Early identification of learners with autism spectrum disorder: drawing on developmental histories

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Abstract

This article examines early developmental histories of learners who attended a government-funded school for children with autism spectrum disorder (ASD) in South Africa from 1992 to 2014. A total of 141 complete historical admission records of learners were analysed. Frequencies, means and correlations were determined for perinatal conditions and developmental milestones. Low birth weight and preterm birth did not occur more than in the general South African population. Only 7.6% of the participants had delayed motor development. Self-help skills, except for feeding, were mostly achieved according to typical developmental criteria. Half of the participants started talking after the age of three years and that was the main reason why parents became concerned about their development. The percentage of participants who were non-verbal and had regressed speech was higher than that reported in other studies. Public information should focus on early developmental factors associated with ASD risk to expedite early identification and diagnosis.

Keywords

Autism spectrum disorder, early developmental histories, early identification, motor development, self-help skills, speech-language development

Globally, early identification and diagnosis of young children with Autism Spectrum Disorder (ASD) have shown to be not only important but also possible (Mandell, Novak, & Zubritsky, 2005). Early intervention should not be delayed, as there is evidence of improved outcomes for toddlers with ASD and parents have shown to recognize features of ASD in their children before the age of two (Dawson et al., 2010; Manning-Courtney et al., 2003; Mitchell, et al., 2006). Middle-class parents in Washington DC were able to recognize ASD features between the ages of 8 and 10 months, based on home video recordings of their children's development (Werner, Dawson, Osterling, & Dinno, 2000). Clifford and Dissanayake (2008) used retrospective parental interviews and home videos of infants who were later diagnosed with ASD to detect signs of ASD. The researchers were able to recognize features of ASD as early as the first 6 months of life (Clifford & Dissanayake, 2008). With the growing emphasis of early identification of ASD, much effort has been directed at determining the reliability and stability of early diagnosis of the condition (Chawarska, Klin, Paul, Macari, & Volkmar, 2009; Johnson & Myers, 2007). Recent studies conducted in the U.S.A have found that that ASD can now be reliably diagnosed at the age of 14 months (Chawarska et al., 2009; Gunthrie, Swineford, Nottke, & Wetherby, 2013). Baron-Cohen et al. (1996) conducted a population-based study screening 16,000 British 18-month-old children for autism with the Checklist for Autism in Toddlers (CHAT). Only 12/16,000 children were diagnosed with ASD. All 10 toddlers were reassessed at age 40 months using the Autism Diagnostic Interview – Revised (ADI-R) and again a diagnosis of ASD was confirmed in all 40 toddlers. Another population-based study conducted in the Netherlands

by van Daalen et al. (2009) found that the inter-rater reliability and stability of the diagnoses of ASD in 131 pre-schoolers at age 23 months were good. However, data in South Africa revealed late identification and diagnosis of ASD. van Biljon, Kritzinger, and Geertsema (2015) conducted a retrospective study in a school for children with ASD in South Africa. They compared the demographic characteristics of learners over two time intervals: 1992–2002 (Group 1) and 2003–2014 (Group 2). The mean age when children were identified was 48.8 months in Group 1 and 52.3 months in Group 2. Their results indicated that after 2002, the learners were identified even later (van Biljon et al., 2015). A small percentage of the participants were identified as late as eight years, with half of the participants (49%) receiving an ASD diagnosis only at age 60–95 months. Possible explanations for the late age of identification and diagnosis might be limited parental knowledge of normal developmental milestones, limited awareness of developmental disorders such as ASD, limited schools and services accessible in South Africa for children with special needs, and limited space in selected special schools. Future research is needed regarding the age of identification and diagnosis of children with ASD in South Africa.

Background

Gardener, Spiegelman, and Buka (2011) conducted a systematic review and meta-analysis of epidemiologic literature published on the association between perinatal factors and ASD risk. Forty studies qualified for the meta-analysis and over 60 perinatal factors were examined. The following factors were associated with ASD risk: abnormal birth presentation, umbilical cord complications, foetal distress, birth injury or trauma, multiple birth, maternal haemorrhage, summer birth, low birth weight (LBW), small-for-gestational age, congenital malformation such as Down syndrome, low Apgar score, neonatal feeding difficulties, meconium aspiration, neonatal anaemia and hyperbilirubinemia. Factors that were not associated with ASD risk were anaesthesia administered to the mother, post-term birth, high birth weight and small or large head circumference (Gardener et al., 2011).

