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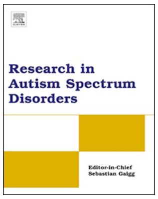

The experiences of adults with autism spectrum disorder: Self-determination and quality of life

So Yoon Kim

Lynch School of Education, Boston College, Chestnut Hill, MA, USA

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ABSTRACT

Background: Researchers have suggested self-determined individuals are more likely to initiate changes to achieve specific goals, resulting in higher quality of life (QoL). However, the links between self-determination and overall life experiences and QoL of adults with ASD are not well understood.

Method: A qualitative review based on critical interpretive synthesis (CIS) framework was conducted to investigate what is currently known about the association between self-determination and the life experiences of adults with ASD. A comprehensive structured literature search was conducted to locate empirical studies in peer-reviewed journals that described first-hand experiences of individuals with ASD over 18 years of age. Of 44 identified studies, 14 studies included evidence of self-determined behaviors in adults with ASD.

Results: Self-determination is implicated in five domains of life experiences– employment status, social participation, advocacy, positive identity, and stress management –and individuals with ASD perceive a relationship between self-determination and QoL. Limitations in the current literature on adults with ASD are identified.

Conclusions: Services and supports that provide more natural opportunities for acquiring and exercising self-determination skills are needed to promote QoL of adults with ASD.

1. Introduction

Autism spectrum disorder (ASD) is a life-long neurodevelopmental disorder characterized by impairments in social reciprocity and repetitive patterns displayed in behavior or interests (American Psychiatric Association, 2013). Individuals with ASD live the majority of their years as adults, yet perspectives of adults with ASD are under-represented in the literature (Camarena & Sarigiani, 2009; Hendricks, 2010). Various demographic and contextual factors such as severity of ASD symptoms, cognitive functioning, language ability, and socioeconomic status have been reported to influence adult outcomes (Levy & Perry, 2011). Even adults with low support needs often do not achieve outcomes that might be expected given their cognitive abilities (Marriage, Wolverton, & Marriage, 2009). Recently, there has been growing interest in transition-age youth with ASD (Hendricks & Wehman, 2009), but little is known about how to provide support for older adults with ASD (Griffith, Totsika, Nash, & Hastings, 2011).

The minimal research related to adults with ASD has primarily relied on parental (Griffin, McMillan, & Hodapp, 2010), sibling, or health care provider reports (DePape & Lindsay, 2016). Such dependence on third-person accounts has limited understanding of what it means and how it feels to experience ASD (Davidson, 2007). Without information coming directly through the voices of individuals with ASD, interventions and support systems may not adequately reflect the views and experiences of adults with ASD (Hendricks & Wehman, 2009; Milton, 2014).

E-mail address: kimagy@bc.edu.

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The literature on the use of quality of life (QoL) measures with children and youth with ASD (Ikeda, Hinckson, & Krageloh, 2014) and adolescents with ASD (Shipman, Sheldrick, & Perrin, 2011) reveals large discrepancies between self-reports and parental reports. In general, self-report measures of QoL result in higher scores than parental proxy evaluations. For instance, Hong, Bishop-Fitzpatrick, Smith, Greenberg, and Mailick, (2016) found that self-reported QoL scores in the social relationship domain were significantly higher than maternal proxy report scores. Also, the correlation between self-reports and parent-reports was lowest in the psychological health domain, while the self-reports and parent-reports were significantly correlated in other domains. Furthermore, while perceived stress or the experiences of being bullied played key roles in self-evaluations of QoL, characteristics that were visible to parents of adults with ASD such as health status and independence were critical elements in their evaluations of the subjective QoL of their adult children with ASD (Hong et al., 2016). These findings suggest discrepancies between the two types of reports may stem from parents' difficulty in assessing psychological or relational features of QoL in individuals with ASD, as well as parental expectations (e.g., degree of independence) that may differ from those of their adult children with ASD. Soliciting the voices of adults with ASD and obtaining their perspectives could elucidate what might be misrepresented or missed in accounts by those speaking on their behalf. A review of the current literature on self-reports of adults with ASD can help clarify what we already know and what we still need to understand, so that future research can be conducted to fill these gaps.

1.1. Self-determination

Wehmeyer (1992) defines self-determination as "the attitudes and abilities required to act as the primary causal agent in one's life and to make choices regarding one's actions free from undue external influence or interference" (p.305). A causal agency implies that the individual's own volitional and agentic acts create changes in his or her life (Wehmeyer & Palmer, 2003) and that s/he possesses personal empowerment to believe s/he has what it takes to achieve volitional goals (Shogren et al., 2015). Wehmeyer, Kelchner, and Richards, (1996) identified autonomous functioning, self-regulation, psychological empowerment, and self-realization as four essential characteristics of self-determination, and these four characteristics emerge as individuals acquire a set of core indicators of self-determination. Wehmeyer (1992) provides a non-exhaustive list of indicators of self-determination, which includes attributes such as choice-making, decision-making, problem-solving, goal-setting and attainment, self-observation, evaluation and reinforcement, an internal locus of control, positive attributions of efficacy and outcome expectancy, self-awareness, self-knowledge and self-advocacy" (p.4).

Previous studies have shown that children and youth with ASD have lower self-determination than their neurotypical peers (Wehmeyer & Shogren, 2008) and peers with other developmental disabilities (Wagner et al., 2007) due to having fewer opportunities to develop the component skills of self-determination or independently practice self-determined behaviors (Fullerton & Coyne, 1999; Stancliffe, 1997; Wehmeyer, Shogren, Zager, Smith, & Simpson, 2010). Some researchers have attributed the difficulty youths with ASD experience in acquiring higher levels of self-determination to their different cognitive processes and communicative challenges (Fullerton & Coyne, 1999; Janzen, 1996). Some limited evidence supports the effectiveness of interventions in promoting self-determination for students with ASD (Algozzine, Browder, Karvonen, Test, & Wendy, 2001), but the focus of the self-determination literature has mostly been on adults with intellectual disability and learning disability (Algozzine et al., 2001) rather than on how self-determination influences QoL in adults with ASD.

1.2. QoL

Self-determination is one of eight core domains of Schalock's (2000) QoL model, which defines QoL as a "multi-dimensional phenomenon composed of core domains that are influenced by personal characteristics and environmental variables" (Schalock, Keith, Verdugo & Gomez, 2010, p. 21). This view of QoL emphasizes that all humans share at least some similar desires and needs, and appropriate services should be provided to support the achievement of each individual's best personal outcome. The eight domains of Schalock's (2000) model of QoL are (a) interpersonal relations, (b) social inclusion, (c) personal development, (d) emotional well-being, (e) self-determination, (f) rights, (g) physical well-being, and (h) material well-being. Each of these eight domains is operationally defined in terms of attitudinal, behavioral or performance indicators (Schalock, 2000; Wang, Schalock, Verdugo, & Jenaro, 2010). Wang et al. (2010) also confirmed the hierarchical model of his QoL framework in populations with mild or moderate intellectual disability from 15 countries. A single second-order factor, QoL, consists of the eight correlated first-order QoL domains, each of which consists of different sets of indicators. Schalock et al. (2002) explains that the value and prioritization of these indicators vary among people at different stages of life, with different cultural backgrounds, or with different levels of need.

