Concept Analysis: Quality of Life for Adults with Autism

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Abstract

The identification and description of quality of life (QOL) as a health standard is a societal viewpoint which has taken precedence in the measurement of outcomes as they pertain to health, well-being, and life satisfaction. The unique qualities of autism warrant a study of QOL that is specific to the adult with autism spectrum disorder (ASD). Definitions of QOL from various perspectives and literature are provided, followed by a thorough review of the literature for the past ten years to identify and describe the concept of QOL for adults with autism. A total of 67 articles are used to develop a modified Walker and Avant (2005) approach to chronicle the antecedents, attributes, consequences, and contextual considerations of this concept in the literature. Corresponding measurement tools are evaluated for efficacy to the concept. The findings and their implications with respect to healthcare, autism treatments, advocacy, resources, stigma, and acceptance are discussed.

Keywords: autism spectrum disorder, quality of life, adult, outcomes, measurement

Concept Analysis: Quality of Life for Adults with Autism

Quality of life (QOL) is a societal viewpoint that has emerged within the past 40 years (Verdugo, Navas, Gómez, & Schalock, 2012). In 2006, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) outlined the most recent rules and conditions to achieve optimal QOL for people with disabilities (Verdugo et al., 2012). Identification, measurement, and how to utilize QOL to affect positive change for the adult with autism spectrum disorder (ASD) has since been studied in-depth. Autism affects one out of every 100 adults in the United States, and 40% of these cases are yet unidentified (Lewis, 2018). Regardless of higher (Asperger's type) or lower (Kanner's type) spectrum, gaps in healthcare exist for these patients (Durand, 2014; Lewis, 2018). When the multidimensional needs of a person have been optimally met, QOL is achieved and a person has opportunity to pursue enrichment and activities beyond those of Maslow's hierarchy of needs (Jonsson et al., 2017; Verdugo et al., 2012).

The definition of QOL is encompassing, requiring the same factors or relationships for all people within the identified group (Verdugo et al., 2012). There are individual subjective and objective components to QOL for an adult with ASD, as well as physiologic, environmental, political, and rights-based considerations (Cuesta Gómez, Casado Muñoz, & Lezcano Barbero, 2010; Verdugo et al., 2012). Adults with ASD have high rates of comorbidities and polypharmacy, requiring medical management and self-care practices (Dijkhuis, Ziermans, Van Rijn, Staal, & Swaab, 2017; Eaves & Ho, 2008; Lewis, 2018; Sterling, Dawson, Estes, & Greenson, 2008). The nature of this disorder produces a lack of self-advocacy, compounding cost and disability (Cashin, Buckley, Trollor, & Lennox, 2018; Leigh & Du, 2015; Sterling et al., 2008). Understanding the unique QOL concept for adults with autism helps the healthcare provider build trust with and collaborate for optimal patient outcomes, a right granted to other members of society (Verdugo et al., 2012). Measuring QOL is now an integral component of determining the efficacy of healthcare-related treatments for adults with ASD (Lin, 2014). The aim of this analysis is to clarify and outline the full meaning of the concept QOL of adults with autism, identifying differences from generic QOL with important considerations to the uniqueness of the autism spectrum.

Background

Synonyms in literature for QOL include a subjective wellbeing (Kapp, 2018; Robeyns, 2016), objective quality of life (Kapp, 2018), health status (Cuesta Gómez et al., 2010; Eiser & Morse, 2001), and outcomes in terms of health (Eaves & Ho, 2008; Pfeiffer, Piller, Giazzoni-Fialko, & Chainani, 2017). The Cambridge Dictionary defines QOL as the extent to which a life is satisfying, comfortable, or enjoyable (McIntosh, 2011). In everyday language, quality of life is a household term to denote personal goodness and satisfaction, and economists and marketing groups use the term (generally on a scale) to define or create an overall feeling or to label a specific factor of life (i.e., wealth) (IESE Insight, 2013). Many people view QOL as a fluid, personal interpretation of life satisfaction which accounts for cultural values, and it is also described as well-being in that QOL is more than the absence of illness (IESE Insight, 2013).

In literature, conceptualization and measurement of QOL have taken two historical perspectives. An older perspective is based on external conditions, including epidemiologic considerations such as education, living situations, and health measures using statistical analyses (Cuesta Gómez et al., 2010; Henninger & Taylor, 2013). For instance, medical health was a strong QOL focus, and institutionalization used to be a poor marker (outcome) of QOL for people with ASD (Eiser & Morse, 2001; Henninger & Taylor, 2013). Outcomes were often reported as poor when indicators such as IQ, expressive language development, or psychiatric comorbidities were used to determine QOL (Kamio, Inada, & Koyama, 2012). The newer approach uses trends and subjective data gathering, measuring overall life satisfaction from an internal perspective (Robeyns, 2016). The focus of older QOL studies reflected a bias towards normalization and identification of deficits (Lam, 2018). Newer focus reflects acknowledgement and respect for neurodiversity, appreciating autistic differences (Donaldson, Krejcha, & McMillin, 2017).

Currently, QOL measures are used by providers to assess efficacy of treatment or baseline status of overall health and happiness (Brown, Schalock, & Brown, 2009). Psychosocial development is influenced by QOL constructs, making these indicators essential to a thorough history and assessment of the patient with ASD (García-Villamisar, Dattilo, & Matson, 2013). A conceptual foundation for QOL with emphasis on capability and with an approach from the point of view of the autistic individual is vital to assessing and intervening on behalf of the person with ASD (Robeyns, 2016).

Methods

To understand the concept of QOL for adults with ASD, a literature review was performed in January of 2019. The Cochrane Database of Systematic Reviews, MEDLINE, CINAHL, and PsycINFO were searched systematically for the following keywords: concept, qualitative, or perspective, and autism/autistic, ASD, or Asperger’s, and quality of life or well-being. The terms child, parent, and sibling were excluded. Articles were included if the work was published between 2009 and 2019 in any language, if it was available in full text or a book chapter; dissertations were also acceptable. Articles were excluded if published exclusively about sibling, parent, caregiver, or children’s QOL, if they were expert opinion, if they were not about ASD, if they were case studies on an individual, or if they were historical perspective only. Anything related to autism causation, genetic testing, counseling, animal research, and intellectual disability (ID)-only research was excluded. Any results featuring ID as a component of the population had to include ASD as a majority portion.

Findings

The literature search returned 212 results. Those results were analyzed manually for exclusion criteria. The total number of relevant search results was narrowed to 58 articles. These articles were reviewed for citations and further inclusion, increasing the relevant results to 67 articles. Adult ages were identified as age 18 and older, with one article allowing for ages 15 and up. See Appendix A for the search schema.

A total of 28 articles identified antecedents to the concept, 32 articles identified attributes, 20 articles identified consequences, and 17 articles identified issues of contextual importance. There was significant overlap due to the multifactorial nature of QOL, creating a circular pattern of cause and effect. Three of the articles identified antecedents, attributes, and consequences each (Kapp, 2018; Kidney, 2016; Teti, Cheak-Zamora, Lolli, & Maurer-Batjer, 2016). Context was identified solely by eight articles and overlapped with the three branches of concept in nine of the others, for a total of 17 articles. A limited number of articles provided an all-encompassing picture of QOL (Cuesta Gómez et al., 2010; Kamp-Becker, Schröder, Remschmidt, & Bachmann, 2010; Knüppel, Jakobsen, Lauritsen, & Telléus, 2018; Lin, 2014; Verdugo et al., 2012). See Appendix B for the relationship patterns between these features in terms of the numbers of articles that identified each aspect of the concept.