Apart from identifying perinatal factors contributing to ASD risk, certain developmental characteristics may also assist early identification. Children with ASD present with delays in early motor development, which are typically not considered as factors in their diagnosis (Bhat, Landa, & Galloway, 2011; Matson, Mahan, Fodstad, Hess, & Neal, 2010). It has been widely reported that children with ASD present with more delays in motor skills than children with other developmental disorders (Krakowiak, Goodlin-Jones, Hertz-Picciotto, Croen, & Hansen, 2008). Matson et al. (2010) assessed the motor skills of 397 toddlers 17–36 months at an early intervention centre in Louisiana. Toddlers who had developmental difficulties or medical conditions likely to result in delay qualified for this study. Three groups were included in this study: ASD, Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) and toddlers with other developmental delays. The researchers found that toddlers with developmental delays had significantly better gross motor skills than toddlers diagnosed with ASD (Matson et al., 2010). Delayed motor development in chil-dren diagnosed with ASD may also predict language development (Leonard, Bedford, Pickles, & Hill, 2015).

A prospective study conducted in the United Kingdom assessed the impact of early motor skills on the rate of language development in children with older siblings with ASD, who are at risk of developing ASD themselves (Leonard et al., 2015). Using the Mullen Scales of Early Learning as predictors of language growth, the researchers found that gross motor scores predicted the rate of expressive, but not receptive language development in at-risk siblings who were later diagnosed with ASD. The results were consistent with Bhat et al. (2011) who reported that early motor difficulties were related to poor communication outcomes in 18-month-old infants.

The identification of early developmental risk factors may guide efforts for early detection, diagnosis, and intervention. In Africa, very little research has been conducted about the early developmental histories of children with ASD. This provides a clear rationale for our study.

Goals of the study

The primary aim of the study was to examine the early developmental histories of children with ASD who attended an autism-specific government-funded school in South Africa from 1992 to 2014. The three sub-objectives that guided our study were: (1) to examine the early motor developmental milestones of learners with ASD, (2) to examine the development of self-help skills of the learners and (3) to examine the early speech-language developmental histories of the same learners.

Method

Setting

The school where our study was conducted was established in 1973 and is situated in an urban area in the Gauteng province. It accommodates approximately 111 learners between the ages of 3 and 18 years. Admission to the school requires an ASD diagnosis and no intellectual disability. The school has a long waiting list and a child may not be admitted directly. The children who are not directly admitted is referred to a school for children with special needs until there is an opening, therefore contributing to late start of education in some children.

Participants

The target population of the study were all learners admitted to the school from 1992 to 2014. The researchers reviewed 141 (35.5%) complete historical records in paper-based files of the total number of 397 children who were admitted to the school during 1992–2014. Participants whose historic records were used in the study had to comply with the following inclusion criteria: diagnosed with ASD according to the DSM-IV (American Psychiatric Associaiton [APA], 1994) or DSM-IV-TR (APA, 2000) and admitted at the school between 1992 and 2014. There were more males (89.4%) in the study sample than females (10.6%) and the male-to-female ratio was 8.4:1. The male-to-female ratio in this study was unusually higher than that described by many studies within the United States and elsewhere where the male–female ratio in children with ASD was 4.1 (Fombonne, 2009; Idring et al., 2015). The reason why there were more males than females in this study could reflect the difficulty of diagnosing ASD in females (New, Triebwasser, & Charney, 2008). Females with Asperger syndrome (now ASD according to APA, 2013) might present as other conditions such as borderline personality disorder or anorexia nervosa (New et al., 2008; Treasure, 2007).

