicians in the consideration of QOL factors, such as the Child Health Questionnaire. The current scales should continue to be used to measure ADHD, but separate scales should be adopted to measure QOL, which potentially provide a combined rating through statistical analysis. In addition, a scale that separates ADHD from comorbid disorders would assist in the measurement of QOL and one to evaluate task completion and capacity for all children with ADHD.

“There are too many rating scales and everyone is using different ones based on cost, preference and experience. We need to develop a uniform approach.” **Dr Saroj Jamdar, Associate Specialist in**

7.3 Patient perception: A validated measure?

Self-perception can be described as the way people feel about themselves. Although the reliability of adolescent self-perception is continually questioned, the self-awareness of a very young child is not. There is evidence that school-aged children with ADHD perceive themselves differently from children of the same age as adolescents their age and it is the perception of their behaviour that stands out the most.³⁹ Children with ADHD score lower than their peers on self-perceived academic performance.³⁹ This discrepancy between self-perception and actual performance is an area which needs to be investigated further.

Children move through a key transitional period between eight and nine years of age in which self-perception changes and peer approval becomes critical. The concept of self-perception is said to be important during this time which is also the time around which ADHD is commonly diagnosed and treated.⁹ Children between 8 and 11 years of age are at a critical point in the development of self-awareness, particularly influenced by

Findings suggest a difference in the way school-aged children with ADHD perceive themselves as compared with their peers.³⁹

7.4 How do we measure self perception in ADHD?

The Harter Self Perception-Profile for children (HSPP) is the most common clinical rating scale to measure child-rated self-esteem scores and is widely used by developmental psychologists. The HSPP is a self-reporting inventory for ascertaining children's perception of themselves in various domains of their life, as well as their sense of self-worth. Although it is currently only validated for use in children aged eight to 11 years, this covers the beginning of the key transitional period from childhood into adolescence. The needs and self-perception of the patient change from around 13 years, in which various other rating scales with adolescent reporting forms can be utilised, such as the Revised Conner's Parent Rating Scale and the Strengths and Difficulties Questionnaire (SDQ).

Although patient perception in ADHD is more commonly taken into account in the US, the recent Prasad *et al* SUNBEAM study is the first UK trial to incorporate child-rated self-perception scores specifically to examine the broader efficacy of pharmacotherapy in ADHD.³⁹

However, in order to eliminate issues of parental influence, the child or adolescent should have the option of a self-reporting form that they can complete themselves. Clinicians should also be sensitive to the question style and the child's age. With regards to ethical sensitivities, clinicians should ensure that the parent or caregiver is at hand to provide support if required and follow a validated self-perception rating scale.

The recent National Institute for Health and Clinical Excellence (NICE) guidance on ADHD recommends that the preferences of the child and his/her parent or guardian are one of the key considerations when choosing a treatment for ADHD.⁹

Evidence suggests that attention should be focused on fostering self-esteem and positive self-perception in children with ADHD through support groups and behavioural training.³⁹

7.5 Measurement of QOL: The new parameter in ADHD

Even though UK clinicians are increasingly recognising the effects of ADHD on QOL, they feel that by treating the symptoms of ADHD, they are subsequently improving the child's QOL. However, using QOL as a measure of the ultimate management goal may not currently be reflected in their assessment and prescribing habits.

Diagnosis and management of ADHD in the clinical environment should therefore include the use of appropriate rating scales that take into account all domains affected by QOL such as self-esteem and social acceptance, in addition to the measurement of core symptoms. Where possible, the views of the patient should be sought in order to provide a comprehensive view of the overall wellbeing of the child or adolescent. The emergence of new and enhanced rating scales that measure ADHD and QOL will enable clinicians to do this more readily.

“When an ADHD management strategy is initiated, parents often report that the child is still suffering from low self-esteem and poor social functioning, even though their hyperactivity, inattention and impulsiveness are seemingly under control. We must endeavour to look beyond these core symptoms.”