Recently, White, Flanagan, and Nadig (2018) reported that self-determination was significantly associated with QoL in adults with ASD. However, the ASD literature is still limited in examinations of each domain's effects on and contributions to overall QoL and of the relationships among the domains. Self-determination status for adults with intellectual disability has been related to the achievement of transition and to such adult outcomes as positive employment experiences, independent living (Chambers et al., 2007; Wehmeyer & Palmer, 2003), community inclusion (Powers et al., 2012), recreation and leisure outcomes (McGuire & McDonnell, 2008), and positive QoL and life satisfaction (Lachapelle et al., 2005; Wehmeyer & Schwartz, 1998). Lachapelle et al. (2005) showed that scores for each of essential characteristics of self-determination predicted the likelihood of membership in the high QoL group of individuals with mild ID. Wehmeyer and Schalock (2001) explain that self-determination enables individuals to initiate changes to achieve specific goals, resulting in the optimization of the individual’s QoL. In sum, previous studies provide evidence for the influence of self-determination on the QoL of individuals with different developmental disabilities and warrant a more in-depth investigation into the links between self-determination and QoL in adults with ASD.

1.3. The current review

Coinciding with the autism self-advocacy movement, there has been growing interest in the perceptions and experiences of individuals with ASD (Carrington & Graham, 2001; Griffith et al., 2011) and acknowledgement of the value of understanding their first-person perspectives (Müller, Schuler, & Yates, 2008). However, the primary focus has been on the experiences of young children and youth still in the K-12 school system (Griffith et al., 2011; Huws & Jones, 2008). The absence of the voices of adults with ASD represents a gap in the current literature. To strengthen efforts to provide programs that support high QoL for adults with ASD and inform client-centered policies and practices, this paper reviews both qualitative and quantitative studies that elucidate the first-hand experiences as well as the unique strengths and needs of adults with ASD. This study adapts a critical interpretive synthesis (CIS) framework (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005) to examine the perspectives and reports of adults with ASD. Instead of pooling and systematizing one type of research design to generate a summary, the CIS process allows inclusion of a variety of types of research to conduct a critical and comprehensive review of the nature and quality of primary studies. It also allows for a synthesis of evidence from both quantitative and qualitative data to generate theories that explain phenomena (Dixon-Woods et al., 2005, 2006; Nicholas, Attridge, Zwaigenbaum, & Clark, 2015).

Within this framework, the purpose of this review was (a) to examine how self-determined behaviors of adults with ASD are manifested and whether they appear to be implicated in their life experiences, and (b) to review the participant characteristics used in previous studies that included self-reports of adults with ASD to reveal whose voices and perspectives are being represented in the current literature. The study did not start out by specifically targeting QoL as the main topic of interest. Instead, five domains of life experiences emerged which were implicated in the production of self-determined behaviors in adults with ASD and paralleled some of Schalock’s domains. Therefore, the domains of life experiences identified in this review serve as proxies for some of the domains of Schalock’s QoL

2. Method

2.1. Search procedures

Two sets of search attempts were made to locate evidence of self-determined behaviors of adults with ASD in the literature. First, in June 2017, a systematic database search using search terms, *autis*, Asperger, adult,* and *self-determination* failed to identify peer-reviewed empirical studies that specifically examined the self-determination of one or more adults with ASD. Therefore, the second search was conducted with broader parameters to identify articles that indirectly capture self-determination in adults with ASD. The author attempted to locate the evidence of self-determination from studies reporting first-person interview and questionnaire data relating to post-school experiences although the studies did not address self-determination as a variable or directly measure self-determination skills. First-person interview and questionnaire data were chosen because self-report data allow access to individuals’ own beliefs and preferences, which are not available through parental or caregiver reports, and therefore can provide an unbiased understanding of the volitional, agentic nature of self-determined behaviors.

In June 2017, the second structured literature search was conducted to locate studies that reported first-person interview and questionnaire data relating to the post-school experiences of adults with ASD. First, the online databases ERIC, PsycINFO, ERC, Medline, and PubMed, were searched for any year of publication using combinations of the following search terms: *autis*, Asperger, adult, experience, lived, survey, questionnaire, ethnography, interview, grounded theory, self-report*, and *first-hand*. Second, a backward and forward search of all identified review articles was conducted to identify additional articles. Third, hand searches of *Autism, Autism Research*, and the *Journal of Autism and Developmental Disorders,* journals which the library database of the author’s institution did not comprehensively cover, were conducted to locate additional articles. The reference librarian at the author’s institution was consulted prior to conducting the second structured search and aided in making decisions about databases to search, combinations of search terms to be used, and identification of journals that should be hand-searched. After duplicates were removed, the search yielded 4420 articles.

After independently conducting abstract screening, the author read the remaining 81 articles in full to identify studies that met the following inclusion criteria: (a) empirical study; (b) inclusion in peer-reviewed, English language journals; (c) inclusion of first-hand accounts or self-report questionnaire data of the post-schooling experiences of one or more adults with ASD, and (d) participants who were 18 years of age or older. Participants, who did not have a formal diagnosis but self-identified as autistic, were included to capture the perspectives of a wider range of individuals who live with the ASD experience. Studies that included both third-party and self-reports were included only if the two kinds of data were separable. Studies in which participants’ age ranges were not reported or which targeted the effectiveness of an intervention with only brief mention of participants’ perceptions of the intervention were excluded. In total, 44 studies met the inclusion criteria for final analysis. See Fig. 1 for the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram of located studies (Moher, Liberati, Tetzlaff, & Altman, 2009).