Procedure

The records reviewed included reports from professionals, a questionnaire completed by parents, and information about the learner's school progress. Parents who apply for admission to the school complete a case history form. During the course of the child's initial assessment and interview with the parents, the school team obtained missing information and this was supplemented by the questionnaire. Based on the information obtained from the parent questionnaire, the researchers were able to create a structured electronic checklist, with important information being captured from the questionnaire. The available historical admission records also included those from the archive and the records of the current learners whose parents completed consent forms. Many records of previous learners were lost, but available files contained the complete information required for the study. Since convenience sampling was used in the study, there can be no generalization beyond this sample.

Statistical analysis

After compiling a data dictionary to map the variables and code the procedures, the researchers captured the data into IBM SPSS [Version 22] (IBM Corp, 2013) in order to facilitate analysis. Means and frequencies were calculated to strengthen and validate the retrospective data obtained. The Pearson correlation coefficient was used to explore the underlying relationships amongst variables.

Ethical considerations

The researchers obtained written permission from University of Pretoria, the Gauteng Department of Basic Education (D2014/268), and the principal of the autism-specific government-funded school. Informed consent was obtained from parents of the participants attending the school at the time of data collection, while the school gave permission that historical records may be reviewed.

Results and discussion

A description of the perinatal characteristics of the participants (n = 141) is presented in Table 1.

As a group, most (83.7%) of the participants were full term at 41.4 weeks, with 14.9% born preterm. Findings from our study correspond with Pattinson (2013) who reported the preterm birth rate in South Africa to be 14.17%%. The frequency of preterm birth in our sample was therefore not more than the national preterm birth rate. Furthermore, our results correspond with findings from a population-based study conducted in Denmark between 1980 and 2009 (Atladóttir, Schendel, Henriksen, Hjort, & Parner, 2016). The researchers investigated whether the association between gestational age and ASD has changed over the past 30 years (Atladóttir et al., 2016). They reported that the risk for ASD from preterm births had decreased over the years since more children with ASD were born at term (Atladóttir et al., 2016).

The mean birth weight was 2407.8 g, which is seen as LBW. Eighty-seven per cent of the participants in our study had had a birth weight of 2500 g or more and only 12.8% had a LBW (<2500 g). Our results are less than the LBW prevalence in South Africa which is 14.7% (Pattinson, 2014).

Significant negative and positive associations were found when considering whether there was a relationship between gestational age and difficulties during pregnancy or after birth (r = -.192; p-value = >.022) and the birth weight of the baby (r = .516; p-value = >.000). The result means that the lower the gestational age and birth weight in the participants, the more difficulties during pregnancy and after birth were experienced. It is well known that preterm birth and LBW are associated

Characteristics	Category	Frequency	%
Gestational age at birth (Mean age = 41.4 weeks)	<36 weeks	21	14.9%
	37–41 weeks	118	83.7%
	>42 weeks	2	1.4%
	TOTAL	141	100%
Difficulties during/after birth (Missing data = 2)	No difficulties	103	74.1%
	Neonatal jaundice	23	16.5%
	Mother had postnatal depression	1	0.7%
	Umbilical cord around neck	4	2.8%
	Respiratory distress	4	2.8%
	Pre-eclampsia	3	2.1%
	Foetal distress	1	1.0%
	TOTAL	139	100%
Birth Weight (Mean birth weight = 2407.8 g)	<1000 g	1	0.4%
	1000 g-1500 g	1	0.4%
	1500 g-2500 g	17	12.0%
	>2500 g	123	87.2%
	TOTAL	141	100%

Table 1. Perinatal characteristics of learners with ASD.

with complications during pregnancy and after the infant is born (Rossetti, 2001). Since the majority of participants were not born preterm, most of the participants (74.1%) did not have any difficulties during or after birth. The parental report showed that jaundice occurred very rarely in the sample (16.5%). Research has found that jaundice is an associated risk for ASD (Atladóttir et al., 2016). Maimburg, Bech, Væth, Møller-Madsen, and Olsen (2010) conducted a population-based study of all children born alive in Denmark between 1994 and 2004. They collected data from four national registers and found that infants who developed neonatal jaundice were 67% more likely to be diagnosed with ASD. Bhutani (2012) report from a multicentre study in the United States that 84% of typical newborns had jaundice. It could be that jaundice was underreported in our study. Participants may have been discharged from the hospital soon after birth, before jaundice could be diagnosed.