A modified Walker and Avant (2005) analysis method was used, excluding model, borderline, contrary, and empirical referent cases. Hupcey and Pendrod (2005) described this process as qualitative and quantitative.

Defining attributes are those characteristics of a concept which, although present in unique circumstances of literature, appear over and over (Walker & Avant, 2005). Clustering attributes is a method of allowing broad concept insight. According to Walker and Avant (2005), antecedents are those events or factors which predate or are required ingredients to creation of the concept's attributes. Consequences are those events which occur as a result, and they can be positive, negative, or neutral (Walker & Avant, 2005).

The defining attributes of QOL for the adult with ASD are multifactorial and fall under factors and domains in literature. Multiple literature sources on QOL in autism accepted the QOL domains for ID as outlined by Verdugo et al. (2012) as basis for the analysis of QOL for adults with autism, and for measurement purposes (Knüppel et al., 2018; Schalock, Verdugo, Gómez, & Reinders, 2016). These domains have been validated culturally and empirically and are not limited to only the field of developmental disability (van Hecke et al., 2017). The first factor of QOL is independence, under which the domains personal development and self-determination exist (Verdugo et al., 2012). The second factor is social, under which come interpersonal relationships, social inclusion and participation, and rights. The third factor is well-being, which contains the domains emotional wellbeing, physical wellbeing, and material wellbeing. All 32 of the articles which named various attributes for QOL in adults with ASD could be categorized under these subheadings with varied nuance, emphasis, or unique perspective.

Antecedents

Antecedents are those things that must be present prior to the concept for its existence. The literature search returned 28 articles which identified various antecedents to QOL for adults with autism. These antecedents were categorized into eight areas.

Identity. Hong, Bishop-Fitzpatrick, Smith, Greenberg, and Mailick (2016) and Rodgers et al. (2018) foremost identified personality traits as an antecedent to QOL. Self-concept, self-perception, self-understanding, and self-determination all fell under the heading of identity as necessary to the formation of a subjective QOL for the autistic adult (Bertilsson, Gyllensten, Opheim, Gard, & Sjödahl, 2018; Kidney, 2016; Rodgers et al., 2018; White, Flanagan, & Nadig, 2018). Literature supports that childhood development and establishment of the self-concept differs greatly for the autistic child versus the neurotypical (NT) child (Attwood, 2015; Durand, 2014; Rodgers et al., 2018). These literature sources tested and proved that personality traits and perception of self are precursors to and mediate a relationship with QOL for the adult with autism. The concept of self is strongly correlated with many indices of emotional well-being.

Social determinants. Social determinants include ability and participation in public or societal affairs. This antecedent is an area that strongly blends into QOL attribute domains, strengthening the idea that for this concept, the antecedent-attribute-consequence triangle is a feedback loop unto itself. The presence of a social network, friends, and/or an informal support network is necessary for QOL to develop (Bauminger-Zviely & Kimhi, 2017; Saldaña et al., 2009; Tobin, Drager, & Richardson, 2014). Tobin et al. (2014) also postulated that formal support group membership and participation in social skills groups were precursors to QOL. In a similar fashion, Jariwala-Parikh (2016) and Pfeiffer et al. (2017) identified social supports and Kapp (2018) identified social environments as determinants of QOL. Palisano et al. (2017) further explained that the availability of a social environment was insufficient; interaction with that environment is a prerequisite to QOL for the adult with ASD. Kidney (2016) explored online involvement, which falls in this category but is not explicitly required for QOL. Carr (2015) and Lin (2014) more generically stated social involvement was precedent, and Kamio et al. (2012) and Rigles (2019) showed that family involvement – both the person with their family, and the family with the autistic individual – were necessary precursors to QOL. In an indirect way, communication apprehension and perceived competence at social skills influenced QOL and should be taken under consideration, as these are characteristic of most people with autism (Siew, Mazzucchelli, Rooney, & Girdler, 2017).

Negative experiences or adaptations. A universal theme for people with autism is that of feeling different from others and having experienced adversity in childhood that could be described as ostracism, bullying, oppression, and/or being misunderstood (Attwood, 2015; Durand, 2014). These experiences play a critical role as antecedent to QOL as they perpetually affect the emotional well-being domain. Hong et al. (2016), Kamio et al. (2012), and Rigles (2019) studied adverse experiences and bullying as antecedent to QOL, while Milton (2016) described oppression and marginalization. Pfeiffer et al. (2017) wrote about the impact of misconceptions by others. Jariwala-Parikh (2016) studied maladaptive coping mechanisms, which was further deliberated by Hull et al. (2017) who noted the coping mechanism of social camouflaging and its impact on both the path to diagnosis and on long-term outcomes. Pre-existing maladaptation and feelings which come under this category include depression, loneliness, and social anxiety according to Reed, Giles, Gavin, Carter, and Osborne (2016), as did perceived stress according to Hong et al. (2016).

Resources. Chiang and Wineman (2014), Lin (2014), and Saldaña et al. (2009) identified community resources as antecedent to QOL. Pfeiffer et al. (2017) supplemented this discourse in discussion of social supports, available interventions, and advocacy. These are essential to QOL development and are evidenced in the ongoing search for resources by parents of autistic children, the stories of moving from state to state to find the best geographical location with interventions for autism, and the constant fight for advocacy by autism groups (Durand, 2014). Historically, this has been one of the greatest QOL antecedents and has gained support and recognition as necessary for good QOL outcomes.

Neurodiversity. Neurodiversity is an emerging concept in psychiatric fields that states neurologic differences can and should be respected, celebrated, and find a place in society instead of being viewed as errant (Donaldson et al., 2017). Under this unique heading falls communication preferences according to Kidney (2016) and autonomy according to Carr (2015). The scored IQ (verbal, performance, and/or total) of the autistic adult is antecedent to the concept and will play a part in the subjective self-report of many QOL domains (Deserno, Borsboom, Begeer, & Geurts, 2017; Kamp-Becker et al., 2010). Carr (2015) and Jariwala-Parikh (2016) described functional independence as an aspect of neurodiversity, and Carr (2015) and Pfeiffer et al. (2017) explained how communication ability is altered by neurodiversity and modifies QOL perception. Neurodiversity is an integral part of what makes autism unique and its acknowledgement is necessary prior to measuring QOL for adults with autism.

Autism qualities. Specific qualities of autism are antecedent to QOL for adults with ASD because those QOL domains reflect the distinctive needs and rights of the autistic individual. The special interests of an individual with ASD are precursor to QOL according to Teti et al. (2016). Cascio (2015) studied how the autism quality of rigidity predated or predicted QOL scoring. Kamio et al. (2012) determined the age of the first use of speech to be influential on both QOL and outcomes. Autism severity was the most-discussed characteristic influencing

QOL, with a variety of findings; Kamio et al. (2012) and Saldaña et al. (2009) found severity of autism not to be associated with QOL, whereas Chiang and Wineman (2014), Jariwala-Parikh (2016), and Kamp-Becker et al. (2010) found it to be significantly associated with lower QOL. Behavioral problems and aggression were shown to be associated with lower QOL and are both antecedent and predictive of lower QOL (Chiang & Wineman, 2014; Kamio et al., 2012).

Health condition. Various health metrics and comorbidities were studied in relation to their antecedent connections to QOL. The presence of comorbidities in general was noted to impact QOL for adults with ASD by three studies (Hong et al., 2016; Kamio et al., 2012; Lin, 2014). Hong et al. (2016) found that male gender positively impacted QOL and that women reported lower QOL. Lin (2014) found that drinking habits also played a role in the development of QOL perceptions and well-being outcomes.

