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Quality of life as a mediator between behavioral challenges and autistic traits for adults with intellectual disabilities

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ABSTRACT

A multiple mediation model was proposed to integrate core concepts of challenging behaviors with autistic traits to increase understanding of their relationship to quality of life (QoL). It was hypothesized that QoL is a possible mediator between the severity of challenging behaviors and autistic traits in adults with intellectual disability. These constructs are of vital importance because they are essential variables for people with autism, and obviously they influence their psychosocial development. Participants were 70 adults with autism spectrum disorders (ASD) and moderate intellectual disabilities (ID). Results indicated that several dimensions of QoL mediated the relationships between autistic traits and challenging behaviors. The dimensions of QoL, Satisfaction, Competence/Productivity, and Autonomy/Independence are mediators between autistic traits and challenging behaviors. Implications of these data are discussed.

1. Introduction

Autism spectrum disorders (ASD) and intellectual disabilities (ID) often co-occur at high rates with the relationship between the two disorders being enigmatic (Matson & Shoemaker, 2009). With the increase in life expectancy in occidental societies, the concern for promoting a positive quality of life (QoL) for adults who have both ASD and ID is growing (Billstedt, Gillberg, & Gillberg, 2011; Cappe, Wolff, Bobet, & Adrien, 2011; Cottenceau et al., 2012; Garcia-Villamisar & Dattilo, 2010; Gerber et al., 2011; Kamio, Inada, & Koyama, 2013; Mahan & Kozlowski, 2011; Sheldrick, Neger, Shipman, & Perrin, 2012).

Although educational and cognitive-behavioral programs are now accepted in most advanced countries as important to helping adults with ASD and ID improve their QoL (Gerber et al., 2011; Thorn, Bamburg, & Pittman, 2007), there is little research addressing co-morbid psychopathology associated with adults with ASD and ID (Kearney & Healy, 2011; Totsika, Felce, Kerr, & Hastings, 2010). However, some research has examined implications of challenging behaviors since these types of behaviors negatively impact a wide range of life domains (e.g., leisure, vocational, social) that influence QoL for people with ASD and ID (Hastings, 2002).

There are a variety of co-morbid psychopathologies that exist with adults who have both an ASD and an ID. These adults have higher vulnerability for developing psychiatric disorders and behavioral challenges than those individuals who do not

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have both of these disabling conditions (Ghaziuddin, 2005). More specifically, these individuals are at risk for behavior problems such as self-injurious actions, stereotyped movements, and aggressive/destructive behaviors, and other psychiatric conditions (Einfeld & Aman, 1995; Matson, Fodstad, & Rivet, 2009a; Matson, Rivet, Fodstad, Dempsey, & Boisjoli, 2009b; Smith & Matson, 2010; Tenneij, Didden, Stolker, & Koot, 2009).

Although behavioral challenges are not pathognomonic symptoms of individuals with ASD and ID, several studies have demonstrated that approximately 13–30% of people with ASD and ID demonstrate some type of challenging behavior (Sturmey, Laud, Cooper, Matson, & Fodstad, 2010). As a result of these behavioral challenges and potential risk of injury, some adults reside in public or private residential facilities (Gerber et al., 2011; Rojahn & Meier, 2009; Rojahn & Tasse, 1996; Totsika et al., 2010). Such behavioral challenges often negatively influence the QoL of these individuals (Gerber, Baud, Giroud, & Carminati, 2008; Totsika et al., 2010).