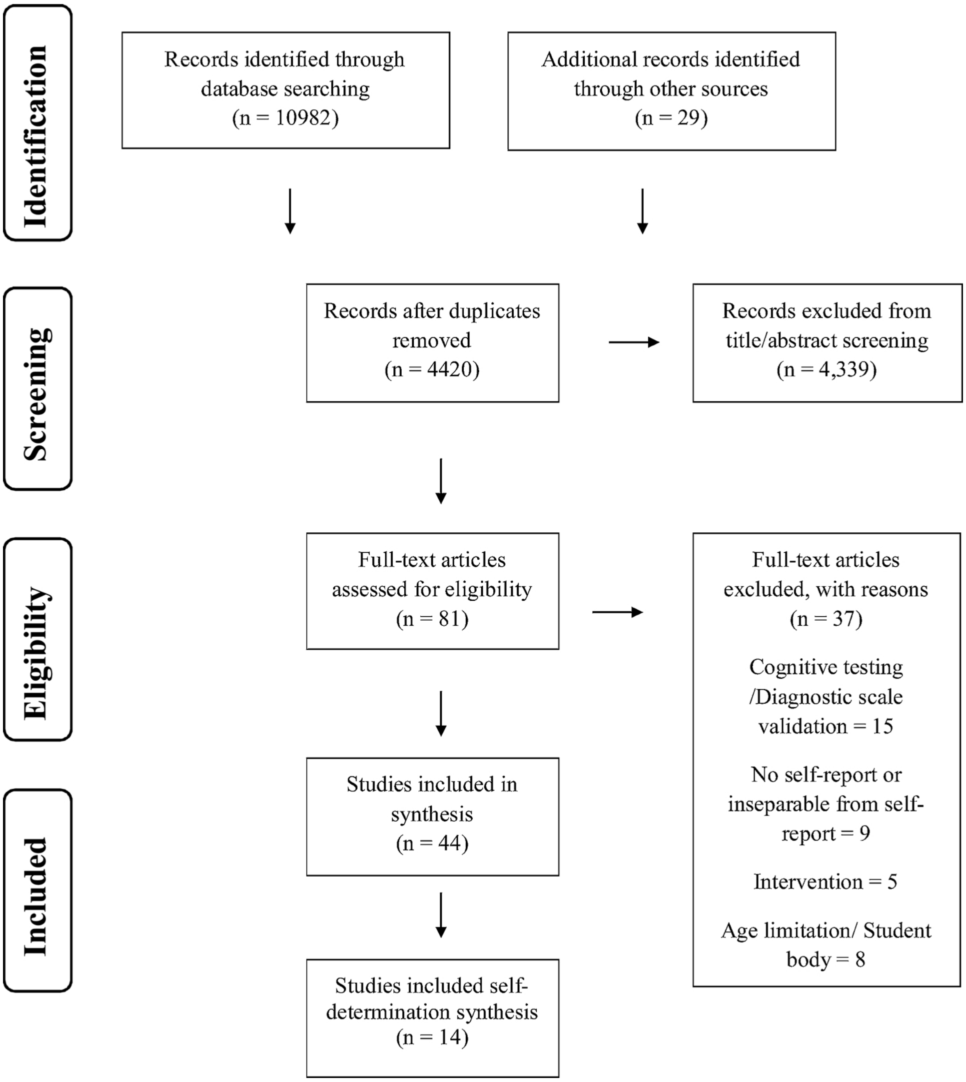

Fig. 1. PRISMA of Included Studies.

2.2. Data extraction

The following information was extracted from the 44 selected studies[1]: (a) type of study, (b) participant characteristics (gender, age, country, level of support needs, and ASD diagnosis), (c) research method, (d) measures to assess independent and dependent variables (if applicable), (e) evidence of self-determined behavior, (f) main findings and (g) limitations of each study. The four essential characteristics of self-determination were used to identify and code self-determined behaviors (component 'e' of the extraction table) from the results sections of primary studies. The four essential characteristics were autonomy (evidence of acting according to one's own principles and priorities), self-regulation (evidence of conscious monitoring and control of one's own behaviors), psychological empowerment (evidence of belief in one's potential to achieve voluntarily chosen goals), and self-actualization (evidence of ability to fully develop one's unique abilities and potential) (Shogren et al., 2015; Wehmeyer, 1992). In addition,

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[1] The 44 included studies are: Baldwin and Costley (2016), Barnet and Maticka-Tyndale (2015), Barnevelda et al. (2014), Bemporad (1979), Benford and Standen (2009), Byers et al. (2012), Byers et al. (2013), Cesaroni and Garber (1991), Crane et al. (2009), Gillespie-Lynch et al. (2014), Gilmour et al. (2012), Gotham et al. (2015), Griffith et al. (2011), Heartl et al. (2013), Hong et al. (2016), Hurlbutt and Chalmers (2002), Hurlbutt and Chalmers (2004), Jantz (2011), Kamio et al. (2012), Kanfiszer et al. (2017), Khanna et al. (2014), Krieger et al. (2010), Lewis (2016a), Lewis (2016b), Lin (2014), Mazurek (2013), Mehzabin and Stokes (2011), Moss et al. (2017), Muller et al. (2003), Muller et al. (2008), Murphy and Mullen (2017), Pfeiffer et al. (2017), Portway and Johnson (2005), Powell and Acker (2016), Punshon et al. (2009), Renty and Roeyers (2007), Schmidt et al. (2015), Scott et al. (2015), Smith and Sharp (2013), Sperry and Mesibov (2005), Strunz et al. (2016), Stuart-Hamilton and Morgan (2011), van der Aa et al. (2016), and Volkmar and Cohen (1985).

the indicators of self-determination in each example were identified to confirm that each example appropriately captured self-determination (See Wehmeyer et al., 2010, for detailed descriptions of each component).

From the initial pool of 44 studies, which included all self-reports of adults with ASD identified in the structured search, the evidence of self-determined behavior was identified in 14 studies. The final list of examples consists of direct quotes from individuals with ASD, direct quotes of descriptions of perspectives of individuals with ASD, and quantifiable data on self-determination. After the author conducted all data extraction, two independent reviewers reexamined the data extraction table for evidence of self-determination in the 14 studies, and initial discrepancies were negotiated to reach 100% agreement. The excluded articles were revisited by the author to make sure no relevant examples were missed from the first round of coding. Any remaining uncertainties were resolved through discussion with a professor who is an expert in self-determination to make sure an accurate concept of self-determination was captured in the dataset.

2.3. Data analysis

The CIS approach emphasizes the development of comprehensive theories by critically reviewing extant literature and evaluating the quality of evidence in order to extract synthesized themes (Nicholas et al., 2015). As explicated by Dixon-Woods et al. (2006), CIS comprises three main steps: (a) reciprocal translation synthesis, in which key information from primary studies is extracted and synthesized; (b) refutational synthesis, in which key findings and study characteristics extracted from each study are contrasted with one another to explain discrepancies; and (c) line of argument synthesis, in which evidence across the studies is organized to develop a "coherent theoretical framework comprising a network of constructs and relationships" (p.5) from emerging and recurring themes.

The slight adaption of CIS in this study was made to capture more detailed perspectives of individuals with ASD and prioritize the actual evidence of first-person reports over the interpretations of the researchers of the primary studies. While the original CIS method considers each study as one unit of analysis (Dixon-Woods et al., 2006; Nicholas et al., 2015), in the current study one example of self-determined behavior was considered as an independent unit of analysis. Each self-determined behavior will be referred to as an *example* hereafter. Therefore, instead of a summary of each study as the key information in reciprocal translation synthesis, examples from each study were used in cross-comparison of underlying evidence to synthesize the findings.