Environment. Daily living situations and environments were found to be an antecedent, attribute, and consequence of QOL, speaking to the cyclical and sometimes transient nature of QOL. Deserno et al. (2017) found the daily activity level of the individual to impact QOL, and Hong et al. (2016) and Kamp-Becker et al. (2010) described independence level as a QOL precursor. Lin (2014) found transportation ability or access was a necessary consideration. Home life – both the living arrangement and the general environment of housing – was identified to be a feature preceding QOL (Deserno et al., 2017; Palisano et al., 2017). For those individuals with greater autism severity, residential status and housing placement by a caregiver or others was found to impact QOL (Chiang & Wineman, 2014; Kamp-Becker et al., 2010). Lin (2014) detailed a feeling of financial security and the freedom to not perceive oneself as a financial burden to others as antecedent to QOL. Employment and the acquisition of skills was therefore considered and found to be both an important antecedent and QOL attribute-indicator (Carr, 2015; Kamp-Becker et al., 2010; Lin, 2014; Pfeiffer et al., 2017). Hayakawa, Okada, Nomura, Tsukada, and Nakamura (2015) found the psychosocial job characteristics of adults with autism to be imperative for QOL development, a finding also written extensively about by the autism expert Attwood (2015). Katz, Dejak, and Gal (2015) explored the concept of work performance as inseparable from QOL antecedent, providing further insight to the recurrent and cyclical theme of QOL. Academic success and education level were studied and found to be requisite to QOL (Carr, 2015; Kamp-Becker et al., 2010, Lin, 2014).

As evidenced by these literature findings, several authors differed on whether an antecedent affected an attribute. For instance, Hong et al. (2016) found that male gender affected QOL, but Lin (2014) found it did not. Carr (2015) found that disability and education level did not contribute to QOL, whereas many other sources indicated that those factors did influence QOL. Thus, a chicken-or-egg argument could be presented for several of these antecedents, and discrepancy exists among sources.

Attributes

Thirty-two articles identified attributes of QOL of adults with autism. These characteristics are clustered according to domains by Verdugo et al. (2012) and are further described by indicators, which are evidence of the QOL when realized tangibly. See Appendix C for the blending of relationships between antecedents, attributes, and consequences, with an outline of factors and their subdomains.

Independence. The first attribute of independence, under which fall the domains personal development and self-determination, is related to the fundamental freedom of an individual (Ayres et al., 2018; Cuesta Gómez et al., 2010; Verdugo et al., 2012). Personal development entails the educational status, personal skills, and adaptive behaviors of the adult with ASD (Cuesta Gómez et al., 2010; Gómez, Arias, Verdugo, Tassé, & Brown, 2015; Knüppel et al., 2018; Verdugo et al., 2012). An important indicator of this QOL function is capacity development for individual interests and the promotion of advancement of personal characteristics (Cuesta Gómez et al., 2010). Self-determination is subjective and involves autonomy, ability to make one's own decisions, and having personal goals (Cuesta Gómez et al., 2010; Kapp, 2018; Kidney, 2016; Knüppel et al., 2018; Rearick, 2016; Verdugo et al., 2012; White et al., 2018). This is exhibited when people with ASD receive individualized training adapted to their behaviors and interests (Cuesta Gómez et al., 2010). Evidence of self-determination is seen when the adult with ASD performs life-planning and exercises control over his or her life when making choices, forming decisions, and setting personal goals (Cuesta Gómez et al., 2010; Verdugo et al., 2012).

Autonomy and independence were identified as key components to self-determination (Eaves & Ho, 2008; García-Villamisar et al., 2013; Verdugo et al., 2012). The objective component of adaptive functioning was identified by Eaves and Ho (2008), Henninger and Taylor (2013), Saldaña et al. (2009), and Verdugo et al. (2012). Under this subheading falls independent living (Kapp, 2018), living arrangements (Henninger & Taylor, 2013), and adaptive behavior (Saldaña et al., 2009).

Literature that supports these domains demonstrates that the indicators of independence are participation in leisure activities, activities of daily living (ADLs), and performance of self-care (Connell, O'Cathain, & Brazier, 2014; Eaves & Ho, 2008; Verdugo et al., 2012). Competence at tasks and productivity were further indicators of this domain (Cuesta Gómez et al., 2010; García-Villamisar et al., 2013).

Social. The social attribute encompasses interpersonal relations, social inclusion, and human rights (Ayres et al., 2018; Cuesta Gómez et al., 2010; Knüppel et al., 2018; Verdugo et al., 2012). The domain of interpersonal relations encompasses interpersonal relationships, including close friendships and the presence of social networks (Cuesta Gómez et al., 2010; Knüppel et al., 2018; Verdugo et al., 2012). Romantic relationships fall into this category according to Connell et al. (2014) and Rearick (2016). A sense of belonging is also identified as a QOL indicator (Connell et al., 2014). Indications of QOL in these areas are seen when meaningful social relationships are promoted for the adult with ASD (Cuesta Gómez et al., 2010).

The subdomain of social inclusion is presented with appreciable nuance in the literature (Verdugo et al., 2012). A synonym for inclusion is participation (Cuesta Gómez et al., 2010; Knüppel et al., 2018). Deserno et al. (2017) described social satisfaction and contribution as the feeling that a person can contribute to the social facet of society. Social networks are a QOL attribute which are split into three groups by Saldaña et al. (2009): people who help with caregiving, people who provide support emotionally, and people who participate in leisure with the individual. Van der Laan, Euser, and van Balkom (2015) described relational autonomy as an acting out of one's own desires to determine which relationships are initiated, an important distinction considering that therapy methods for adults with ASD can include a push towards increasing and improving social skills which may be desirable but anxiety-inducing for the ASD individual (Durand, 2014). Communication, or the ability to communicate and engage in social interaction, is another component of the social domain which is vital to this concept (Rearick, 2016; Robeyns, 2016). The desire for this is varied when considering the vast spectrum nature of autism; no two people with similar spectrum score levels are alike in either their presentation or their desire for communication (Durand, 2014).

The most-studied QOL topic under the social domain is that of relationships in terms of family, friends, and animals (Eaves & Ho, 2008; Henninger & Taylor, 2013; Hong et al., 2016; Kamio et al., 2012; Kamp-Becker et al., 2010; Lam, 2018; Lin, 2014; Mazurek, 2014; Pisula, Danielewicz, Kawa, Pisula, & Kawa, 2015; Saldaña et al., 2009). Having any one of these types of relationships is important to most adults with ASD, but autistic traits can inhibit their development (Pisula et al., 2015). Hong et al. (2016) showed that regarding social relationships, self-report by the autistic adult was higher versus maternal report, indicating mothers under-rated the social QOL of an adult child with ASD. Relationships with pets and animals has been identified as an important QOL attribute for people with ASD, and they are also a source of coping, which blends into other QOL domains (Lam, 2018). Indicators of high QOL include community involvement and inclusion (Cuesta Gómez et al., 2010; Verdugo et al., 2012). This merges into a consideration for human and legal rights which support the inclusion of people with disabilities and special needs (Verdugo et al., 2012).

Human and legal rights are the third subdomain of the social factor which span many other aspects of QOL domains (Cuesta Gómez et al., 2010; Knüppel et al., 2018; Verdugo et al., 2012). These include the ability to be understood by others (interpretation) according to Robeyns (2016) and the availability of services that facilitate adults with ASD to partake in all areas of life, including education, work, recreation, religion, and pursuit of life satisfaction according to Cuesta Gómez et al. (2010), Eaves and Ho (2008), and Rearick (2016). Robeyns (2016) further identified the right to proper care for lower-spectrum individuals. Jones (2017) discussed academic retention as a factor of QOL, and Billstedt, Gillberg, and Gillberg (2011) identified the availability of a structured education as vital to QOL for ASD adults.