Lisa Mangle, Specialist ADHD Nurse

8. Foundations for the Future: A Call to Action

Considering the evidence contained within this report, it is clear that ADHD significantly impairs a child's QOL. As a result, UK clinicians are urged to:

- **Consider improving QOL as the goal of ADHD management.**
 - It is essential that professionals working in the field of ADHD consider both the short and long-term impact of impaired QOL and the implications it can have on the child and their family.
- **Embrace a consistent approach to understanding, managing and evaluating QOL in ADHD, supported by the growing clinical evidence base.**
 - This will be paramount to improving the management of the condition and ultimately improving the overall wellbeing of children and adolescents with ADHD.
- **Use standard, objective measures, such as validated clinical rating scales and patient perception tools, as measures of QOL in ADHD.**
 - Clinicians are recommended to use two or three validated rating scales that provide the interviewer with information on both the patient's core symptoms, QOL outcomes and the broader efficacy of medications.
 - These tools allow clinicians to gain an accurate picture of the patient's overall wellbeing in addition to core symptom presentation at different points throughout a child's life, thereby providing a basis for clinicians to build the most appropriate management strategy around the patient's needs. There is no 'one size fits all' approach.
- **Promote the formation of a widescale network to ensure an integrated approach to QOL in ADHD by clinical, educational, social, advocacy and government services.**
 - The current inconsistency in approach towards considering QOL in ADHD extends beyond the clinical setting. A joined up, multi-disciplinary approach will ultimately prove the most effective method of increasing long-term clinical and social outcomes for all children and adolescents with ADHD and their positive impact on society.

“Although conditions such as Dyslexia and Autistic Spectrum Disorders (ASD) are fully accepted, ADHD is the poor relation with regards to special needs education in the UK at this time.”

Fintan O'Regan, Behaviour Management Consultant

“Although therapy is generally assessed in terms of its effectiveness in controlling the core symptoms of ADHD, the ultimate goal should be to improve the long-term functioning of the child. Clinicians need to lead the way and set new standards in the management of ADHD.”

Professor Harry Zeitlin, Emeritus Professor of Child and Adolescent Psychiatry

“We must call upon other agencies charged with responsibilities for these children and young adults to play their part by learning more about how ADHD affects them and delivering services that take this into account. It is no longer good enough just to get by; these people are our adults of the future and they deserve a better chance in life.”

Phil Anderton, Former Senior Police Officer

“We need more support for parents and families with ADHD, at an emotional, social and an educational level.”

Andrea Bilbow, Founder and Director of ADDISS

9. Appendix 1: A Guide to Common Clinical Rating Scales

This guide has been developed to provide you with a quick reference guide to commonly used clinical rating scale in the UK. Please note that this list is not exhaustive and other rating scales are available.

| Date established | Measures | Age range | Time to complete | Rater | Number of items | Comments |
|---|--|---|--|---|---------------------------------------|--|
| 1. SCALES FOR ASSESSING ADHD | | | | | | |
| ADHD Rating Scale-IV⁴⁰ | | | | | | |
| 1998 | Initial diagnosis of ADHD and evaluating treatment outcomes | Children and adolescents aged 5-17 years | 5-10 minutes | <ul style="list-style-type: none"> Parent Teacher | 18 | <ul style="list-style-type: none"> Alternative to SNAP-IV Separate scoring profiles for females and males Home and school versions Require permission to reproduce |
| ADHD Symptom Rating Scale-IV⁴¹ | | | | | | |
| 2001 | Measures treatment outcomes | Children and adolescents aged 5-18 years | 15-20 minutes | <ul style="list-style-type: none"> Parent Teacher Self report | 56 | <ul style="list-style-type: none"> Good sensitivity to treatment effects Incorporates other DSM sources in addition to DSM-IV No collection of adolescent self-report data |
| Brown ADD Scales (BADDS)⁴⁰ | | | | | | |
| 1996, 2001 | Screening, assessment and monitoring of ADHD in all age groups | Children and adolescents aged 3-7 years, 8-12 years, 12-18 years and adults 18 years plus | 15-20 minutes | <ul style="list-style-type: none"> Parent Teacher | 40-50 | <ul style="list-style-type: none"> Measures go beyond hyperactivity Overall Brown "package" includes diagnostic forms and procedure |
| Conner's Parent Rating Scales – Revised⁴⁹ | | | | | | |
| 1998 | Assessment of problem behaviours by parents | Children and adolescents aged 3-17 years | Short version: 5-10 minutes Long version: 15-20 minutes | <ul style="list-style-type: none"> Parent Teacher Adolescent self-report | Short version: 27 Long version: 80 | <ul style="list-style-type: none"> Short and long versions Hand-scoring |
| SNAP-IV Rating Scale⁴⁰ | | | | | | |
| 1983 | Scale for diagnosing ADHD in children and screening a wide variety of other non-ADHD disorders | Children and adolescents | 30-40 minutes | <ul style="list-style-type: none"> Parent Teacher | 90 | <ul style="list-style-type: none"> Easy to use Used in epidemiological studies Includes items from the DSM-IV that may overlap with other disorders Lengthy completion |
| Vanderbilt ADHD Rating Scale (VARS)⁴¹ | | | | | | |
| 2003 | Newer DSM-IV based rating scales | Children aged 6-12 years | 10-15 minutes | <ul style="list-style-type: none"> Teacher (VADTRS) Parent (VADPRS) | 43 | <ul style="list-style-type: none"> Subscale to measure anxiety and depression Measures ODD and Conduct Disorder |

