

Quality of Life for People with Autism: Raising the Standard for Evaluating Successful Outcomes

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Quality of Life (QoL) is a critical measure of treatment outcome for people with mental and physical health concerns. However, little research has been conducted toward evaluating outcomes in autism by utilizing real-world measures, such as employability, self-sufficiency, and social support to gauge treatment success, despite longitudinal research that indicates poor outcomes for people with autism. Utilizing QoL indicators as the standard for developing treatments and evaluating outcomes in autism is advantageous. After a brief description of the domains and indicators comprising QoL, this paper reviews the literature describing the course of autism, followed by an examination of indicators which contribute to QoL for people with autism in particular. In conclusion, a model for utilizing QoL indicators to measure and evaluate outcome for people with autism will be proposed.

Keywords: Autism; quality of life; outcome; treatment

Introduction

Since the 1970s, Quality of Life (QoL) has been widely studied in an effort to improve outcomes by raising the standards for treating and managing many chronic disabilities and medical conditions (Gladis et al., 1999; Mulhern et al., 1990; McNary, Lehman, & O'Grady, 1997; Power et al., 1999). A PsycInfo search of 'Quality of Life' including all years yielded 15,859 hits ranging from QoL of people with eating disorders (de la Rie, Noordenbos, & van Furth, 2005), to language delays (van Agt et al., 2005), schizophrenia (Caron et al., 2005), depression and anxiety (Hansson, 2002).

Despite improvements in accurate diagnosis at increasingly earlier ages and proliferation of interventions, QoL research for people with autism is lacking. Limiting PsycInfo search parameters for QoL to 'autism' yielded only seven articles directly referring to the QoL of people with autism, none of which suggested utilising QoL as a measure of treatment success.

Indicators of Quality of Life

Although development of a conceptual model of QoL has been underway since 2002 (see Schalock et al., 2002 and Cummins, 2005), the field has not yet adopted a unified construct for its measurement. Ongoing debate includes which indicators constitute a satisfactory QoL, whether some indicators are more important than others, and whether there are certain indicators in specific populations that are more predictive of QoL.

While the broad domains that comprise QoL are generally agreed upon, research has indicated that for specific populations certain indicators may be more predictive of QoL. For example, de la Rie et al. (2005)

and Button (1990) found that self-esteem predicted QoL in adult and child eating disorder populations and Caron et al. (2005) found that two specific components of social support predicted QoL for people with schizophrenia. In their study of QoL in paediatric psychiatric populations, Bastiaansen et al. (2004) discovered that QoL indicators differentially impacted children according to diagnosis. Thus, while social support, satisfactory employment, fulfilling relationships and self-determination are good predictors of QoL in general, it will be important to tease out whether these or other aspects of these domains will predict QoL for children with autism, whether certain aspects of these domains are more predictive than others or whether there are other indicators that must be considered.

Quality of Life domains

There is some consistency in domains of QoL across child and adult populations. Generally agreed-upon domains of adult QoL are: interpersonal relationships, social inclusion, personal development, physical well-being, rights, environment, family, recreation and leisure, and safety/security (Verdugo et al., 2005). In the paediatric QoL literature, domains that have been studied include: physical functioning, emotional functioning, social functioning, and school functioning (Bastiaansen et al., 2004; Goodwin, Boggs, & Graham-Pole, 1994; Bastiaansen et al., 2004). Each domain can be broken down into indicators that are the actual factors measured. For example, social functioning can include indicators of the quality of friendships and the availability of social networks and social support. Emotional functioning may include self-esteem, happiness and mental health. A constant challenge for QoL research is to develop measures that tap the most

predictive indicators for specific populations, especially in paediatric populations, since it is an understudied group.

Subjective and objective aspects

Researchers generally agree that the concept of QoL is comprised of subjective and objective indicators (Summers et al., 2005; Caron et al., 2005; Hansson, 2002). Subjective indicators (also referred to as functional indicators) measure feelings of satisfaction with physical, emotional, and social functioning (Bastiaansen et al., 2004) or ideas of feeling satisfied with one's life, health, roles, self-esteem and vitality (Hansson, 2002). Objective indicators (also called structural indicators) include quantifiable aspects, such as the amount of social support in one's environment (Bastiaansen et al., 2004; Hansson, 2002). Using social support as an example, a subjective rating would tap the quality of friendships and their perceived ability to enhance one's life, while an objective rating would measure how many friends a respondent has. Bastiaansen et al. (2004) identified four dimensions of QoL in child populations (physical functioning, emotional functioning, social functioning, and school functioning) and described each in subjective and objective terms. This and other QoL studies indicate the necessity of measuring both aspects of QoL.