Indicators that rights are being attained include human respect and dignity (Cuesta Gómez et al., 2010; Verdugo et al., 2012). Verdugo et al. (2012) further labelled equality, legal access, and due process as vital components of this objective QOL marker. Cuesta Gómez et al. (2010) stated that an indicator of rights is the guarantee of physical safety, which integrates into the physical well-being structured under the third and last attribute.

Well-being. Well-being is the third major attribute, under which falls emotional, physical, and material well-being (Ayres et al., 2018; Connell et al., 2014; Verdugo et al., 2012). Cuesta Gómez et al. (2010) described this as “quality referred to the person” (p. 120). Connell et al. (2014) further distinguished the absence of ill-being.

Emotional well-being is described by many literature sources as paramount to QOL in adults with ASD (Cuesta Gómez et al., 2010; Knüppel et al., 2018; Rearick, 2016; Teti et al., 2016; Verdugo et al., 2012). This is further differentiated into parallel similitudes with variations on this subject matter. Hong et al. (2016), Kamio et al. (2012), Kamp-Becker et al. (2010), and Pisula et al. (2015) described psychological well-being, whereas Jones (2017) overtly applied the term mental health to this theme. Lin (2014) evaluated the impact of psychiatric comorbidities on the QOL of adults with ASD, and vice versa, determining that diagnoses such as anxiety, depression, and obsessive-compulsive disorder were strongly associated with lower QOL self-scores. Kamio et al. (2012) and Kamp-Becker et al. (2010) augmented these same findings. Four studies evaluated coping as an integral component of QOL, which is an area that bleeds into the consequences of the QOL concept (Krämer, Gawronski, & Vogeley, 2016; Pisula et al., 2015; Teti et al., 2016; van der Laan et al., 2015).

Billstedt et al. (2011) and García-Villamisar and Dattilo (2011) placed leisure, an activity discussed under the social factor, in this domain, whereas Verdugo et al. (2012) placed leisure under the domain of physical well-being. This supports the recognition of leisure as an integral component of QOL for the autistic adult. This is further supported by literature from renown experts in autism on the qualities that define ASD (Attwood, 2015; Durand, 2014). These authors, the International Statistical Classification of Disease and Related Problems (ICD-10), and the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) identify this as special interests, a required component of an autism diagnosis. Leisure and recreation ties into the ability to participate in hobbies and activities of special interests.

Specific feelings that accompany emotional well-being are explored by numerous sources. Cuesta Gómez et al. (2010), García-Villamisar et al. (2013), and Mazurek (2014) described life satisfaction as an emotion or feeling which is subjectively and qualitatively explored and identified. Cuesta Gómez et al. (2010) expanded on the importance of aspiring and expecting, whereas Bonis (2012) and Verdugo et al. (2012) emphasized contentment. Lin (2014) identified perceived happiness as a feeling indicating emotional well-being. Self-perception was evaluated by Connell et al. (2014), and Johnson and Joshi (2016) and McDonald (2017) emphasized the importance of self-esteem on QOL. Johnson and Joshi (2016) also explored the influence of perceived discrimination as a feeling which comprises emotional well-being.

The indicators of emotional well-being include the presence of a positive promotional environment and emotional stability within the individual (Cuesta Gómez et al., 2010). The establishment and support of individualized programs which are developed for behavioral interventions are markers of this domain (Billstedt et al., 2011; Cuesta Gómez et al., 2010). Cuesta Gómez et al. (2010) expanded on this topic to state that people with ASD and their concerned support parties should be given preference in the planning, execution, and evaluation of individual development plans, with support for individualized attention to each case.

Physical well-being, often described as self-rated physical health, is another domain of QOL (Connell et al., 2014; Cuesta Gómez et al., 2010; Hong et al., 2016; Kamp-Becker et al., 2010; Knüppel et al., 2018; Lin, 2014; Pisula et al., 2015; Rearick, 2016; Saldaña et al., 2009; Verdugo et al., 2012). Physical safety is manifested once again (Cuesta Gómez et al., 2010; Rearick, 2016). With respect to a key feature of autism, Robeyns (2016) identified the absence of sensory overload as an essential component of physical well-being, as literature and self-report by autistic individuals shows that sensory overload manifests as physical discomfort and even pain (Attwood, 2015; Durand, 2014). Billstedt et al. (2011) placed excellent staff-and-caregiver knowledge of autism in this domain, which is further synthesized into human rights, a prior category.

Indicators of physical well-being are many-fold and include good health and nutrition according to Verdugo et al. (2012). Cuesta Gómez et al. (2010) wrote that healthcare program availability and correct administration of pharmacologic treatments are markers of this domain. Like emotional well-being, individualized interventions are displayed in this arena, as well as hygiene, safety, and individualized preventive health measures (Cuesta Gómez et al., 2010).

The last domain of well-being is material or welfare (Cuesta Gómez et al., 2010; Gómez et al., 2015; Knüppel et al., 2018; Verdugo et al., 2012). Kapp (2018) identified employment in this domain, and Billstedt et al. (2011) further described QOL to include employment at level of capacity, indicating the autistic adult finds QOL working at their maximum ability. Living in an environment with access to services and transportation was reinforced under this domain, as these are considered assets or means to attain or increase wealth (Cuesta Gómez et al., 2010; Hong et al., 2016; Kamp-Becker et al., 2010; Pisula et al., 2015).

Material well-being as a QOL domain is established when the financial status, housing status, or possessions of a person are evident or satisfactory (Verdugo et al., 2012). Verdugo et al. (2012) also placed security into this domain. Cuesta Gómez et al. (2010) described a respect for privacy as integral to material well-being and defended the promotion and respect for personal belongings as a criterion for this domain.

Consequences

Consequences are those attributes which come about as a direct result of the concept. When QOL exists there are positive, negative, and neutral consequences that should be considered. Consequences can be measured as outcomes, reviewed for changes in legal policies, or used to re-define the original problem. The literature showed that positive consequences outweighed negative consequences. Twenty articles identified consequences of QOL for adults with autism, and four categories emerged from this review.

Community. Verdugo et al. (2012) determined community involvement to be a direct result of QOL. Lam (2018) described engagement as consequential and reciprocal. Shochet et al. (2016) and Lam (2018) wrote about the concept of connection, or an inter-relatedness between adults with autism and others. In and of themselves, these community concepts are a neutral outcome of QOL, except when community involvement establishes or improves public view and understanding of autism.

Positive consequences of self. Many articles identified positive consequences which were found after QOL was determined or improved via various measures. Kapp (2018) and Lawson (2016) found acceptance to be an important consequence, although Kapp argued against normalization as a form of acceptance and argued for acceptance of diversity. Kapp (2018) and Ripamonti (2016) considered the growth of the neurodiversity movement to be a positive consequence of adult autism QOL, and further pinpointed reclaimed identity as a positive consequence of self. Teti et al. (2016) found that the autistic individual could perform reframing, a mental exercise that used QOL to express or perceive oneself differently and more positively with a new self-concept viewpoint. Bottema-Beutel, Park, and Kim (2018) found authenticity to be a QOL result, which was similarly described by Lam (2018) as self-expression. Other attributes found to grow out of QOL included resilience (Shochet et al., 2015; Szatmari et al., 2016), pride (Teti et al., 2016), hope (Connell et al., 2014), and personal growth (Lam, 2018). Robeyns (2016) pointed to the increased achievement levels, improved overall functioning, and self-capability that is developed after QOL, and Toor, Hanley and Hebron (2016) named higher education as a secondary consequence of both QOL and other positive QOL repercussions.