To conclude, it appears that most of the participants were term infants, with LBW, and only a small percentage had jaundice after birth.

The early motor and self-help developmental histories of the participants are provided in Table 2.

Only a small percentage of participants from our study had delayed motor development. A single self-help skill, feeding, appeared to be delayed. The participants' motor milestones and self-help skills followed a typical sequence of development according to expected patterns. Significant, positive associations between the following motor milestones and self-help skills were found: crawling and walking (r = .554; p-value = .000); crawling and running (r = .241; p-value = .010); walking and running (r = .514; p-value = .000), running and toilet-training (r = .358; p-value = .000); self-feeding and toilet-training (r = .297; p-value = .001) and toilet-training and dressing unassisted (r = .286; p-value = .002).

The results showed that the majority of participants (92.3%) were sitting without support between the ages five and nine months. Our results correspond with a cross-sectional study conducted by Lloyd, MacDonald, and Lord (2013) in three centres in North Carolina, Chicago and Michigan. They found that the mean age for sitting without support in children with ASD was 7.19 months. Normal developing children are able to sit unassisted between the ages of four and nine months

Characteristics	Category	Frequency	%
Age when participant started sitting	<4 months	2	1.7%
(Mean age = 7.1 months)	5–9 months	108	92.3%
(Missing data = 24)	>10 months	7	6.0%
	TOTAL	117	100%
Age when participant started crawling	>6 months	1	0.9%
(Mean age = 9.3 months)	6–12 months	108	91.5%
(Missing data = 23)	>13 months	9	7.6%
	TOTAL	118	100%
Age when participant started walking	<9 months	0	0%
(Mean age = 13.5	9–18 months	111	95.7%
months)(Missing data =	>19 months	5	4.3%
25)	TOTAL	116	100%
Age when participant started running	12–31 months	107	93.0%
(Mean age – 22.9 months)	32–51 months	7	6.0%
(Missing data = 26)	52–72 months	1	1.0%
	TOTAL	115	100%
Age when participant was able to self-feed	<11 months	0	0%
(Mean age = 20.5	12–20 months	19	15.0%
months)(Missing data =	>21 months	97	85.0%
27)	TOTAL	114	100%
Age when participant was toilet-trained	<15 months	1	0.8%
(Mean age = 32.3	15–42 months	83	72.2% %
months)(Missing data =	>43 months	31	27.0%
26)	TOTAL	115	100%
Age when participant was able to dress unassisted	<37 months	32	28.8%
(Mean age = 46.5	38–60 months	73	65.7%
months)(Missing data =	>61 months	6	5.5%
30)	TOTAL	111	100%

Table 2. Early motor developmental and self-help skills histories of learners with ASD.

(Lightfoot, Cole, & Cole, 2013). Therefore children from our sample achieved the milestone for sitting within the normal age ranges associated with typical development.

Most of the participants (91.5%) started crawling between the ages of 7 and 12 months. The findings suggest that participants from our study started crawling within the expected age ranges related to normal development since typically developing children are able to crawl between eight and nine months (Lightfoot et al., 2013).

Learning to walk unassisted is another important developmental milestone, which is normally achieved around 12 months of age in typically developing children (Adolph & Robinson, 2013; Onis, 2006). The majority (95.7%) of participants from our study were only able to walk unassisted between the ages of 9 and 18 months with the mean age being 13.5 months. Hence, children from our sample were able to walk unassisted within the expected age ranges associated with normal development.

The mean age when participants from our sample were able to run well was 22.9 months and majority of participants (93.0%) were able to run well between the ages of 12 and 31 months. Our results agree with Gerber, Wilks, and Erdie-Lalena (2010) who reported that typically developing children are able to run well at the age of 18 months. Therefore, participants in our study were able to run well within normal ranges reported in literature (Gerber et al., 2010).