The extracted examples from the 14 studies were then reviewed in full. The process of reciprocal translation synthesis and refutational synthesis was iterative, and each example was individually reviewed and categorized for a gradual identification of recurring themes. First, the extracted statements from seven studies were sorted into theme clusters based on shared meaning and frequency. Each additional example from the seven remaining primary papers was then constantly compared to emerging theme clusters to consolidate categorization of evidence and to specify the relationship between the emerging theme clusters in a reciprocal translation synthesis process. Lastly, from line of argument synthesis, the theme clusters were then collapsed into five synthesized domains that represent the domains in which self-determined behaviors are manifested and influence the life experience of adults with ASD: social participation and relations, advocacy, positive identity, employment, and stress management.

To provide a range of perspectives, a social worker and a medical doctor were consulted in the process of generating synthetic domains from emergent themes. Also, a female adult with an ASD diagnosis reviewed the five domains, the list of relevant examples, and the indicators of self-determination of each example and confirmed that self-determination influenced her life experiences in each synthetic domain.

3. Results

First, participant characteristics in the 44 studies will be examined to explore whose perspectives are being represented and whose voices are being under-represented in the current literature including self-reports of adults with ASD. Subsequently, the rest of the review will describe the evidence of self-determination from the 14 relevant studies in relation to the five identified synthetic domains.

3.1. Participant characteristics

The 44 studies identified as having self-report data included a total of 2526 adults with ASD, whose ages ranged from 18 to 84. Only three studies reported IQs. Among the 21 studies that reported a breakdown of the ASD diagnosis under DSM-IV diagnoses criteria, 62.7% of participants had diagnoses of Asperger's or were described as having high functioning autism (HFA). The remaining 23 studies did not present the exact percentage of each diagnosis, but reported that the participant samples consisted of varying combinations of autism, including Asperger, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), informal diagnosis, self-identification with ASD, or collectively ASD. The male to female ratio of participants was approximately 1:1 (49.9% participants self-identified or were reported as male and 48.3% as female). Participant and study characteristics of the 44 studies are presented in Table 1.

The 14 studies in the synthesis of self-determination data included 705 adult participants, of whom 37.2% were male. The median number of participants in each primary study was 14.5. Only six studies included information about race or ethnicity. Across all 14 studies, 81.3% of the participants had formal diagnosis of ASD, which included autism, Asperger, PDD-NOS, and 18.7% were self-diagnosed, had informal diagnoses from health professionals, or were in the process of obtaining a formal diagnosis. Among those who had formal diagnoses, 320 (55.8%) were described as having HFA or Asperger's syndrome under DSM-IV diagnoses criteria. Müller et al. (2003) and Müller et al. (2008) shared the same participants. Also, three participants in Hurlbutt and Chalmers (2002)

Table 1

Participant/study characteristic of 44 studies that included first-hand accounts or self-report questionnaire data of the post-schooling experiences of one or more adults with ASD.

Participant/study characteristics	Frequency (Percentage)
Gender	
Male [a]	1261 (49.9)
Female [b]	1221 (48.3)
Studies that reported breakdown of diagnosis of participants	21 (47.7)
Participants with high-functioning autism (HFA) or Asperger (%) among 21 studies	1413 (62.7)
Participants with formal diagnosis[a]	2224 (87.4)
Studies that included information on race	16 (36.4)
Caucasians among 16 studies (%)	N/A (80.1–94.3)

N = 2526. *Notes*: Mean and standard deviation of age range were not calculated because some studies did not report the mean age of the participants. [a] and [b] do not add up because some participants did not identify with one gender. N/A = not applicable.

Table 2

Participant Characteristics of 14 studies Included in Synthesis of Self-determination.

Author (year published)	Study Type	n	% male	Diagnostic status	CA	
					Mean (SD)	Range
Barnet and Maticka-Tyndale (2015)	Qual	24	25[d]	NR	37	18–61
Gillespie-Lynch et al. (2014)	Quant	291	23.4	Autism, 87 participants did not have formal diagnosis	32.3 (11.2)	18–84
Griffith et al. (2011)	Qual	11	63.6	Asperger syndrome, 2 participants in the process of obtaining a diagnosis	46.4 (7.2)	37–57
Heartl et al. (2013)	Qual	6	50	Autism[b]	NR (NR)	27–55
Hurlbutt and Chalmers (2002)	Qual	3	66.7	Asperger, autism	42.3 (NR)	31–61
Hurlbutt and Chalmers (2004)	Qual	6	50	Asperger, autism	48.8 (NR)	25–65
Krieger et al. (2010)	Qual	6	66.7	Asperger	36.8 (NR)	32–45
Lewis (2016a)	Qual	77	52.6	Asperger, PDD, ASD, 17 participants in the process of obtaining a diagnosis, or had informal diagnosis from a mental health professional	39 (NR)	18–65
Müller et al. (2003)[e]	Qual	18	72.2	Asperger, autism[a], PDD, or 2 participants had informal diagnosis from mental health professional	37.2 (NR)	18–62
Müller et al. (2008)[e]	Qual	18	72.2	Asperger, autism[a], PDD, or 2 participants had informal diagnosis from mental health professional	37.2 (NR)	18–62
Punshon et al. (2009)	Qual	10	70	Asperger	NR[c] (NR)	22–45
Smith et al. (2013)	Qual	9	55.6	Asperger, autism[a]	33.44	25–49
Sperry and Mesibov (2005)	Qual	18	94.4	Autism[b]	34 (NR)	22–49
Strunz et al. (2016)	Quant	229	40.2	Autism[a], PDD-NOS	34.9 (10.3)	18–58

NR = not reported in the primary study. Qual = qualitative study, Quant = quanitative study. [a]= some studies reported the participants had the diagnosis of High-Functioning Autism. This was referred to as autism in this chart [b]= ASD. [c]= although mean was not reported, authors reported median of participant age, which was 31. [d] = percentage of individuals who endorsed masculine identity. [e]= shares the same participants.

were included in the analysis of Hurlbutt and Chalmers (2004). To avoid redundancy, therefore, participant information from Muller et al. (2008) and Hurlbutt and Chalmers (2002) was not included when calculating overall participant information. Participant and study characteristics of the 14 studies included in the synthesis of self-determination data are presented in Table 2.

3.2. *Self-determination*

The rest of this review focuses on how and when adults with ASD engage in self-determined behaviors and how self-determination or lack of self-determination influences employment status, positive identity, stress management, social participation, and advocacy. The presence of skills related to indicators of self-determination was treated as evidence of the emergence of self-determined behavior in each domain. As the review relies on first-hand testimonies of adults with ASD, it does not refer to observations of self-determined behaviors but only to the perceptions of the adults with ASD. Although self-determination was not directly addressed in any studies with first-hand reports by adults with ASD, 38 examples were extracted from the pool of 14 studies, reporting evidence of self-determined behaviors in first-person accounts without identifying them as such. Table 3 provides a summary of examples of self-determination and related domains and relevant references for each example. Each domain and evidence from the reviewed articles is discussed below.

