

HEALTH-RELATED QUALITY OF LIFE AS AN OUTCOME MEASURE FOR AUTISM INTERVENTION

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Abstract: Autism is a neurodevelopmental disorder affecting communication, socialization, and behaviour. There are many interventions for children with autism, such as behaviour management, communication intervention, diet modification, and sensory integration. While some clinical interventions are empirically based, many are not evidence-based. It is difficult to compare and evaluate treatment efficacy as different treatments have varying outcome measures. The objective of this paper is to propose the use of Health-Related Quality of Life (HRQOL) as an outcome measure for autism intervention. The paper outlines the relationship between autism and HRQOL, autism intervention and outcome measures, and why they use of HRQOL is an ideal outcome measure for any autism intervention.

Keywords: HRQOL, Autism & Outcome Measure

INTRODUCTION

Autism is a pervasive neurodevelopmental disorder (Volkmar, Rogers, Paul & Pelphrey, 2014). It affects many areas of a child's life, from the fundamentals of childhood such as playing and learning, to the core of life, such as socializing, understanding others and being understood. In some cases, it affects behaviour, attention, and results in a multitude of socially unacceptable characteristics (Lai, Lombardo & Baron-Cohen, 2014).

Intervention for children with autism is legislated in many countries, and are largely provided as part of the healthcare and educational system.

Private healthcare and education providers also provide autism intervention. There is a wide range of treatment available for autism; while many of these are supported by empirical data, non-evidence-based treatments are also still rampantly provided.

Outcome measures are an important indicator of the effectiveness of a particular treatment. Different treatments target different areas of development and as a result, have different outcome measures. Regardless of the intervention or the outcome measure used, there should be a way to measure the benefit of the intervention to the patient and the family, as well as the impact of the intervention on the patient's life.

From experience, unpublished data and personal communication with families of children with autism rarely have the real-life impact of intervention been measured or even investigated. For example, children attending speech therapy may achieve the goal of increasing their vocabulary and even their sentence length, but this does not necessarily mean that they are enjoying more conversations or having more friends.

What is needed may be a general outcome measure that measures how the intervention has affected the everyday functioning of the patient. HRQOL beautifully and quite succinctly measures aspects of daily life pertinent to children with ASD and would reflect the true benefit of intervention better than a compartmentalized outcome measure.

This article proposes the use of HRQOL as a universal outcome measure for autism intervention. We describe HRQOL, why it will be a useful outcome measure for children with autism, and how to best utilize it.

METHODOLOGY

A literature search was conducted to identify the concepts and uses of HRQOL, types of autism intervention, and the outcome measures utilized. Points are presented as to why HRQOL is a suitable outcome measure for autism intervention, as well as suggestions on how and when to utilise it.

RESULT

This section will explain the concepts of HRQOL and autism intervention, as well as how and why these two concepts merge.

HRQOL

Health-related quality of life (HRQOL) is the perception of the impact an illness/injury, medical treatment and/or health care policy has on one's life (Spieth & Harris, 1996). HRQOL, although specifically measuring health issues, is still multidimensional and includes physical, emotional, and social functioning. (Varni, Burwinkle, Seid & Skarr 2003). Where quality of life is broad and general, covering a wide range of a person's life, HRQOL is more focused and deals mainly with factors that are related to health, interventions, health care providers & the health care system they are in (Wilson & Cleary, 1995). While there are many models for HRQOL, the three major models that are most frequently used are Wilson and Cleary, Ferrans, or World Health Organization (WHO) (Bakas et al., 2012).

The Wilson and Cleary model (1995) is a conceptual model of health-related quality of life (HRQOL) that includes not only biological but psychological aspects of health outcomes. There are five different levels in this model, which comprise physiological factors, symptom status, functional health, general health perceptions, and overall quality of life. This model has been used with many populations, including individuals with chronic illnesses and disabilities.

The Ferrans model (2005) is a revision of the Wilson & Cleary model. While the basis remains similar, this model includes information on the causal relationships among the elements of the HRQOL model and taxonomy of the variables that often have been used to measure HRQOL. The World Health Organisation (WHO) in 1948 defined health as "a state of complete physical, mental, and social wellbeing, not merely the absence of disease or infirmity". The HRQOL is an ideal instrument to measure health, as it takes into consideration mental and social wellbeing as well.

Autism

History of Autism

Autism was first discovered by Kanner in 1943, and in 1944, a form of high functioning autism was identified by Asperger. When Kanner (1943) first described autism, he was only describing a small group of children, mostly his patients, who had somewhat similar characteristics. While this first group of children identified with autism was similar to each other,

their characteristics were starkly different from other typically different children. These children, although having high intelligence, had a strong preference for being alone and always insisted on keeping everything the same, which Kanner described as an “obsessive insistence on the preservation of sameness.”