In summary, it appears that only small percentage (7.6%) of children from our study presented with motor developmental delay as reported by their parents. Children from our study were able to sit, crawl, walk and run within the expected age ranges associated with normal development. Fournier, Hass, Naik, Lodha, and Cauraugh (2010) reported that the reason why some children with ASD present with motor developmental delay is that they have poor motor coordination skills which prevent them from achieving the typical motor developmental milestones.

The self-help skills of the learners with ASD were also investigated. Anderson, Jablonski, Thomeer, and Knapp (2007) reported that children with ASD have difficulty learning self-help skills such as eating, dressing and toileting. Therefore, a primary goal for all children with ASD is to be able to function independently in their completion of daily living activities, such as eating, getting dressed and using the toilet (Lucker, 2009). The mean age when participants in our study were able to self-feed was at the age of 20.5 months. Eighty-five per cent of the participants were able to self-feed after the age of 21 months and only 15% were able to self-feed between 12 and 20 months. Typically developing children are able to self-feed between the ages of 15 and 18 months (Carruth, Ziegler, Gordon, & Hendricks, 2004). Therefore, most participants from our study show delayed self-feeding skills.

Less than one per cent of the participants were toilet-trained before the age of 15 months. The results show that the majority of participants (72.2%) were toilet-trained between the ages of 15 and 42 months (mean age 32.3 months). Twenty-seven per cent of the participants were toilet-trained only after the age of 43 months.

Our results correspond with a longitudinal survey conducted in Wisconsin, United States, by Schum et al. (2002) who found that typically developing children were toilet-trained by the age of 32.5 months for girls and 35.0 months for boys. Therefore, the majority participants from our study did not show delayed toilet-training skills.

The mean age when participants were able to dress unassisted was 46.5 months. Twenty-eight per cent of the participants were able to dress unassisted before the age of 37 months. More than half (65.7%) of the participants were able to dress unassisted between the ages of 38 and 60 months.

Only five per cent of the participants were not able to dress unassisted after the age of 61 months.

Our results correspond with a study conducted in Japan by Anme and Segal (2003) who pursued to standardize an evaluation scale to measure the development of children. Anme and Segal (2003) found that typically developing children were able to dress unassisted by the age of 56 months. Participants from our study were able to dress unassisted within the age range associated with normal development.

In conclusion, participants from our study presented with delayed self-feedings skills, but very few delays in toilet-training or dressing unassisted. Table 3 describes the early speech-language

developmental histories of learners with ASD. Both verbal and non-verbal participants were accepted for school admission.

Speech-language developmental norms indicate that typically developing children are able to produce their first words between the ages of 12 and 18 months (Owens, 2015). According to norms provided by Owens (2015), participants from our study started talking later than typical developing children which agrees with the study by Mitchell et al. (2006) who confirmed that language delay is already apparent early in life in children with ASD.

It appears that parents were very late in becoming concerned about their children's development. By far, the majority of parents (93.5%) became concerned when their child was older than 36 months (mean age was 50.5 months), even though their children already showed late emergence of first words by that time. Studies of parental concerns about children who were later diagnosed with ASD showed that many parents recognized atypical development by their child's second birthday (Chakrabarti, 2009; Chawarska, Klin, Paul, & Volkmar, 2007). The age at identification of ASD symptoms by parents in our study also differed from the age of children in four Australian states (South Australia, New South Wales, Queensland and Victoria) where parents had developmental concerns about their children before their first birthday (Young, Brewer, & Pattison, 2003). It appears that parents from our study could have been unaware that their child had a developmental delay and consequently unable to identify the developmental concerns early.

The main concern why parents became concerned about their child's development was delayed speech (64.3%). The results show that late emergence of speech was as a warning signal for the parents, but only after some time had passed (on average at 50.5 months). Our results correspond with De Giacomo and Fombonne (1998) who also reported that the most common parental concern in children with ASD was delayed speech and language development. It appears that parents were unaware of ASD, which is confirmed by the result about the advanced age of identification of the child.