3.2.1. *Employment*

First, the relations between self-determined behaviors and employment experience will be examined. Adults with ASD who practiced self-determined behaviors made positive changes in their own vocational lives and work environments.

Table 3
Examples of self-determined behaviors in experience of adults with ASD from 14 studies.

Identified domains in the review	Examples of self-determination in included studies	Schalock's QoL domain (2000)	Relevant indicators within Schalock's domain	References
Employment status	Being aware of their own strengths and weaknesses helped maintain employment	Material well-being	Employment status	Smith et al. (2013)
	Transforming interest in the choice of profession	Emotional well-being, Material well-being	Employment status	Krieger et al. (2010)
	Educating the job coach/ Distributing an article on Asperger Syndrome to all of his co-workers	Material well-being,	Employment status	Müller et al. (2003)
	Desire to be involved in the development of private or national foundations that cooperate with employers to provide more meaningful job choices for the larger autistic population	Social inclusion	Community roles, community participation	Hurlbutt et al. (2004)
	Not having a choice in job selection and lack of self-determination were often associated with difficulty obtaining and keeping employment	Material well-being	Employment status	Heartl et al. (2013)
	Successful employment experience increases self-determination in return	Emotional well-being	Self-concept, self-worth, self-esteem	Hurlbutt and Chalmers (2004); Krieger et al. (2010)
Social relationships and participation	Engaging in intentional, open, and explicit communication	Interpersonal relations	Relationships, interaction	Barnet and Maticka-Tyndale (2015)
	Dependence on avoidance coping strategies in marital relationship related with lower levels of individual adaptation and more psychosocial stress	Interpersonal relations	Relationships, support	Strunz et al. (2016)
	Choosing to be in a relationship	Interpersonal relations	Relationships, interaction	Sperry and Mesibov (2005)
	Actively seeking to find the right social support groups or social skills intervention types	Social inclusions	Social support network	Hurlbutt et al. (2002)
	Participation in a preferred group activity	Social inclusions	Social support network	Müller et al. (2008)
	Choosing to use computer-mediated communication or social media to find support groups to meet their relationship goals	Social inclusions	Social support network	Gillespie Lynch et al. (2014)
Positive identity	Choosing and working to accept ASD into their identity	Emotional well-being	Self-concept, identity, self-worth, self-esteem	Sperry and Mesibov (2005)
	Knowing identity helps identification of strength	Personal development	Personal competence, skills	Krieger et al. (2010)
	Seeking formal diagnosis and right service with proper diagnosis	Physical well-being, Emotional well-being	Self-concept, identity, health care, diagnosis	Heartl et al. (2013); Lewis (2016a); Punshon et al. (2009)
Stress management	Developing and experimenting with self-regulated strategies for sensory stimulation, purposive activity	Emotional well-being	Lack of stress, predictability and control	Barnet and Maticka-Tyndale (2015); Müller et al. (2008); Smith et al. (2013); Sperry and Mesibov (2005)
Advocacy	Becoming an expert in ASD by reading books and articles or by attending conferences, wishing for their voices to be heard in making recommendations for future research and development of support systems and interventions	Personal development	Education, personal competence	Griffith et al. (2011); Hurlbutt and Chalmers (2002); Müller et al. (2008); Lewis (2016a)
	Desire to help other individuals with ASD, volunteering or participating in fundraising activities for autism research	Personal development, Rights	Purposeful activity, Advancement	Müller et al. (2008)

3.2.1.1. Personal interest and ability. Smith and Sharp (2013) found that self-awareness of their own strengths and weaknesses helped adults with ASD interact positively with employers and colleagues and win their admiration, which boosted their confidence and self-acceptance. For example, a 37-year-old participant stated,

> "I have always been very strong at grammar, spelling, flow, and so on. This has helped me obtain an expert position at work as an editor of others' work… A lot of this has to do with sound. I can tell very readily when a sentence sounds wrong (Smith & Sharp, 2013, p. 904).

Similarly, Krieger et al. (2010) quotes a response of one participant who said, "As long as I can remember, I was thirsty for knowledge…My professional success can be explained in the choice of an introverted profession in a technical field and a knowledge-intensive environment" (p.149). The choice to work in an environment that aligns with personal interests and abilities were enabled by self-awareness of personal strength and often led to longer-term pursuits and maintenance of careers.

3.2.1.2. Seeking accommodations. Adults with ASD also felt that employers' and job coaches' awareness was important for finding better employment matches. Several participants reported becoming self-advocates for more successful employment experiences. One participant disclosed his Asperger diagnosis to all of his co-workers and distributed an article on Asperger Syndrome to help them better understand who he was and why he behaved the way he did (Müller, Schuler, Burton, & Yates, 2003). Another individual described educating his job coach about ASD and the types of vocational challenges unique to this population (Müller et al., 2003). Increasing others' awareness occasionally led to advocating for more opportunities in job market. Some wished to be involved in the development of foundations that cooperate with employers to provide more meaningful job choices for adults with ASD (Müller et al., 2003). One 65-year-old participant described a specific plan that involved "having [a local provider] expand its facilities from its base of operation to the rest of the country; initiate and expand apprenticeship programs for those who are talented in a field; and job fairs to be held at all future autism conferences" (Hurlbutt & Chalmers, 2004, p.220). Although these behaviors were not labeled as self-determination, these adults clearly were setting goals and making choices in order to problem solve. They combined self-awareness, knowledge, and self-advocacy skills to increase others' awareness in order to locate, secure and sustain employment, leading to overall life satisfaction.

On the other hand, Heartl, Callahan, Markovics, and Sheppard, (2013) investigated currently employed adults who could perform "better and more challenging work if the environment were correct and … people were willing to make adaptations" (p. 36), but many did not request such accommodations for fear of resentment from employers and colleagues unwilling to make adaptations. Others shunned association with ASD and therefore chose not to disclose their diagnoses, which often resulted in difficulty obtaining and keeping employment.

3.2.1.3. Influence of employment on self-determination. One participant in Krieger et al.'s (2010) study reported that work experience helped him learn more about himself and how to find satisfaction in work. "This trial and error attitude has provided me with many learning experiences…I am open to new ideas but in the end I must experience them as my own" (Krieger et al., 2010, p. 149). A 43-year-old female participant in Hurlbutt et al.'s (2004) study explains her lack of genuine interest in her college major or in the jobs she took led to several unsuccessful and short employment experiences. However, at the time of the interview, she was working at a pre-school for children with special needs and had newly discovered an interest in education and was considering pursuing another academic degree in social work or teaching. These examples show that not only does self-determination influence employment experience, but successful employment also may lead to higher self-determination by fostering self-knowledge and positive attitudes toward goal-setting and attainment.