Since the early 1970s, interest in the concept of QoL has increased significantly, both in research and clinical practice and it has been increasingly applied to people with ASD (Billstedt et al., 2011: Cappe et al., 2011; Cottenceau et al., 2012; Gerber et al., 2011; Kamp-Becker, Schroder, Remschmidt, & Bachmann, 2010; Plimley, 2007; Shipman, Sheldrick, & Perrin, 2011; Totsika et al., 2010). QoL has emerged as an important parameter for evaluating the outcomes of health care and associated services (Moons, Budts, & De Geest, 2006), particularly for people with ASD (Johnson, Frenn, Feetham, & Simpson, 2011; Kamp-Becker et al., 2010; Kuhlthau et al., 2010; Moons et al., 2006)

In the present study we explored the relationship between the level of QoL in a group of adults with ID and ASD and the severity of behavioral challenges. Our aim was to determine if these behavioral challenges were mediated by QoL over time. We hypothesized that a possible link exists between reduction in the severity of behavior problems and increase in QoL.

2. Method

2.1. Participants

Participants included 70 adults between 18 and 43 years ($M = 26.60$; SD = 10.01) with ID and ASD. The average of Leiter Test was 53.39 (SD = 9.94). Participants were recruited from a facility for people with ASD located in Las Rozas, a residential community of Madrid, Spain and other institutions for people with ID. All participants were diagnosed with an ID and ASD by a psychiatrist or clinical psychologist with several years of diagnostic experience with people who have both an ID and ASD. Participants were screened to exclude co-morbid severe psychiatric illness (e.g., schizophrenia, anxiety, major depression) and neurological disorders that might influence brain functioning (e.g., epilepsy). The ethics commission of the Nuevo Horizonte Association reviewed and approved this study. An explanation of the study was given to participants, their tutors, and their families before the study was initiated. All participants or their guardians provided informed consent. Individuals for whom we could not obtain consent were excluded from the study.

2.2. Measures

2.2.1. Leiter International Performance Scale (LIPS)

The LIPS (Leiter, 1980) is a non-verbal intelligence test designed for people between 2 and 18 years age, although it can be applied to all ages. No speech is required from the examiner or participant. The tasks are self-explanatory and, after an initial demonstration, the examiner does not need to interact with the subject. The LIPS is useful for testing people with ASD. The LIPS was scored according to the method outlined in the manual and was derived and adjusted as recommended by Leiter (1980).

2.2.2. Autism spectrum disorders–diagnosis for adults (ASD-DA)

The ASD-DA (Matson & Rivet, 2007) is an instrument aimed at diagnosing ID adults with ASD and contains 31 items which are scored as either "0" for "not different, no impairment" or "1" for "different, some impairment." The test can be administered in approximately 10 min. The ASD-DA has adequate inter-rater and test–retest reliabilities. Internal consistency was excellent (Cronbach's $\alpha = .94$), and factor analysis produced a three factor solution that mirrors the three classes of core symptoms outlined in the DSM-IV-TR (i.e., impairment in socialization, communication, and restricted behavior) (Matson, Gonzalez, Wilkins, & Rivet, 2008; Matson, Wilkins, Boisjoli, & Smith, 2008). Belva, Matson, Hattier, Kozlowski, and Bamburg (2012) investigated the validity of the ASD-DA when compared with the Pervasive Developmental Disorder/Autism subscale of the Diagnostic Assessment for the Severely Handicapped-II (DASH-II; Matson, Gardner, Coe, & Sovner, 1991). The total scores and subscale scores of the ASD-DA correlated at the $p < .001$ level with PDD/Autism subscale scores on the DASH-II. These findings suggest that the ASD-DA is a valid measure for assessing autistic symptoms in adults with IDs.

2.2.3. The autism spectrum disorders–behavior problems for adults (ASD-BPA)

The ASD-BPA was planned as an informant-based behavioral screener and is the only assessment instrument developed to specifically measure challenging behaviors of adults with ASD (Matson & Rivet, 2007, 2008). The measure is comprised of 19 items rated on a Likert-type scale corresponding to different challenging behaviors commonly showed by adults with ASD. Initial psychometrics for the scale estimated that the ASD-BPA has internal reliability ranges from .43 to .83 for all subscales, average test–retest reliability approaches .60, and average inter-rater reliability is .43 (Matson & Rivet, 2008).