Asperger (1944) added to Kanner’s description of individuals with autism, particularly what used to be termed as Asperger’s syndrome, after its founder. Asperger noted that these individuals were “deviant by their position, look, voice, and manner of speaking.” It is interesting to note that how an individual speaks was highlighted as one of the core characteristics of autism, even way back in 1944, in its early stages of introduction.

After the discovery and description of the characteristics of autism in the early 1940s, children with autistic features were frequently confused with childhood schizophrenia, especially in the 1960s (Baker, 2013). During the 1970s, this perception was finally cleared with distinctions made to separate autism from childhood schizophrenia (Hingtgen, Bryson & Gair, 1972) Autism was then recognized as a neurodevelopmental disorder. (Baker, 2013).

Advancements in the diagnosis of autism were made in the 1980s, with the development of the Childhood Autism Rating Scale (CARS) (Schopler, Reichler, DeVellis, & Daly, 1980). New criteria for autism was published in DSM III, officially distinguishing it from childhood schizophrenia (American Psychiatric Association APA, 1980).

Significant changes were recently made in the latest edition of the DSM 5, with only one category of autism spectrum disorder, rather than a few subcategories such as Asperger’s and Pervasive Developmental Disorder in DSM IV. Despite the changes, the core characteristic and definition of autism remains similar to when it was first described, with the DSM 5 highlighting impaired social communication and/or interaction and restricted and/or repetitive behaviours as the main categories of autism (APA, 2013).

Prevalence of Autism

The prevalence of ASD in Malaysia is approximately 1.6 in 1,000. (Family Health Division. Ministry of Health Malaysia, 2006). In the USA, the

overall prevalence of ASD is 14.7 per 1,000 (one in 68) children aged 8 years old. (Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators; Centers for Disease Control and Prevention, CDC 2014). The prevalence of ASD has increased markedly over the past two decades, rising from 2 per 10,000 in 1990 to between 1 in 50 and 1 in 88 children (Blumberg, et al., 2013; Centers for Disease Control and Prevention, 2012).

The actual number of children with autism may vary, due to the different diagnostic criteria and referral policies at various healthcare centres. The fact remains, however, that autism is a serious developmental disorder, and its impact on those affected is beyond statistics, affecting social interactions, school performance, and even family functioning.

Characteristics and Impact of Autism

Autism was first documented based on the core characteristics demonstrated by children affected by it. From its first appearance, throughout the multiple changes in diagnostic criteria, right up to current publications and clinical guidelines, the core characteristics of autism are defined as:

- Difficulty with social communication (APA, 2013)
- Restricted and repetitive behaviour (APA, 2013)
- Narrow interests (APA, 2013)
- Atypical language development (Lai, Lombardo, & Baron-Cohen, 2014)
- Inconsistent or atypical language abilities (Lai, Lombardo, & Baron-Cohen, 2014)
- Motor abnormalities (Lai, Lombardo, & Baron-Cohen, 2014)
- Excessive attention to detail (Lai, Lombardo, & Baron-Cohen, 2014)

The impact of autism on the affected child is poor relationships and school performance, often leading to other behavioural issues. There is also a substantial impact on families, with increased stress and financial and parenting burdens (Karst & Van Hecke, 2012; Kogan et al., 2008).

Children with autism have also been documented in lower HRQOL compared to the general population. Kuhlthau et al. (2010) and Kose et al. (2013) also found that children with autism demonstrated lower HRQOL compared to children with chronic medical conditions.

The lower HRQOL among children autism spectrum disorder (ASD) may be explained by the pervasive nature of the disorder. Children affected by autism have difficulties in social communication, social interaction, and having restricted and repetitive behaviour, interests, or activities (APA, 2013).

Observation in paediatric clinics, child psychiatry clinics, speech therapy, and occupational therapy clinics and waiting areas reveal children with autism displaying a wide range of behaviours as described in the literature and DSM 5. Children can be seen playing alone with objects such as strings or bottle covers. They may also be flapping their arms or doing other repetitive behaviours. They are often heard crying. Yet, there are those who seem to blend in very well, sitting quietly playing with electronic devices or having snacks.

This shows that there can be a wide range of behaviours among children with autism, as documented and observed in the clinical setting. The impact, then, will correspond to the level of functioning of each child.

Impact of Autism on Families

Upon receiving the diagnosis of autism for their children, many families feel a deep sense of loss and devastation (Mulligan, MacCulloch, Good, & Nicholas, 2012). Parents report increased levels of stress. In a survey of parents with autistic children in Canada, all of the participants reported wanting practical advice on how to apply what they learned from books or training programs to everyday living with their children (Murphy & Tierney, 2006). The majority of parents also stated that meeting other parents of children with ASDs who had or were experiencing similar difficulties was beneficial and that strategies should be put in place to facilitate this (Murphy & Tierney, 2006).