Negative consequences of self. Establishment and identification of QOL is not without its bleaker outcomes. These are acknowledged to be sequela resulting from malevolent antecedents or poor QOL reports in specific areas, and are divided into three areas: internalized, externalized, and compensatory.

Negative internalized consequences include emotions and feelings which require further work on the part of the adult with autism and their partnering healthcare providers. These include anxiety, which is a common pre-existing comorbidity of autism (Attwood, 2015; Durand, 2014; Maloret & Scott, 2018; Robertson et al., 2018). Mazurek (2014) identified loneliness as consequence, whereas Hull et al. (2017) noted exhaustion to be an outcome of both having and working towards QOL without a support network. Hull et al. (2017) also noted the need for time to recharge or freedom to be oneself lest the individual experience social exhaustion. Connell et al. (2014) identified hopelessness, a negative view of the future. This consequence is directly related to finding meaning and purpose and to partaking in leisure that the individual finds fulfilling.

External negative consequences were defined as stigma, which was further deliberated by five articles (Bottema-Beutel et al., 2018; Johnson & Joshi, 2016; Kidney, 2016; McDonald, 2017; Szatmari et al., 2016). As awareness of autism grows, and the person with autism engages more in society and activities he or she enjoys, stigma and ignorance are likely to be uncovered and directed towards the autistic adult, which influences employment and social opportunities (Durand, 2014).

The final negative consequence category is compensations. Hull et al. (2017) wrote about the masking that autistic people perform. Hull et al. (2017) defined masking as creating the correct facial expressions as anticipated or expected by society in a given situation and for which contributes to exhaustion. Compensation is the neutralization or offset of acting or becoming a way a person is expected to act in exchange for being oneself, and cyclically contributes to lower QOL. Social camouflaging is another form of masking and requires elaborate and immense effort on the part of the autistic individual (Durand, 2014; Hull et al., 2017). Hull et al. (2017) described this as “putting on my best normal” (p. 2517). This is spurred by a desire to fit in but threatens self-perception and self-acceptance.

Public consequences. Public and organizational consequences were identified by Schalock and Alonso (2013) and span all forms of ID. These QOL consequences include the emergence of provisional services by government and business systems. These prompt the development of evidence-based practices and quality improvements in systems, and encourage evaluation of outcomes for specific individuals, such as those with autism (Schalock & Alonso, 2013). These consequences lead to the redefining and renaming of conditions and services that they may receive reduced stigma and greater clarity. For instance, in 2013 the DSM-5 changed autism criteria and removed Asperger's type autism from the definition based on these consequences to provide therapies and funding more fully to all individuals on the spectrum (Attwood, 2015; Durand, 2014).

Contextual Considerations

Seventeen articles discussed contextual considerations to QOL for adults with autism alongside the QOL concept. The first consideration is parental perspectives and comparisons of differences between QOL reports between a parent and adult child (Hong et al., 2016; Knüppel et al., 2018), or from other family members' perspectives, including siblings (Cuesta Gómez et al., 2010). The results vary; for certain domains a family member will overestimate or underestimate the QOL of the autistic individual. Cuesta Gómez et al. (2010) identified the autism professional's perspective; as part of QOL development, the healthcare professional must have excellent understanding of QOL in respect to autism and should participate in team-based interventions. The professional must also have a certain level of satisfaction in their work to continue providing quality therapy to an individual with autism (Cuesta Gómez et al., 2010).

Hwang, Foley and Trollor (2017) described aging well and identified this as a different concept tangential to QOL for the adult with autism. Having autism did not explicitly hinder aging well, but other QOL domains did impact the perception of growing old (Hwang et al., 2017).

Sexuality, apart from the realm of relational domains, was studied by Barnett and Maticka-Tyndale (2015) with the implication that stigma associated with autism results in less sex education and more risky activities leading to poorer health outcomes. One finding indicated some benefit to camouflaging sexual behaviors to fit into stereotyped norms in such a way that sexualized behavior would not be construed as harassment or encroach on topics such as illegal stalking (Barnett & Maticka-Tyndale, 2015). Unintentionally inappropriate sexual or stalking behaviors have been studied and documented among autistic adults by Attwood (2015) and Durand (2014). This finding opposes the view that autistic qualities should be normalized and accepted (Kapp, 2018). Sexual well-being was studied by Byers, Nichols, Voyer, and Reilly (2013), indicating that less autism severity and male gender was associated with greater satisfaction and that sexual satisfaction was an important component to emotional well-being, and reiterated that sexual knowledge was deficit. Pearlman-Avnion, Cohen, and Eldan (2017) found that sexual well-being could be likened to a consequence of QOL with respects to improved social inclusion.

Johnson and Joshi (2016) and Rearick (2016) discussed the concept of workplace well-being as consequential of emotional well-being; they found that stigma associated with ID in the workplace triggered threat and reduced QOL, and these findings were influenced by age of diagnosis. Earlier age of diagnosis was positively associated with lower perceived discrimination upon disclosure of ASD to an employer (Johnson & Joshi, 2016).

Academic success and retention in school was studied in-depth by several articles (Jones, 2017; Siew et al., 2017; Toor et al., 2016; van Hees, Moyson, & Roeyers, 2015). Quality of life directly impacts and is directly impacted by academics and the support of a given school. Hume et al. (2018) and Jones (2017) discussed the context of academic transitions, a noted challenge for autistic individuals as they age from adolescents into independent adults and high-schoolers into collegiate learners.

De Jaegher (2013) enacted an approach to autism with sense-making based on the unique sensory experiences of the autistic individual and applied this to a QOL outcome. This spoke to the antecedent of autism qualities and studied the difficulties of applying antecedents and experiences as neurotypicals understand the world to match those experiences felt by the atypical autistic mind.

Van der Laan et al. (2015) emphasized the role that a culture or value system has on QOL and its domains. The studies pulled from literature spanned the globe and multiple languages, publishing from Taiwan, Japan, Australia, Spain, Germany, England, Central America, and the United States. Although these cultures favor certain domains or values over others, an acceptance of core domains and factors of QOL for adults with autism appear to be universally accepted. The outcome measurements for these domains should be compared to those in the geographic locale for the use of improving interventions and outcomes that are valued by the adult with ASD within their societal context (van der Laan et al., 2015).

Measurement

A vast range of measurements for QOL exist; some are untested on ASD populations and others are meant to measure environments or are from a parent or caregiver perspective (Ayres et al., 2018; Knüppel et al., 2018; van Heijst & Geurts, 2015). This literature review identified four validated measurement tools for QOL of the adult with autism: the Integral Scale by Verdugo et al. (2012), the Quality Indicators Guide by Cuesta Gómez et al. (2010), the INICO-FEAPS Scale by Knüppel et al. (2018), and the World Health Organization (WHO) QOL-BREF by Ayres et al. (2018), Jariwala-Parikh (2016), Kamio et al. (2012), and Pisula et al. (2015). Although commonly used and validated, WHOQOL-BREF domains are negatively predicted by the existence of comorbidities which are common among adults with ASD, and in some instances, the questions have been reported as difficult for autistic individuals to answer (McConachie et al., 2017).