The great majority of participants (84.3%) at the time of school entrance were non-verbal and 46.8% had regressed speech. Our results are higher than that reported by Springer, Van Toorn, Laughton, and Kidd (2013) who found that 72.4% of the participants in the tertiary hospital clinic in the

Characteristics	Category	Frequency	%
Age when participant said first word	<11 months 12–	17	12.0%
	18 months	48	34.0%
	>19-60 months	69	48.9%
	Non-verbal	7	4.9%
	TOTAL	141	100%
Age when parents became concerned about child's development	24–35 months	9	6.3%
	36–47 months	60	42.5%
(Mean age = 50.5 months)	48–59 months	25	17.7%
	60–71 months	33	23.4%
	>72 months	14	9.9%
	TOTAL	141	100%
Reason why parents became concerned about child's development	Delayed speech development	92	65.2%
	Autistic behaviour	26	18.4%
	Suspected hearing loss	3	2.1%
	Speech regressed	18	12.7%
	Struggling to cope academically at school	2	1.4%
	TOTAL	141	100%
Speech-language developmental history	Verbal at time of school admission	22	15.7%
	Non-verbal at time of school admission	119	84.3%
	Total:	141	100%
	Speech regression	66	46.8%
	No speech regression	75	53.2%
	TOTAL	141	100%

Table 3. Early speech-language developmental histories of learners with ASD.

Western Cape were non-verbal and 17.2% had regressed speech. The results correspond with a population-based case–control study in California by Hansen, Ozonoff, and Krakowiak (2008) who reported that up to 40% of children with ASD experience regressed speech. Regressed speech or loss of spoken language commonly occurs at 19–21 months and is considered a clear 'red flag' for ASD (Webb & Jones, 2009).

In summary, participants from our study started talking late and that was also the main reason why parents became concerned about their development. Parents only became concerned about their child's development at a late age, despite the children already showing late emergence of first words (mostly after 19 months – see Table 3). Furthermore, the majority of participants were non-verbal at the time of school entrance and almost half had regressed speech.

Limitations

The researcher relied solely on secondary data from the school's historical admission records. Therefore, data were abstracted from historical admission records which were not validated against direct contact and observations. Another limitation was the convenience sampling technique due to the small number of complete school records. Randomized selection of records would have ensured a representative sample of the school population over the years. Lastly, data on some variables were missing for a portion of the sample but did not have an influence on the statistical analysis and results.

Recommendations and future research

Future research should focus on examining the perinatal characteristics of children with ASD to confirm and understand the findings in the study. Early motor skills is important for the development of other domains; therefore, it is essential that more research should focus on the early motor developmental histories of children at risk for developing ASD (Iverson, 2010). Observational research will provide more reliable data than the file records used in the present study. Further research should be conducted to examine the self-help skills of children with ASD, as it is an important skill to master self-help skills for independence. Reasons why parents only became concerned about their children after three years of age should be investigated in further studies. There may be unidentified barriers to early detection of ASD in South Africa.

Conclusion

In this article, we provide evidence that it is important to document the early developmental histories of children with ASD. Further research is required to establish whether children with ASD in South Africa present with a distinctive developmental profile. Knowledge of the early developmental histories of children with ASD in South Africa and parental response to delayed development may hold the key to develop awareness programmes for early identification and diagnosis. LBW and preterm birth did not occur more than in the general South African population. Only 7.6% of the children in the sample had delayed motor development, and self-help skills were mostly according to typical developmental criteria. Almost half (48.9%) of the children started talking late (>19-60 months) and that was also the main reason why parents became concerned about their development. Parents only became concerned about their child's development at a mean age of 50.5 months, despite the child already showing late emergence of first words. The large number of participants who were non-verbal and had regressed speech is higher than that reported in other studies. The study highlights distinctive speech developmental characteristics of children in an autism-specific school which may provide the opportunity to improve early identification rates of ASD. Parents should be made aware that late talking and regressed speech in a child are reasons for seeking professional help without delay. The identification of developmental risks in early

childhood may guide efforts for timely detection, diagnosis and intervention of children with ASD. It is therefore important to educate the public about the early developmental factors associated with ASD risk to expedite and facilitate early identification and diagnosis of ASD.

Disclosure statement

No potential conflict of interest was reported by the authors.

Notes on contributors

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