Intervention for Autism Spectrum Disorder

Many intervention options are currently available for the treatment of autism. In addition to mainstream therapy and medication, there are

countless claims of a ‘cure’ for autism through diet modification, alternative and complementary medicine, and a host of behaviour modification techniques. Not all intervention or treatment methods have been scientifically proven to be effective in treating autism.

Generally, intervention programs work towards improving core autism symptoms, such as language, communication, play skills, social skills, and behaviour. Some treatment approaches focus on reducing or controlling behaviour problems such as stereotypical behaviour, persistent or obsessive behaviour, or aggressive behaviour.

The most thoroughly researched and practiced intervention method is most likely to be Applied Behavioural Analysis (ABA). Schreck & Miller (2010) in a review article on treatment options for autism have documented that ABA is the most empirically validated treatment option for autism. ABA is a way of teaching and can be used to teach virtually any skill that can be broken down into components. ABA works by breaking down a skill into smaller components and teaching it, all the while providing reinforcement when each small skill is achieved. ABA is also an intensive program and part of its success lies in providing sufficient practice for a child to learn new skills and to retain those skills. ABA utilizes methods of behavioural psychology such as discrete trial and positive reinforcement to analyse information and behaviour.

ABA can be used to teach skills such as attention, sitting, language, social skills, and communication. The goal of a good quality ABA program is to help each child to achieve his maximum learning potential (Granpeesheh & Tarbox, 2014). Other treatment options include speech therapy, working on improving speech, language and communication skills, as well as occupational therapy, which works on attention, behaviour, play and cognitive skills.

The outcome measures utilized vary depending on the type of intervention. Many use scores on standardized assessments such as the Communication and Symbolic Behaviour Scales (Hilton & Seal 2007) and Children’s Communication Checklist (Mohammadzaheri, Koegel, Rezaee, & Rafiee, 2014). Some use general measures such as mean length of utterance (Mohammadzaheri, Koegel, Rezaee, & Rafiee, 2014) and behaviour reports by parents (Warren, Veenstra-VanderWeele & Stone 2011).

For insurance claim purposes, measurement of client progress is listed as one of the requirements (Behaviour analyst certification board guidelines for health insurance plan coverage, 2012). The inclusion of HRQOL will be an added benefit as it will make it easier for insurance companies to measure the outcome. There is also pharmacological intervention, typically used to address aggressive behaviour and hyperactivity among children with autism.

Incidentally, the first and currently only known study that utilized HRQOL as an additional outcome measure was a pharmacological trial. They found that the drug Aripiprazole, from the results of the clinical trial, had positively reduced irritability associated with autistic symptoms. The researchers then did a post hoc analysis to see the effect that the drug had on HRQOL, and it showed improvement as well (Varni et al. 2012).

DISCUSSION

Why use HRQOL as an outcome measure for autism intervention?

There are many reasons to support the use of HRQOL as an outcome measure for autism intervention. Based on the nature of autism, the expected outcome of the intervention, and the characteristics of the HRQOL measurements, it is indeed an ideal measure to use to assess if the intervention has been effective.

Firstly, the HRQOL measure is universal and can be used across languages and intervention. This is especially useful for speech therapy or language interventions. Many developing countries, including Malaysia, lack standardized language assessments, making assessment and progress monitoring difficult. The HRQOL has been translated into many languages including Malay and can be easily administered.

The HRQOL is typically measured via parent or individual/child reports where possible. Most instruments are short and can be quickly filled in by parents or children. This makes it a very cost-effective option. Most outcome measures are clinician-rated and administered. The views and perceptions of the patient or the family are rarely measured or sought throughout the treatment. Most HRQOL measures are self-reported or parent-reported, so the patient's point of view is measured, not just in

terms of medical personnel point of view. This is in line with patient-centred and family-centred practice.

The HRQOL measures very practical and functional areas, such as schooling and socialization. This is ultimately the aim of every intervention to generalize real-life situations. An excellent way to measure generalization is via the HRQOL, which assesses real-life gain from intervention.

As the healthcare industry moves towards evidence-based practice (EBP), all recommended intervention must have empirical evidence. Utilizing the HRQOL measures in addition to other outcome measures will help to enhance EBP with the added advantage of HRQOL empirical evidence.

CONCLUSION

There are many benefits of using the HRQOL as an outcome measure for autism intervention. It is recommended that clinical trials and other autism intervention programs should include pre and post-intervention HRQOL measures to provide more meaningful outcome measures.

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