To the purpose of measuring the 8-domain model, the Integral Scale by Verdugo et al. (2012) was deemed comprehensive. According to Verdugo et al. (2012), this tool was built from articles of the UNCRPD and was later tested for validity by Gómez, Arias, Verdugo, and Navas (2012) on ASD populations. Integral was developed on the previously described three factors and eight domains of attributes and has been proven valid and reliable by multiple sources. The variables include independence, social, well-being, personal development, self-determination, interpersonal relations, participation, rights, emotional well-being, physical well-being, and material well-being. Delivery method is via survey, and the levels of measurement are in nominal and ordinal variables. The Integral Scale has a reliability coefficient of 0.98 and a real person reliability of 0.89. The Integral Scale's validity was determined using classical test theory foremost, followed by self-organizing maps, generative topographic mapping, and non-metric multidimensional scaling. Its Cronbach's alpha coefficient is ($\alpha = .89$). See Appendix D for the full Integral Scale survey.

Discussion

Schippers and Van Hove (2017) discussed three stages for the use of QOL. These are identified as input, throughout, and output. Schippers and Van Hove (2017) emphasized the focus on the output, or outcomes and consequences. These consequences are the phenomena that demonstrate the occurrence of QOL. Study of the QOL concept brings about many considerations in the preparation to improve QOL, discovery and acceptance of QOL domains, and the outcomes which come full circle to influence or create new antecedents. See Appendix C for these relationships.

Healthcare Considerations

Focusing on unmet needs rather than enhancing met needs to the maximum should be a priority for healthcare providers. Family physicians play a pivotal role in augmenting the autistic adolescent's transition to adulthood (Ally et al., 2018). Some of the most important uses for acknowledging and measuring QOL are to identify and support autistic people reporting depression, loneliness, and social anxiety, because these are indicators of the lowest reported QOL that are manageable health conditions (Eaves & Ho, 2008). The practitioner or healthcare provider in any environment can use this information to enhance awareness of the cyclical nature of QOL and understand that health and therefore well-being develop continuously throughout life (Palisano et al., 2017). The development of patient-centered outcomes should focus on these outcomes as identified by QOL study and their indicators (McDougall et al., 2018). Jariwala-Parikh (2016) showed that healthcare costs could be minimized through use of an appropriate QOL measurement tool with interventions built to fit needs, not stereotypes. Furthermore, stereotypes in healthcare lead to negligence in assessment and preventive education (Barnett & Maticka-Tyndale, 2015). Kamio et al. (2012) found that early diagnosis and maternal support favored higher QOL, a children's healthcare metric which influences adult QOL outcomes.

Treatment Advances

These findings suggest that professionals' use of cognitive behavioral therapy (CBT) in psychotherapy would benefit from understanding of QOL from the autistic adult's perspective. Lewis (2018) stated both the increased need for and difficulty in finding access to adult therapists who understand autism. The training of professionals and the development of social-communication skills would be enhanced through improved perspective-taking (Krämer et al., 2016). Acknowledgement that coping skills influence QOL and vice versa points to a need for improved practitioner training in teaching this life skill to adults with autism (Krämer et al., 2016). One consideration for both children and adults is that therapy which addresses aggression and behavioral problems may have a significant impact on QOL (Chiang & Wineman, 2014; Kamio et al., 2012).

Social Supports

The literature shows that social support is a primary factor in the maintenance of health-related QOL, both in the home and in structured work environments (Hayakawa et al., 2015). Increased job control and governance and increased scrutiny were associated with increased stress and lower work-related QOL (Hayakawa et al., 2015). In all literature addressing the social attribute, social deficits were noted to greatly impact QOL negatively (Lin, 2014). Therefore, facilitation of and support for social functioning would have the greatest impact. Cuesta Gómez et al. (2010) argued for enhanced social networks and increased availability of resources for lifetime services and support. Models which consider a resource as an end to themselves should be evaluated in terms of QOL for the individual and replaced with those that define and effect change that displays positive and improved results for the intended target, the adult with autism (Cuesta Gómez et al., 2010).

Acceptance

In the pursuit of improving the lives of adults with autism, it should be noted that improvements in QOL as perceived by those individuals may be discordant or uncomfortable for improvements felt needed by the public or the healthcare practitioner. Lam (2018) wrote passionately for a change from deficit-focused thinking and normalization to a more accepting approach of appreciating diversity and neurodiversity. Ripamonti (2016) also stimulated discussion on this topic, emphasizing acceptance over asking the adult with autism to camouflage and mask their true nature. Rather than centering attention on the social skills deficits or disability, Robeyns (2016) aimed to focus on capability. Hull et al. (2017) explained that to increase QOL for this population, acceptance and even encouragement of true self expression should be implemented in all areas – work, home, school, and healthcare.

Future Research & Limitations

The use of QOL as an indicator or outcome for pharmacologic research is lacking (Bertelli et al., 2013). Use of language, autism severity, and IQ level as antecedents have significant impact on QOL reports but remain resistant to intervention, suggesting more research funding should be funneled towards those outcomes that are amenable to change (Henninger & Taylor, 2013). Some autism organizations encourage the use of finances to improve family QOL and outcomes rather than to study causation in a push for true acceptance of ASD (Autistic Self Advocacy Network, 2019).

The heterogeneity of autism is the major factor that prompts such diversity of QOL indicators (Robeyns, 2016). Via literature review, this influenced diverse and sometimes opposing findings. These findings are largely by self-report of the autistic adult, although in some instances a caregiver or parental report was used either for comparison with or replacement of self-report in instances where autism severity was high, and the autistic individual was unable to complete a questionnaire. Subjective QOL would be of limited use in those cases due to poor communication and socialization in response to certain questions (Saldaña et al., 2009). This gives prominence to the need for family resources, who constitute a great proportion of first-hand caregivers for adults with severe forms of autism. Some QOL indicators were based on questions and surveys which required either parental or personal recall of distant memory; thus, memory bias and time passage may have influenced the results of some antecedents, such as childhood bullying, age of first use of language, or age of first diagnosis (Kamio et al., 2012). Healthcare providers and researchers alike need to understand that QOL for adults with autism has unique features requiring specialty measurement and intervention focus to improve the QOL and overall life trajectory outcomes of their autistic patients.