3.2.2. Social relationships and participation

3.2.2.1. Choosing modes and types of socialization. Self-determined behaviors were also associated with developing social relationships and community involvement. For instance, a participant shared that her experiences with applied behavior analysis intervention were negative and that her preferred type of social skills intervention was Social Stories, which "help[ed] [her] with socializing with her peers" (Hurlbutt & Chalmers, 2002, p.109). Müller et al. (2008) found that adults' self-determined behavior in the form of choosing the kinds of social activities they favored often reported enjoying participating in such activities. They reported that structured social activities, such as school choir or band, and groups organized around such interests as chess, hiking, and electronics provided social opportunities and a sense of community involvement. They also reported improving personal skills for social relationships by learning to understand what they found difficult in social situations and making a deliberate effort to improve the skills they think they lacked, suggesting how self-observation, self-awareness and evaluation, and reinforcement helped them to develop socially. Furthermore, participants reported that their social understanding continued to improve with time and effort (Müller et al., 2008).

Adults with ASD were also found to use computer-mediated communication or social media to find support groups or communicate with others with shared interests (Gillespie-Lynch, Kapp, Shane-Simpson, Smith, & Hutman, 2014; Mazurek, 2013). These platforms enable people with ASD to share their expertise and enjoyments while making choices to meet their relationship goals (Gillespie Lynch et al., 2014). A recent study also showed computer-mediated communication promoted the expression of empowered individual and collective identity of adults with ASD against the dominant neurotypical social norms (Kim & Bottema-Beutel, under review).

3.2.2.2. Romantic relationships. Self-determination was also implicated in positive sexual, romantic or marital relationships. Adults with ASD often reported not having received adequate disability-relevant sexual or relationship education at home or in school (Barnet & Maticka-Tyndale, 2015; Strunz et al., 2016). In the absence of such education, some participants independently formulated a number of strategies for achieving desired sexual and relationship outcomes (Barnet & Maticka-Tyndale, 2015). These goal setting, decision-making, and problem-solving behaviors were based on self-awareness and knowledge, markers of self-determination.

Participants in Barnet and Maticka-Tyndale (2015) study planned to establish shared expectations and engaged in intentional, open, and explicit communication, referred to as "literal declaration," with intimate romantic partners to plan sex or to manage heightened emotions, anxiety, or sensory overstimulation. Engaging in such literal declaration with their partners helped many adults with ASD maintain successful intimate relationships. Some adults observed that being in a relationship depended on choice, a clear marker of self-determination, just as with neurotypical individuals. For example, one participant observed, "If you really want to make it work, you will go for it. I mean it makes me so angry when people say, 'Well, normal people can get married and autistic people can't'" (Sperry & Mesibov, 2005, p.372).

Interestingly, Strunz et al. (2016) found that the use of avoidance coping strategies was related to lower levels of individual adaptation in both men and women and with more psychosocial distress in marital adaptation for men with ASD. Lazarus and Folkman (1984) report that dependence on passive avoidance strategies such as distancing was a significant predictor of negative individual adaptation as measured by the Symptom Checklist-90 (SCL-90; Arrindell & Ettema, 2003; Derogatis, 1977), a 90-item self-report questionnaire widely used to assess psychological distress. In sum, exercising active problem solving skills, a sign of self-determination, helps adults with ASD to locate their social difficulties and learn to overcome them as well as set personal goals such as finding a partner or being meaningfully involved in social participation.

3.2.3. Stress management

Self-determined adults with ASD were also able to develop self-initiated coping mechanisms to deal with daily stress. Müller et al. (2008) reported that adults with ASD emphasized the importance of having various self-regulation strategies such as playing an instrument, engaging in physical and outdoor activities, attending spiritual or religious practices, and having alone time. When asked how to handle social stress at work, one participant with ASD reported expressing emotions in a personal journal (Sperry & Mesibov, 2005). Gender of this participant was not disclosed in the original article.

3.2.3.1. Familiarization and preparedness. Similarly, Smith and Sharp (2013) reported that some participants found self-initiated ways to calm themselves and to self-regulate sensory overstimulation. For instance, some participants said that to lessen the stress in unfamiliar environments they proactively tried to prepare themselves to make new situations more predictable. A 49 year-old female participant says "If im going somewhere new i need to go look at it on my own first and get the layout" (Smith & Sharp, 2013, p.900). Also, 31-year-old male participant notes he is able to manage doctors touching him by "Because [he is] prepared for it. [he] knows[s] what to expect when [he] go[es] into a consultation."

3.2.3.2. Physical strategies. After learning by accident that putting physical pressure on the skin may help self-regulation and ease frustration, one 30-year-old participant experimented with different amounts of physical pressure on the body with help of her tai chi teacher to find her threshold of tolerance. Experimenting with pressures was pleasurable to her because "as a scientist, experiments appeal[ed] to [her]" (Smith & Sharp, 2013, p.901). Many participants in Smith and Sharp's (2013) study used self-initiated strategies to damp down sensory experiences, making them less intense and thereby more manageable. Barnet and Maticka-Tyndale (2015) introduce a female participant whose "successful strategy" for dealing with stressful situations was to hold hands with her friends, which gave her some relief. In such ways, adults with ASD became aware of their needs and developed physical self-regulation strategies to relieve their stress and overstimulation, a process that required the self-determination skills of self-awareness and active solution-seeking.

3.2.4. Positive identity and diagnosis

The literature provides evidence of the effects of self-determination on adults with ASD on very personal and individual levels.

3.2.4.1. Acceptance of diagnosis. For some adults with ASD, acceptance of ASD into their identity was a matter of choice. One participant from Sperry & Mesibov (2005) voiced,

> "I had a choice… "that's okay, I'm not going to get in the way of whatever help they can offer me. And I think when I made that decision to do that, then things really started to skyrocket and go in the right direction" (p.372).

Confirmation of diagnosis gave many participants relief and opened the path to self-acceptance. Some felt empowered or saw the diagnosis as "a light in the darkness, best thing that happened" to them (Lewis, 2016a, p.350). A participant in Krieger et al. (2010) mention how knowing diagnosis helped him make some decisions and says, "understanding myself as Aspi helps me to reason why I am more talented in some fields than in others" (p.151). Although some needed a period of learning to accept and re-evaluate how they viewed themselves, many reported that self-awareness gave them tools to improve their lives.

