Review

What are the ages of persons studied in autism research: A 20-year review


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ABSTRACT

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder that affects individuals of all ages. Currently, the majority of autism research is focused on children and adolescents. Although this trend has been a norm, there has not been research showing this pattern. The current review aimed to systematically review autism research in the past 20 years to determine who is being studied. The results of this review revealed that 94% of the reviewed studies (n = 2688) included younger population (infants, toddlers, children, and adolescents). Implications regarding these findings are discussed.

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1. Introduction

Autism spectrum disorder (ASD) is now considered one of the most prevalent neurodevelopmental disorders, characterized by social and communication deficits and the presence of restricted and repetitive behaviors (Chowdhury, Benson, & Hillier, 2010; Fodstad, Matson, Hess, & Neal, 2009; Horovitz & Matson, 2010; Matson, Belva, et al., 2012; Matson, Boisjoli, Hess, & Wilkins, 2010; Matson, Gonzales, Wilkins, & Rivet, 2008; Tidmarsh & Volkmar, 2003; Worley & Matson, 2012). ASD often co-occurs with medical conditions such as gastrointestinal disorders, epilepsy, visual and hearing impairments, and motor disorders (Canitano, 2007; Kilinen, Rantala, Timonen, Linna, & Moilanen, 2004; Rosenhall, Nordin, Sandstrom, Ahlsen, & Gillberg, 1999). ASD also has high comorbidity rates with intellectual disability (ID) and other

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psychopathology including attention deficit hyperactivity disorder (ADHD), anxiety disorders, and obsessive–compulsive disorder (Ghaziuddin, Tsai, & Ghaziuddin, 1992; LaMalfa, Lassi, Bertelli, Salvini, & Placidi, 2004; Leyfer et al., 2006; Matson & Bojsjoi, 2007; Matson, Rivet, et al., 2009; Matson, LeBlanc, & Weinheimer, 1999; Matson & Shoemakers, 2009; Matson & Smiroldo, 1997; Matson, Smiroldo, Hamilton, & Baglio, 1997; Paclawskyj, Matson, Bamberg, & Baglio, 1997; Simonoff et al., 2008; Tureck, Matson, May, & Turygin, 2013). Challenging behaviors are particularly problematic (Matson et al., 2005). These problems can trigger the use of a range of restrictive treatments, particularly drugs, which may have serious side effects (Advokat, Mayville, & Matson, 2000; Matson, Carlisle, & Bamberg, 1998; Matson & Wilkins, 2008). In addition to various behavior and medical problems, many skill deficits such as adaptive behavior are also major issues (Matson, Dempsey, & Fodstad, 2009).

The prevalence rates of ASD have dramatically increased in the last several decades (Baron-Cohen et al., 2009; Center for Disease Control and Prevention [CDC], 2012). In 2003, approximately 5.7 per 1000 children in the United States were estimated to have a diagnosis of ASD (CDC, 2006). Currently, ASD is affecting approximately 1 in 88 children in the United States (CDC, 2012). Due to its high prevalence rate and the complex symptom presentation, ASD has been studied extensively (Matson, Tureck, et al., 2012; Matson & Jang, 2013; Tanguay, 2000).

ASD was once considered untreatable resulting in a significant lifelong condition (Kanner, 1971; Lotter, 1978). With the increased awareness of ASD, advancement of ASD diagnosis/screening, and empirically supported treatment approaches such early intensive behavioral intervention (EIBI), better outcomes in individuals with ASD have been reported (Howlin, 1998; Lovaas, 1987). But, even so, autism symptoms are life long (Billstedt, Gillberg, & Gillberg, 2005; Gardiner & Iarocci, 2012; LoVullo & Matson, 2009; Matson & LoVullo, 2009; Matson & Rivet, 2008). When left untreated, ASD symptoms as well as comorbid psychopathology and challenging behaviors may interfere with effective education, social behavior, and overall quality of life (Matson, Carlisle, & Bamberg, 1998; Matson, LeBlanc, & Weinheimer, 1999). Furthermore, family members of affected individuals may face additional challenges including financial difficulties. While ASD affects individuals of all ages, the current autism research is heavily focused on children. Although this trend has been a norm, there has not been previous research showing this pattern. Therefore, the goal of the current study was to systematically examine autism research in the past 20 years to determine who is being studied.

2. Method

The search engine Scopus was used in the current study. It is the largest database of peer-reviewed journals, covering 53 million records and over 20,000 titles from 5000 international publishers. Technical areas covered include social sciences, psychology, medicine, health professionals, and arts and humanities. A search of the autism literature was conducted using the term autism for the past 20 years (from 1994 to 2014). The search was limited to journals that were specifically about autism or developmental disabilities/disorders. The following seven journals were included for this review: American Journal on Intellectual and Developmental Disabilities, Autism, Journal of Autism and Developmental Disorders, Journal of Developmental and Physical Disabilities, Journal of Intellectual and Developmental Disability, Research in Autism Spectrum Disorders, and Research in Developmental Disabilities.