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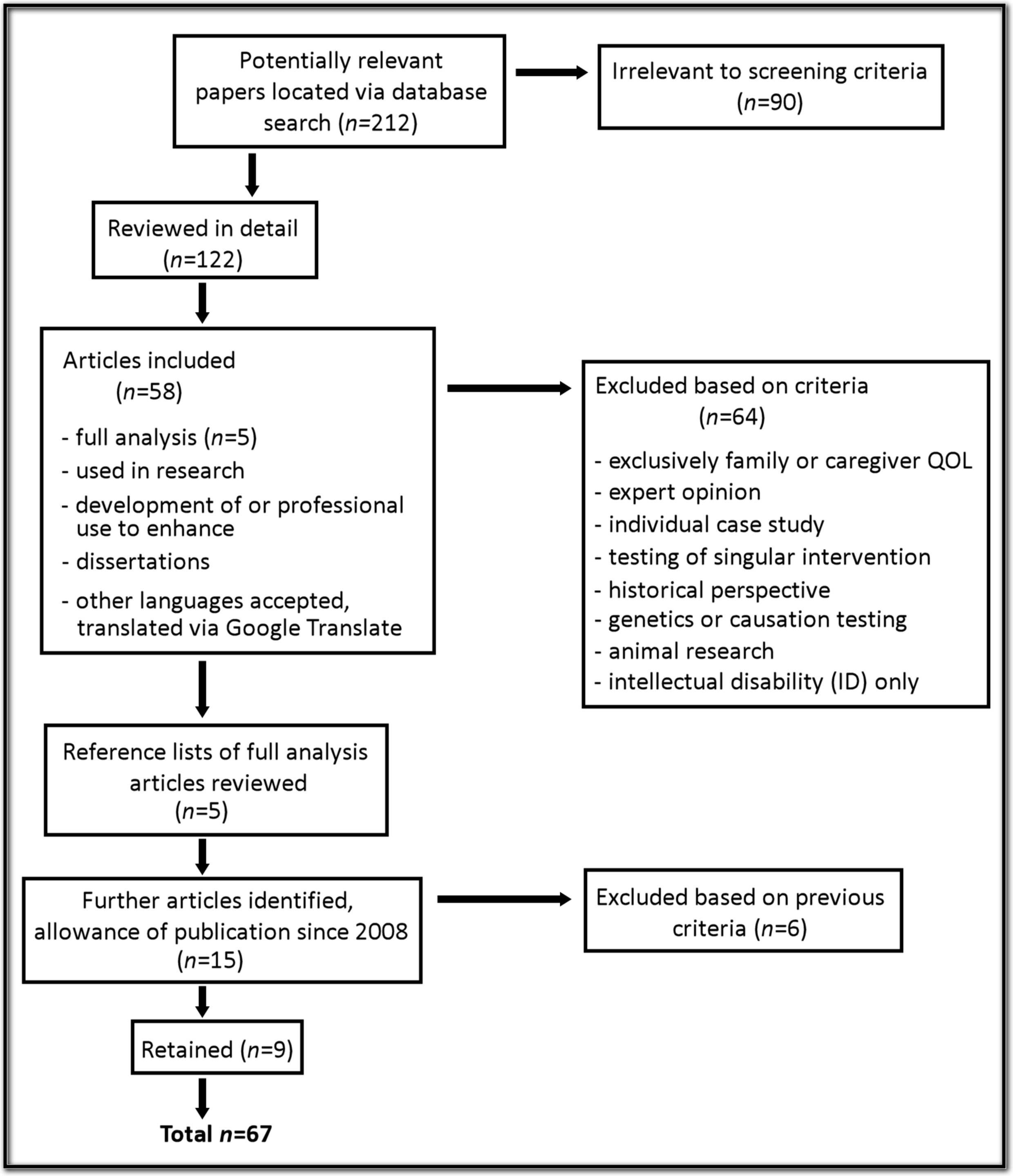
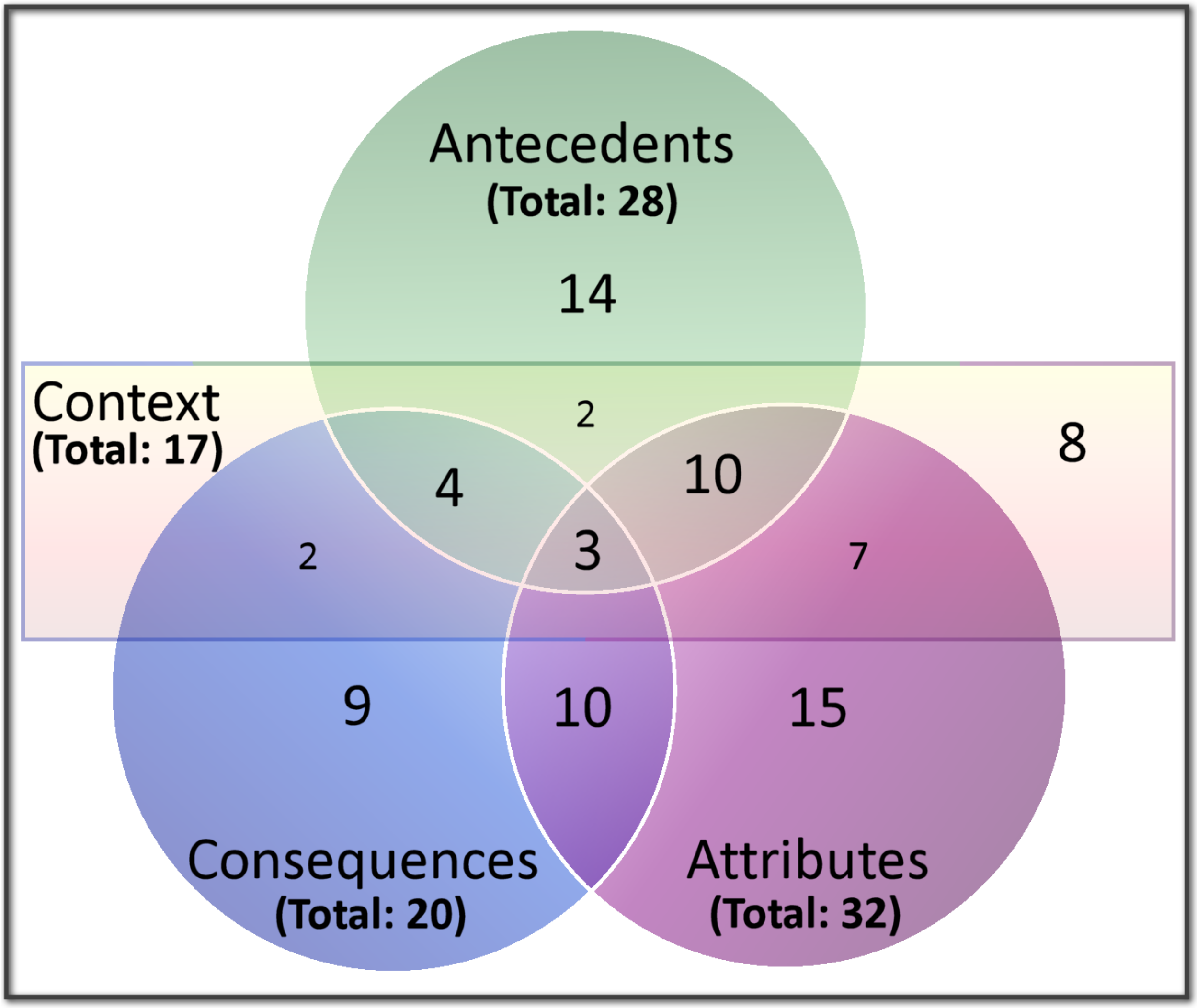
Appendix A