Longitudinal course of autism

In 1968, psychiatrist Leo Kanner presented a follow-up study of 11 patients on whom he first reported in 1943, a study that culminated in the first published description of the disorder 'infantile autism' (Kanner, 1971). He found that only two of his original patients enjoyed even a marginal satisfaction with life. Notably, these outcomes occurred without treatment for autism, as no treatments were available at the time. However, comparing Kanner's findings to the findings of more recent follow-up studies (see Howlin, 2003 and Shea, 2005), the outcome continues to look bleak for people with autism, despite the proliferation of treatments and interventions over the past 30 years.

In a landmark study, The National Autistic Society of Great Britain (Barnard et al., 2001) surveyed 450 adults with autism, including people at both the high (average range IQ and language development) and low (borderline range or lower IQ and impaired language development) ends of the autism spectrum, about their education, employment, living arrangements, and mental health. The survey concluded that only 3% at even the highest end of the spectrum lived fully independently and nearly half (49%) lived at home. Only 10% could manage tasks of daily living without assistance. Only 2% at the low end and 12% at the high end of the spectrum worked in full-time, paid jobs. Thirty-one percent of both high and low functioning adults had no social involvement outside of their family. Not surprisingly, 32% suffered poor mental health. Notably, since the time of Barnard et al.'s survey, the prevalence rate of autism in the United States has increased nearly 20% (Newschaffer, Falb, & Gurney, 2006). Given this surge in prevalence, predicting and improving outcomes for children with autism grows increasingly critical.

Although it is important to prepare children to achieve a satisfactory QoL in adulthood, it is also critical to view QoL in terms of a developmental framework and not merely as an end-goal. Thus, childhood QoL is a critical concept. A large scale study conducted by Seltzer and Krauss (2002) surveyed 405 individuals with autism, 62% of whom were adolescents. Of the total sample, only 22% socialised with non-family members and only 14% socialised with someone from school. Ninety-eight percent of the adolescents had difficulty making friends, a persistent problem affecting 95% of the adults in the sample. In terms of mental health, approximately 30% of adolescents were also diagnosed with ADHD or Obsessive-Compulsive Disorder.

Current autism outcome measures

Two commonly used outcome measures in the field of autism are cognitive functioning and academic achievement (see Boyd & Corley, 2001; Delprato, 2001; Gresham & MacMillan, 1997, 1998; Lovaas, 1987; Mayes & Calhoun, 2001; McEachin, Smith, & Lovaas, 1993; Smith, Groen, & Wynn, 2000). However, while scores on these standardised measures may show improvement, longitudinal research indicates that these do not predict improved QoL for people with autism. In their longitudinal study of 48 children diagnosed with autism, McGovern and Sigman (2005) found that it was not IQ that predicted better functioning, but the quality of emotional engagement with peers. Their study, among others, has neither supported the common assumption that IQ is related to good outcome nor that IQ is a predictor of QoL (McGovern & Sigman, 2005; Shea, 2005; Howlin, 2003; Szatmari et al., 2003; Sternberg et al., 1995; Rief & Turnbull, 2002). School placement (i.e. mainstreaming) and academic achievement have been used to measure outcome, but have not been supported in the literature as indicators of future functioning (Shea, 2005; Farrelly, 2001; Seltzer & Krauss, 2002).

Even in typically developing populations, IQ and academic achievement alone are not good predictors of QoL. For example, Sternberg et al. (1995) explain that predictors of school success are not predictive of success outside of school. They suggest that a real world quality of life criterion like employability, which is relatively unrelated to performance on standardised measures of cognitive performance or academic achievement (Sternberg et al., 1995), is more predictive of outcome. Kazdin and Weisz (1998) suggest that broad-based outcome assessment, including measures of 'real world' functioning, is a critical component in empirical validation of treatments for adolescents. However, very few autism treatment or outcome studies rely on these types of measures.