3.2.4.2. Getting diagnosed. For others, especially those who were not formally diagnosed as children, getting the diagnosis was itself a product of self-determined behavior. Often adults with ASD, after having self-diagnosed for a long time, had to fight to be formally diagnosed in their adulthood in order to understand and accept themselves by recognizing how ASD contributed to who they were or to take advantage of resources in the community (Heartl et al., 2013; Lewis, 2016a; Punshon, Skirrow, & Murphy, 2009). Many had not been diagnosed until adulthood due to their family's denial or concern over stigma, or a clinician's lack of knowledge (Punshon et al., 2009). Seeking their own diagnosis in adulthood was often a conscious effort to understand and accept themselves better.

3.2.4.3. Delayed diagnosis. Both positive and negative emotions were reported in connection with late formal diagnosis (Lewis, 2016a; Punshon et al., 2009). Lewis (2016a) found that some individuals reported low self-concept and feelings of not fitting in. Many individuals described a lack of competency of healthcare professionals as barriers to formal diagnosis (Lewis, 2016a). Self-determined adults with ASD, who could choose to accept their authentic selves, were actively advocating for their own and collective rights, wanted to educate and lead others with ASD to paths of self-acceptance, and use their voices to change the misconceptions and stereotyping on the part of neurotypical individuals. All these self-determined behaviors are closely related to positive self-identity.

3.2.5. Advocacy

Some adults described their experience of becoming self-advocates, as well as advocates for autistic adults more generally. Some started blogs and online or in-person support groups, became speakers, and participated in research studies in an effort to help the adult ASD community (Lewis, 2016a). Others became experts in the study of ASD by reading books and articles, attending conferences, and talking to professionals in the field (Hurlbutt & Chalmers, 2002). Through self-initiated education, in combination with their own experiences, they made specific recommendations for ways to improve the occupational situation of others with ASD who were underemployed or unemployed. Many participants who wanted their voices to be heard became active in making recommendations for future research and the development of support systems and interventions (Griffith et al., 2011; Hurlbutt & Chalmers, 2002; Hurlbutt & Chalmers, 2004). Participants in Müller et al. (2008) also expressed their desire to help other individuals with ASD by actively organizing support groups, sharing their experiences at conferences, volunteering at summer camps for children with ASD, or participating in fundraising activities for autism research as a way to contribute to the advancement of the people in autistic community. This self-determined behavior highlights the quest for greater awareness and accurate information to help people on the ASD spectrum to support themselves appropriately as well as to challenge the biases and misconceptions of the neurotypical public and researchers.

4. Discussion

The current study provides evidence of participants' engagement in self-determined behavior and its importance in the positive experiences of their adult lives. These findings suggest that self-determination underlay the participants' ability to enhance their social participation and learning, actively pursue valued employment, develop positive self-identities, seek appropriate health-care services, create a stable social environment, and engage in personal development. Such self-determined behaviors as goal-setting, decision making, problem solving, and self-management had positive influences on their employment status, social participation, advocacy, positive identity, and stress management.

4.1. Self-determination and the five domains of life experience

These findings from the review are the basis of a model comprising five domains of life experience (social participation and relations, advocacy, positive identity, employment, and stress management) with self-determination at the core, which might be used to understand QoL in adults with ASD (Fig. 2).

Fig. 2. Domains Influenced by Self-Determined Behavior Per Self-Report in Adults with ASD.

While not equivalent to Schalock's (2000) model, the five synthetic domains of life experience identified in this review reference or exemplify some of Schalock's QoL domains, including material well-being, emotional well-being, physical well-being, interpersonal relations, and social inclusion (Wang et al., 2010). For example, employment status in the present model is one indicator of Schalock's (2000) material well-being domain, and positive identity is a factor in emotional well-being (Table 3). While mediating effects have not yet been fully identified or studied, Schalock's (2002) QoL model presupposes that the presence of positive relevant indicators of each domain enhances QoL. This review shows how self-determination can be implicated in each of the five domains of experience reported by adults with ASD and therefore may impact QoL. For example, the self-determined behavior of educating a job coach will likely improve the services rendered to an individual and his/her employment status, thereby enhancing the individual's material well-being in Schalock's model and ultimately his/her QoL.

Because no study included in this review targeted self-determination as a distinct variable, it is likely that participants did not report all instances when they capitalized on self-determination skills, so actual individual skill levels could not be described. However, the significant correlation between quantitative measures of overall QoL and self-determination scores among young adults with ASD (White et al., 2018) supports the conceptual structure of the proposed model by confirming the importance of self-determination to positive QOL. As noted, the model is also in line with Schalock's QoL framework, which simulates a social model for disabilities with emphasis on self-determination and self-advocacy (Robertson, 2010; Schalock, 2000).

Although some researchers sought to identify a hierarchy among Schalock's eight core QoL domains (Bonham et al., 2004; Elorriaga, Garcia, Martinez, & Unamunzaga, 2000; Schalock, Gardner, & Bradley, 2007; Wang et al., 2010), there is no consensus on a hierarchy or on cause and effect relations among Schalock's QoL domains. Also, Schalock's model (2000) and its proposed hierarchical relations were not developed to reflect the disability profile of the adult ASD population or empirically verified with this population. The need for a hierarchical configuration specific to adults with ASD warrants serious attention as the QoL model stresses that individuals from different backgrounds or needs may have different priorities among indicators (Schalock et al., 2002).

This review is the first qualitative study to identify elements of self-determined behaviors and the patterns of behaviors that emerge in various aspects of the life experiences of adults with ASD. Toward this end, it adds to the diversity of perspectives on adults with ASD and on how self-determined behaviors affect the general quality of their lives. Because participants frequently included their own perceptions and evaluations of their self-determined behaviors or self-instigated decision-making processes, the first hand reports facilitated depiction of the volitional and agentic nature of self-determined behaviors and allowed more direct access to internal motivations of adults with ASD than when they are filtered through parental or secondary reports. Therefore, this review corroborates the value of relying on first-hand reports when examining self-determination.

4.2. *Considerations for further development of the model*

It is important to note again that this review did not investigate all of Schalock's (2000) QoL domains per se, and instead focused on the themes relevant to QoL that emerged from the examination of how self-determined behaviors were presented and discussed in the existing studies that included self-reports of adults with ASD.

As the proposed model is based on a set of hypotheses about how the synthesized themes relate, this review presents a suggested framework for future quantitative or mixed-methods research to validate the model's effectiveness in accurately determining the influence of self-determination on the suggested five synthetic domains. Also, the influence of self-determination on other domains of QoL not mentioned in this review and how the relationships among domains may lead to improved overall QoL need to be examined in future research. Furthermore, a quantitative study of Zalewska, Migliore, and Butterworth, (2016) found that only psychological empowerment of self-determination was significantly associated with whether or not individuals with ASD had held a paying job since high school, while composite self-determination or other characteristics were not. This insight warrants future studies investigating how each essential characteristic of self-determination is implicated with each domain of QoL of adults with ASD.