| Date established | Measures | Age range | Time to complete | Rater | Number of items | Advantages |
|---|--|---|------------------|--|-------------------------|--|
| 2. SCALES FOR MONITORING AND MANAGING ADHD AND MEASURING QOL | | | | | | |
| Child Health Questionnaire (CHQ) ⁴² | | | | | | |
| 1994 | Assessment of physical, emotional and social wellbeing | Children 5 years and above | 30-50mins | <ul style="list-style-type: none"> Parent (CHQ-PF50) Child (CHQ-CF87 aged 10 years+) | Parent: 50 Child: 87 | <ul style="list-style-type: none"> Generic measure of quality of life for use across different disease areas Measures both physical and psychological wellbeing |
| The Child Behaviour Checklist (CBCL) ⁴⁰ | | | | | | |
| 1991 | Broad screening instrument for a wide variety of disorders including ADHD | Children and adolescents 1.5-5 years and 6-18 years | 40-50 minutes | <ul style="list-style-type: none"> Parent Teacher Adolescent | 118, plus 2 open-ended | <ul style="list-style-type: none"> Very broad and not sensitive to change due to a 3-point scoring band Sensitive to patient's mood Lengthy completion |
| Child Health and Illness Profile (CHIP) ⁴³ | | | | | | |
| CHIP-AE 2000 CHIP CE 2001 | Measures the health of children from the parents' perspective | Children aged 6-11 years (CHIP-CE) and adolescents aged 11-17 (CHIP-AE) | 20 minutes | <ul style="list-style-type: none"> Parent | 76 | <ul style="list-style-type: none"> Provides holistic perspective of the child's health Very broad Does not specifically assess ADHD |
| Harter Self-Perception Profile for Children (HSPP) ⁴⁰ | | | | | | |
| 1985 | Questionnaire to evaluate self-esteem across 5 specific domains plus a global self-worth measure | Children aged 8-11 years | 15-20 minutes | <ul style="list-style-type: none"> Patient (teacher-child instrument only) | 36 | <ul style="list-style-type: none"> Easy to use Questions the child's self-perception Cannot be used in children below aged 8 years due to reading ability and concept of self-worth |

| Date established | Measures | Age range | Time to complete | Rater | Number of items | Advantages |
|--|---|--|------------------|---|-----------------|--|
| 3. OTHER SCALES | | | | | | |
| Dundee Difficult Times of the Day Scale (D-DTODS) ⁴⁴ | | | | | | |
| 2006 | Assessment of the typical day with ADHD, including potential times of difficulty | Children (not specified) | 5-10 minutes | <ul style="list-style-type: none"> • Clinician (completed with the parent or child together) | 10 | <ul style="list-style-type: none"> • Measures all times of the day • Quick completion • Offers opportunity to develop specific action plan for difficult times of the day |
| The Strengths and Difficulties Questionnaire (SDQ) ⁴⁷ | | | | | | |
| 1997 | Brief behavioural screening questionnaire for assessment and evaluation of treatment progress | Children and adolescents aged 4-16 years | 5-10 minutes | <ul style="list-style-type: none"> • Parent • Teacher • Adolescent | 25 | <ul style="list-style-type: none"> • Four subscales that can be totalled for an overall difficulties score • Easy to use • Focus on strengths as well as difficulties • Quick completion • Does not specifically rate ADHD symptoms |

cales

10. References

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