Autism and indicators of QoL

No studies to date have identified indicators predictive of QoL for children (or adults) with autism. To begin the process, it is helpful to look toward QoL studies of other paediatric samples. What follows is a review of several aspects of QoL that are possible predictors of QoL in autism.

Social support

Social support is highly predictive of QoL in non-autism populations (Caron et al., 2005; Helgeson, 2003; Brown & Brown, 2005; Pilisuk, 2001; Bramston, Chipuer, & Pretty, 2005). To discover whether and how measures of social support predict QoL in children with autism, it is important to consider how to best define and measure this construct. A linear definition may suppose that the amount of support is predictive of QoL. However, the stress-buffering theory of social support indicates that during times of stress it is not the amount of available support, but the quality of support that predicts QoL. Helgeson (2003) suggests that it is the functional aspect, or quality, of social support that serves to buffer life stress and enhance respect, belonging and self-esteem, indicators that are important to QoL.

Bauminger and Kasari's (2000) findings support a differentiation between the structural and functional aspects of social support. They found that it is not the number of friends but the quality of the friendships that are predictive of satisfaction or loneliness for children with autism. For children with autism, friendships lacking intimacy, reciprocity and emotional enrichment led to more intense and frequent loneliness compared to non-autistic peers, despite the common belief that children with autism prefer to be alone (Bauminger & Kasari, 2000). Thus, even if a child with autism might have a structural social network at school, the functional friendships – those resulting in invitations to birthday parties, sleep-overs, or games – may impact QoL more profoundly.

Current social skills training outcomes in autism highlight the importance of the structural-functional distinction. In their meta-analysis of social skills training (SST) for children, Gresham, Sugai and Horner (2001) found that weak effects of SST were due in part to flaws in how treatment success was assessed. By measuring social cognition, or the understanding of social rules, the viability of social training is overlooked. A measure of social cognition may show that a child knows social rules (structural) but does not indicate whether the child can use social rules to engage with peers (functional). These findings highlight the importance of including both subjective and objective (or structural and functional) measures when assessing outcomes and predicting QoL.

Academic success and preparation for satisfactory employment

Studies suggest that future employability may be a better predictor of QoL than academic achievement. While academic achievement is often assumed to predict QoL in child populations, it may not predict QoL in autism. Longitudinal outcome studies indicate that although some adults with autism completed basic education, and in some cases earned college degrees, their QoL remained low in terms of job satisfaction, independent living, self-determination and social support (see Farrelly, 2001; Seltzer & Krauss, 2002; Barnard et al., 2001). Mawhood and Howlin (1999) point out that although many children with autism successfully complete mainstream education, employment levels remain low in long term outcome, even when they have traits that employers find desirable (trustworthiness, punctuality, honesty, attention to detail). Often,

the social component of employment and adaptability to new work environments limit work satisfaction for people with autism.

Academic achievement as a predictor of QoL may have limited predictive value for other child populations as well. For example, studies have found that self-esteem may predict academic achievement, but not necessarily that academic achievement predicts success (see Heyman, 1990). A study of gifted children with high academic achievement found that their self-esteem remained low despite academic success (Pearson & Beer, 1990). It will be important to determine the role of academic success in childhood QoL since its impact on children remains unclear. While studies have focused on objective indicators, such as grades, promotion, attainment of a diploma, no studies of children with autism have tapped subjective indicators, such as happiness in school or self-esteem, or whether and how academic achievement predicts future employability or job satisfaction.

Satisfactory employment is a construct that predicts QoL for adults in general (Bastiaansen et al., 2004; Lindsay, 2002; Helgeson, 2003; Hansson, 2002; Frisch, Cornell, & Villanueva, 1992; Verdugo et al., 2005) and for autistic adults in particular (Garcia-Villamizar, Wehman, & Navarro, 2002; Ruef & Turnbull, 2002; Mawhood & Howlin, 1999). Meaningful, paid employment is a source of pride and meaning for people with and without autism, while lack of employment often leads to psychiatric problems such as anxiety or depression. Traits sought by employers, including motivation and enthusiasm, flexibility and adaptability, initiative and pro-activity, communication, and team working, (InCharge, 2003; The Conference Board of Canada, 2006), may provide a springboard toward developing predictors of QoL in autism. Because the germination of these skills and traits often begins during primary education, it may be helpful to include them in children's assessments of QoL, chiefly because of their impact on future QoL.