Researchers generally agree that self-determination can be taught with appropriate intervention and support (Fullerton & Coyne, 1999; Shogren et al., 2015; Wehmeyer, Palmer Agran, Mithuag, & Martin, 2000) and endorse its value in transition services for youth (Wehmeyer & Schwartz, 1998; Wehmeyer & Palmer, 2003). Youths need the guidance of teachers and family members to become self-determined (Avery et al., 1995; Fullerton & Coyne, 1999; Ward, 1994), suggesting the need for research on self-determination and its incorporation into the skill set of individuals with ASD and ways to raise awareness of its value among their family members and educators. This indicates appropriate social support system that provides natural opportunity to develop self-determination is needed in addition to taking immediate measures to teach self-determination skills to individuals with ASD.

Furthermore, challenges experienced by adults with ASD in executing self-determined behaviors may be a symptom of inadequate support and services. For instance, individuals with high support needs including difficulties in communicating may also be able to achieve their full potential in gaining and expressing self-determination skills when appropriate support is provided. While acknowledging the significance of self-determined behavior, more research on the relationship between various levels of need for independent execution of self-determination skills and the adequacy of current support systems is warranted.

4.3. *Limitation of current literature and implications*

When interpreting the findings of this synthesis, it is important to be mindful of several limitations. Indeed, the limitations of the 44 studies featuring self-reports also apply to this review. Overall, the available literature on the experiences of adults with ASD is not representative of the full population. First, participants in these studies tended to have diagnoses of Asperger or HFA, or self-diagnosis of ASD. Most studies included individuals who were able to verbally report their experiences. While this limitation calls for caution in generalizing these findings, it also highlights the need to develop new methods and conduct further research to investigate the experiences of individuals with high support needs or who are nonverbal.

Second, the percentage of male participants included in the 44 studies was 49%, indicating that the male to female ratio was lower than the prevalent estimate of 4.3:1 (Fombonne, 2003). The high proportion of females included in this synthesis of self-determination is a limitation in generalizing and interpreting the proposed model and warrants more work before applying the model to the full spectrum of individuals with ASD. The high ratio of female participants included results mostly from studies with quantitative designs, whose percentage of male participants ranged from (23.4%–40.2 %), while the percentage of male participants of qualitative study ranged from (25%–100%). Interestingly, except for Baldwin and Costley (2016), who specifically recruited female participants, the studies with the highest proportion of female participants (Gillespie-Lynch, Kapp, Shane-Simpson, Smith, & Hutman, 2014; Strunz et al., 2016) recruited the participants through the Internet. Gillespie-Lynch et al. (2014) reports that this gender ratio is more representative of spectrum of individuals with ASD online and indicates previous online studies have repeatedly shown higher percentages of female participants. Therefore, future studies should take this inconsistency in gender ratio between qualitative and quantitative studies into consideration when designing online or offline designs.

While researchers attribute the extreme heterogeneity found within the ASD population to the difficulty of locating a representative sample (Tobin, Drager, & Richardson, 2014), it may as well be the precise reason for recruiting participants from the full spectrum. Therefore, more structured measures should be taken to ensure that representative participant samples of the entire spectrum of individuals with ASD are recruited so that the individuals in any place on the spectrum are taken into account to receive necessary and appropriate support.

Third, out of 44 studies, 42 studies were conducted in English speaking countries or Europe. Thus, this review may provide limited and biased information about influence of cultural and socioeconomic factors on the experience of individuals with ASD. Fourth, it focuses disproportionately on Caucasian individuals with low support needs. Only 16 studies included information on race, and when it was reported, it revealed that the sample primarily consisted of Caucasians (range = 80.1 ~ 94.3%). Fifth, the majority of studies did not report clear descriptions of participant characteristics (e.g. diagnosis status, race, or gender). Omission of such information complicates analyses and generalization of their findings and limits further examination into the moderating or mediating influences of socio-demographic factors. The limited participant diversity and failure to report participant demographics such as ethnic, racial and cultural information found in previous studies (Pierce et al., 2014; West et al., 2016) compromise the external validity of existing research.

Sixth, some studies included individuals who were self-diagnosed as well as clinically diagnosed, but did not differentiate between the two populations in the findings. Also it was impossible to determine an average age or age-range of diagnosis in 14 or also in 44 studies because this information was rarely provided. Although some researchers contend that self-diagnosis is similar to the formal diagnosis process, (Lewis, 2016a; Punshon et al., 2009), it is noteworthy that many young adults (age = 18–35) had already recognized themselves as being different from others prior to formal diagnosis (Portway & Johnson, 2005). Among the participants in the 14 studies included in the synthesis of self-determination, 18.7% had an informal diagnosis by a health care provider, were in the process of getting a diagnosis, or had diagnosed themselves as having ASD. However, we believe the inclusion of these participants is warranted, given the significant barriers that many adults (e.g., individuals who are linguistic and cultural minorities) face in securing a formal diagnosis.

Finally, another limitation of this review was the participants' age range of 18–84, which suggests a wide range of perspectives. A 20-year-old and a 65-year-old participant will each perceive employment status differently. Attempts to specify the age ranges were often thwarted because many studies (n = 23) included age ranges exceeding 30 years without reporting specific ages in interpretations of participants' responses. Incomplete representations of ages weakens the applicability of findings of the current review to specific age groups, a limitation that calls for more consideration of specifically defined age groups of adults to allow for more accurate characterization of support needs at critical life stages.

In sum, there were biases in population selection and a lack of information on participant characteristics, indicating a gap in understanding the perspectives and needs of those who are "undiagnosed and inaccessible" (Portway & Johnson, 2005). Thus, more research is needed to understand how experiences might be shaped by disability in relation to gender, age, level of support needs, and other socio-demographic factors. Moreover, future research should include subclinical and self-diagnosed adults with ASD as a population to examine how their perceptions and experiences might differ from those of the clinical group, to identify barriers to formal diagnosis, and to facilitate their access to community resources or professional support services.

5. Conclusion

This review employed a CIS framework on studies that included first-hand account of adults with ASD and identified self-determination as an important factor in several domains of QoL – employment status, social participation, advocacy, positive identity, and stress management – and positive experiences of adults with ASD. While recent literature increasingly includes the emic perspective of adults with ASD, this review argues for a clearer description of participant characteristics and inclusion of a more varied range of participants in empirical studies to strive toward better identification of undiagnosed individuals and effective support systems as well as a better understanding the influence of various socio-demographic factors on the perceptions of daily life. The unique challenges of living with ASD and the strengths of individuals at all points on the spectrum must be considered when working to enhance self-determination in the broad population of individuals with ASD.

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*Indicates studies included in the systematic review of participant characteristics. **Indicates studies included in the analysis on self-determination (n = 14) and also in the systematic review of participant charactieristics.