Schema of article selection



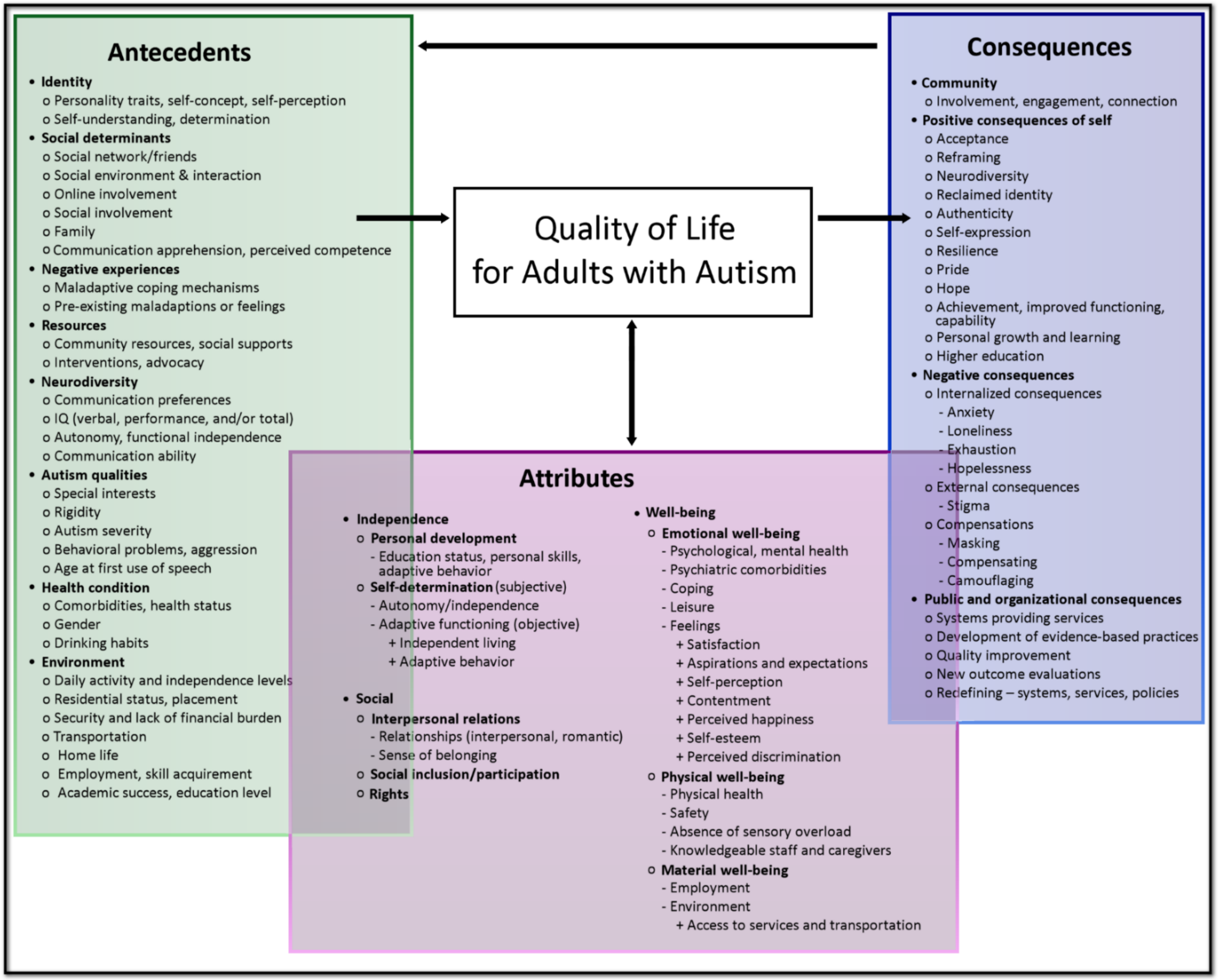
Appendix B

The relationship between literature review findings in numbers of articles that identified antecedents, attributes, consequences, and context



Appendix C

The relationship between antecedents, attributes, and consequences



Antecedents

- **Identity**
  - Personality traits, self-concept, self-perception
  - Self-understanding, determination
- **Social determinants**
  - Social network/friends
  - Social environment & interaction
  - Online involvement
  - Social involvement
  - Family
  - Communication apprehension, perceived competence
- **Negative experiences**
  - Maladaptive coping mechanisms
  - Pre-existing maladaptions or feelings
- **Resources**
  - Community resources, social supports
  - Interventions, advocacy
- **Neurodiversity**
  - Communication preferences
  - IQ (verbal, performance, and/or total)
  - Autonomy, functional independence
  - Communication ability
- **Autism qualities**
  - Special interests
  - Rigidity
  - Autism severity
  - Behavioral problems, aggression
  - Age at first use of speech
- **Health condition**
  - Comorbidities, health status
  - Gender
  - Drinking habits
- **Environment**
  - Daily activity and independence levels
  - Residential status, placement
  - Security and lack of financial burden
  - Transportation
  - Home life
  - Employment, skill acquirement
  - Academic success, education level

Quality of Life
for Adults with Autism

Consequences

- **Community**
  - Involvement, engagement, connection
- **Positive consequences of self**
  - Acceptance
  - Reframing
  - Neurodiversity
  - Reclaimed identity
  - Authenticity
  - Self-expression
  - Resilience
  - Pride
  - Hope
  - Achievement, improved functioning, capability
  - Personal growth and learning
  - Higher education
- **Negative consequences**
  - Internalized consequences
    - Anxiety
    - Loneliness
    - Exhaustion
    - Hopelessness
  - External consequences
    - Stigma
  - Compensations
    - Masking
    - Compensating
    - Camouflaging
- **Public and organizational consequences**
  - Systems providing services
  - Development of evidence-based practices
  - Quality improvement
  - New outcome evaluations
  - Redefining – systems, services, policies

Attributes

- **Independence**
  - **Personal development**
    - Education status, personal skills, adaptive behavior
  - **Self-determination** (subjective)
    - Autonomy/independence
    - Adaptive functioning (objective)
      - + Independent living
      - + Adaptive behavior
- **Social**
  - **Interpersonal relations**
    - Relationships (interpersonal, romantic)
    - Sense of belonging
  - **Social inclusion/participation**
  - **Rights**
- **Well-being**
  - **Emotional well-being**
    - Psychological, mental health
    - Psychiatric comorbidities
    - Coping
    - Leisure
    - Feelings
      - + Satisfaction
      - + Aspirations and expectations
      - + Self-perception
      - + Contentment
      - + Perceived happiness
      - + Self-esteem
      - + Perceived discrimination
  - **Physical well-being**
    - Physical health
    - Safety
    - Absence of sensory overload
    - Knowledgeable staff and caregivers
  - **Material well-being**
    - Employment
    - Environment
      - + Access to services and transportation

Appendix D

The Integral Scale

Emotional Wellbeing (EW)
EW1_I don't feel like doing anything
EW2_I am happy with my life
EW3_I am happy with myself
EW4_I am happy with my appearance

Material Wellbeing (MW)
MW1_I have enough money to buy the things I need
MW2_I' m happy with the things I have
MW3_My home is comfortable
MW4_I am happy with the money I make
MW5_I like the conditions of my house
MW6_I am happy with the place where I work
MW7_The place where I work is clean and safe

Physical Wellbeing (PW)
PW1_I sleep well
PW2_At the health care centre (for example, hospital, health clinic, etc.) they provide me with the care I need
PW3_I feel full of energy
PW4_I am happy with the attention I get at the health care centre
PW5_My health problems cause me continuous pain and discomfort
PW6_I feel good physically
PW7_I am happy with my health

Social Inclusion (SI)
SI1_The leisure activities in my town that I participate in are boring
SI2_I participate in my neighbourhood like everyone else
SI3_I feel excluded from society
SI4_I participate in associations that interest me
SI5_There is good communication between the members of my family
SI6_I am as integrated into my family as any other member

Personal Development (PD)
PD1_I go shopping in stores and supermarkets
PD2_The things that I have been taught are important
PD3_I do what is necessary to keep my room clean and tidy

Interpersonal Relations (IR)
IR1_The people at work accept me the same as everyone else
IR2_I don't have many friends to go out with to have fun
IR3_I have a good relationship with my parents
IR4_My relationships at work are good
IR5_I need more friends
IR6_I have people who will teach me the things that I don't know how to do
IR7_I have good relationships with people of different ages

Self-determination (SD)
SD1_I choose the activities that I do in my free time
SD2_I am allowed to choose the work that I like to do the best
SD3_I can achieve what I want if I try hard enough
SD4_I find it difficult to choose

SD5_I am allowed to invite my friends home (or to my residence) whenever I want
SD6_Other people decide where I should work
SD7_My parents/guardians/tutors let me spend money on what I want
SD8_I have decorated my room myself the way I like it
SD9_I am allowed to defend my ideas and opinions

Rights (RI)
RI1_The people around me respect my privacy
RI2_I have the same rights as everyone else
RI3_People treat me the same as everyone else
RI4_If someone robs me, I know how to report it to the police

(Gomez et al., 2012, p. 149-150).