Family life

QoL pertains not only to the child with autism, but to the QoL of their parents and siblings. A child's own QoL depends heavily on the health and happiness of their family system. The disruptions to family life presented by a child with autism are significant and the negative effects on siblings and parents of meeting the needs of a disabled child are well documented (see Lobato, Kao, & Plante, 2005; Berge & Patterson, 2004; Pitman & Matthey, 2004; Sales, 2002; Mates, 1990; Piven et al., 1990; Freeman & Hagan, 1990).

Several potential predictive indicators of family QoL emerge in the literature. Sales (2003) notes that chronic illness, which places heavy caregiving demands and long-term dependency on caregivers, exacts the largest toll on family QoL. Caregiver burden can be categorised into five dimensions: disturbed family relations, financial costs, poor social performance, assistance in Activities of Daily Living, and problem behaviour of the patient (Maurin & Boyd, 1990). This model has been expanded to: patient economic dependence, disruption of routines, behavioural management, time and energy demands to negotiate health care system, negative interactions with service providers, financial cost of

illness, deprivation of other family member's needs, curtailed social activities, impaired relations with outside world, and inability to find satisfactory care settings (Lefly, 1996). These 10 dimensions are relevant to autism caregiver burden as the vast majority of those diagnosed with the disorder remain chronically impaired, requiring lifelong services and dependence on the family.

While caregiver burden appears to be an important predictor of family QoL, the psychosocial impact of the disorder on the family should not be overlooked. At the core of disability policy and practice is the tenet that disability impacts the entire family, that children are best served within the context of family life, and that when professionals work in partnership with family members the needs of the child are better met. Yet, little research has been conducted to determine the best way to address the needs of the family or to measure service effectiveness in terms of family outcomes in autistic populations.

The family should be recognised as an integral component of the treatment team and their needs must be considered equally with the needs of the child with autism. A predictor of parental stress or caregiver burden in response to a child's chronic illness may be 'life management' skills. Nota et al. (2003) studied the families of developmentally disabled or delayed children and found that parents' experience of well-being and adaptive coping were highly predictive of family QoL. Specifically, those parents who were able to develop adaptive coping strategies, maintain a positive outlook, reframe negative thoughts and feelings, balance roles and responsibilities, and identify and utilise resources were most likely to experience a satisfactory QoL. These parent characteristics, if assessed routinely, may be powerful treatment indicators and significant indicators and predictors of QoL for autism populations.

Self-determination

Included in this concept are control, choice, and personal autonomy. The level of self-determination predictive of well-being depends on both cultural and individual indicators and thus must be thoughtfully applied to any population. Cummins (2005) suggests that working within the concepts of primary and secondary control, based on the work of Rothbaum, Weisz and Samuel (1982), may extend the construct to a measurable, culturally and individually relevant predictor of QoL. While primary control is largely a Western concept that values one's influence over the environment to benefit personal well-being, its bias toward the fulfillment of individual versus group well-being makes it of little value in measuring the predictive value of self-determination in communal societies. Secondary control describes the adjustments made when primary control is not possible. It may also be more predictive of QoL in non-Western cultures than primary control, while in Western culture it has less predictive power in terms of QoL (Cummins, 2005).

Choice is critical to a measure of QoL (Brown & Brown, 2005; Cummins, 2005). Children's ability to become increasingly more independent of parents influences their development. As they grow older, their need to display competence, autonomy, and responsibility becomes stronger and leads to the development of

new discoveries and new ideas that are critical to continued healthy development. Children with autism tend to have few choices and opportunities for personal growth or self-management. They typically do not attend camp or after-school or extra-curricular activities, venues that provide opportunities for increased competence, independence, exploration and self-management. This lack of self-determination can foster low self-esteem, dissatisfaction with life roles and high incidence of depression in adolescence.

Self-determination, self-esteem, choice and opportunities for independence are widely accepted as indicators which, when present, enhance, and when absent, inhibit aspects of QoL for typically developing children (see McGrath & Power, 1990; Flink, Boggiano, & Barrett, 1990; Adleman & Taylor, 1990; Lishin, Bostanzhieva, & Provorova, 1990) and for special populations such as diabetic youth (Kuttner, Delamater, & Santiago, 1990), children with eating disorders (Button, 1990), academically gifted children (Pearson & Beer, 1990), children who are obese (O'Brien et al., 1990), intellectually disabled (Felce & Perry, 1996; Brown 1999) and learning disabled children (Heyman, 1990). However, there are no data to determine the effects of these indicators on the lives of children with autism.