Studies that included individuals with a diagnosis of autism spectrum disorder were included for this review. Reviews, meta-analyses, letters to the editor were excluded. Each article was reviewed for age ranges of the participants and the topic studied. The mean age of the participants was used instead if the age range was not reported. Studies that did not report any age data were excluded. Participants were categorized into four groups: infants/toddlers (0–3 years), children (4–9 years), adolescents (10–19 years), or adults (>20 years). Data were collected by Ph.D. students in clinical psychology program over a 1-month period.

3. Results and discussion

Initially, a total of 3635 articles were identified and reviewed, and 778 articles that did not meet inclusion criteria were excluded. A total of 2857 articles were included in the current review. This review may not be completely exhaustive as we limited our search to seven journals and excluded those studies that did not include data on age; however, we believe that the review is representative of current ASD research as these seven journals were specifically about autism or developmental disabilities/disorders.

Reviewed studies covered a variety of topics including diagnosis, assessment, treatment, challenging behaviors, comorbidity, cognition, social/communication, repetitive and restricted behaviors, pharmacology, etiology, and more. With the increased prevalence rates of ASD, autism research has become a popular area of study in the last two decades (Matson, Tureck, et al., 2012). In agreement with this statement, the results of the current review showed a clear pattern of increase in ASD research in the last 20 years (Fig. 1).

Studies were categorized into 10 different age groups: All ages range (ages 0 to >20), adolescents to adults range (ages 10 to >20), children to adults range (ages 4 to >20), children to adolescents range (ages 4–19), infant/toddlers to adolescents range (ages 0–19 years), infants/toddlers to children range (ages 0–9), adults only range (ages >20), adolescents only range (ages 10–19), children only range (ages 4–9), and infants/toddlers only range (ages 0–3). Seventy-two studies included participants from small children to older adults. Two hundred and twenty eight studies focused on adolescents and adults, 118 studies on children, adolescents, and adults, 769 studies on children and adolescents, 265 on infants/toddlers, children,
and adolescents, and 401 studies on infants/toddlers and children. Moreover, 187 studies focused on adult participants only, 276 studies on adolescents only, 364 on children only, and 177 studies on infants/toddlers only (Fig. 2).

In total, 94% of the studies reviewed (n = 2688) included infants, toddlers, children, and adolescents (up to 19 years of age). As most readers would expect, ASD research has been extensively focused on children and adolescents. More specifically, 32% of the reviewed studies (n = 915) included infants and toddlers. Seventy percent of the reviewed studies (n = 1989) included children, and 60% (n = 1728) included adolescents. Finally, 21% of the reviewed studies (n = 605) included adults of 20 years or older. These data were highly biased toward the young and the very young (Fig. 3).

To our knowledge, this is the first study to systematically examine age ranges of the participants in ASD research in the last two decades. The heavy focus on younger populations with ASD is encouraging as it is imperative to identify the disorder as early as possible and to study relevant topics such as comorbidity and challenging behaviors in order to effectively treat it (LoVullo & Matson, 2009; Matson, Rieske, & Tureck, 2011; Smith & Matson, 2010a,b,c). However, we should not overlook the fact that the largest segment of the ASD population consists of adults. Based on our review, approximately 20% of autism research included individuals over 20 years of age. Also, it should be noted that health, education, and mental health services
Fig. 3. A total number of studies by age groups.

are particularly lacking among these older persons. Given that autism symptoms persist through adulthood, the attention that adults with ASD is receiving is not enough. Furthermore, the mean age of the adults was approximately 38 years old, and the median was 35 years old. Only 3% of reviewed studies (n = 75) included individuals over 60 years of age. This trend is problematic because the majority of a person’s life is spent as an adult, and it is likely that the types of services needed for adults are different from those needed for younger individuals (Matson & Jang, 2014).

Previously, researchers looked at outcomes of individuals who were previously diagnosed with ASD both prospectively and retrospectively (Billstedt et al., 2005; Howlin, Good, Hutton, & Rutter, 2004; Seltzer et al., 2003). These studies yielded mixed results. For example, Billstedt and colleagues (2005) found that their sample children who were diagnosed with autism in the 1960s, 1970s, and 1980s had poor outcomes about one or two decades later. On the other hand, Seltzer et al. (2003) reported overall improvement in functioning and decrease in problematic symptoms in their sample population (ages 10–53 years) compared to when they were 4–5 years of age. Howlin and colleagues (2004) reported that a few adults with ASD gained independence; however, most had poor outcomes, heavily dependent on their family members and still exhibiting significant core symptoms of ASD.

Moreover, many studies looking at outcome for children receiving EIBI have been conducted and showed promising results. Children who received EIBI significantly improved in adaptive behaviors, challenging behaviors, and communication skills (Eikeseth, Klintwall, Jahr, & Karlsson, 2012; Eldvik, Hastings, Jahr, & Hughes, 2012; Fava et al., 2011; Makrygianni & Reed, 2010; Peters-Schiffer, Didden, Kozulius, & Sturme, 2011). While this is promising, whether these positive results persist into adulthood is not yet known. Hence, more research focusing on adults with ASD and early on treatment effects is needed. Further, how their symptom expressions differ from those of children and issues that are associated with work and social behavior should be studied. Future research examining symptom presentation, comorbid psychopathology, intervention, and care and support in adults with ASD are in dire need to help adults with ASD function adequately and independently.

References