Summary

This paper has highlighted the need for assessment of Quality of Life outcomes for people with autism beginning in childhood. Despite advances in early detection, intensive intervention and therapeutic approaches, QoL for children with autism remains poor, with a majority having little or no social support, meaningful relationships, future employment opportunities or self-determination. Few studies have utilised specific QoL indicators in order to evaluate treatment outcomes for children with autism, leaving this area of study largely untapped.

Both medical and mental health outcome research has been increasingly informed by QoL outcomes over the past 30 years. In a recent paper, Weisz et al. (2005) call for an evidence-based treatment approach to promoting youth mental health; one that relies on clarifying the conditions under which programmes fail or succeed and testing interventions in real-world contexts. However, to date, there has been little empirical support of programmes for autism in terms of real-world, evidence-based, and QoL contexts. Rather, many autism programmes remain focused on utilising measures of success that lack predictive validity and salience to real-world contexts (e.g. IQ score, academic success). Future efforts to develop real-world predictors of success (employability, participating in the least restrictive and most stimulating academic environment, self-determination, social support and meaningful relationships) would be of considerable benefit to autism outcomes.

In designing a measure of QoL in autism, it is helpful to look toward the general QoL literature in determining which indicators to measure, such as subjective versus objective or structural versus functional elements, and to look toward QoL studies within specific populations to develop a predictive model. While viable templates

exist from other childhood disorders, issues unique to autism should be considered.

In predicting QoL outcomes in autism, age-appropriate measures should be developed that are autism-specific, multidimensional and clinically useful. Studies have shown differences in QoL predictors across populations (see Nota et al., 2003), thus it will be critical to develop a measure with sufficient sensitivity for indicators specific to autism. This paper has suggested several possible indicators of QoL for children with autism including social support, academic functioning and/or satisfactory employment, family life, and self-determination. There is a need for future research to determine if these are indeed most predictive of QoL for an autism population and whether other indicators might be discovered. As there is a great deal of heterogeneity in level of disability and symptoms in the general autism population, future studies should also explore whether the same QoL indicators predictive in a 'higher functioning' population would also predict QoL in a 'lower functioning' population of children with autism.

Several considerations should be taken into account when designing an age-appropriate measure. Very young children and non-verbal children may lack the ability to accurately report on their well-being or comprehend the meaning of items. Some children with autism may have difficulty identifying or discriminating between feeling states. A possible solution is the use of multiple reporters, an approach that has previously proved successful (see Goodwin et al., 1994) to gain an accurate assessment of a child's QoL. Studies utilising multiple informants suggest that children tend to report more on subjective indicators (i.e. emotions) and parents tend to report more on objective indicators (observable behaviours). Measures utilising multiple informants may more accurately capture the full experience of a child's overall well-being.

In addition to age-appropriateness and population-specificity, multidimensionality will allow the measure to tap the broad range of indicators that might contribute to QoL. It is unlikely that one domain alone would predict QoL. Rather, a constellation of domains and indicators are likely to influence the level of satisfaction a child feels with life. For example, a child may enjoy a high level of satisfaction with family life but a low level of satisfaction with school. Thus, the child's overall QoL may be mitigated by either one of these, which, taken alone, may not accurately portray the level of overall subjective well-being.

Lastly, an autism QoL measure must demonstrate clinical utility. The measure should be easy to use and interpret and must above all inform and influence treatment. With biomedical, psychological, educational, occupational, and sensory treatments, among many others, becoming more widely available, it will be important that a QoL measure provide a roadmap for families and clinicians to determine the best course of intervention while maintaining an acceptable QoL for the child and his or her family.

With over one million children diagnosed with autism world-wide, and the prevalence rates showing an increasing trend, it is important to focus treatments toward ensuring a satisfactory QoL for children with autism. The trend in medical research and treatment

for the past 30 years has been toward assessing QoL to determine 'successful' outcomes and to guide the evolution of better interventions. It is time now for autism research and treatment to close the gap between itself and the standard of treatment that has been utilised in medicine for over three decades.

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