

Onset of intervention for learners in autism-specific government-funded schools in South Africa

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Abstract

Late identification of children with ASD remains a concern. Due to limited research in low and middle-income countries (LMICs) such as South Africa (SA), the early management of autism spectrum disorder (ASD) should be further explored. The aim was to describe the demographic characteristics and typical early management of learners attending the six autism-specific government-funded schools in SA. Participants included 234 (28.4% of total approached) caregivers of children with ASD enrolled at the only six autism-specific government-funded schools in SA. Data were collected from parent-completed questionnaires. The majority of caregivers became concerned about their child's development on average at 25.2 months, but only a few (3.8%) thought it was ASD. Late identification was significantly associated with the respondent, nationality, qualification of the father and qualification of the mother. It appears that late identification sets a trajectory of late intervention. Factors underlying the trajectory appear to be unfamiliarity with ASD, and limited services and schools for children with ASD. Public awareness should focus on early symptoms associated with ASD risk to expedite early intervention.

Keywords: Autism spectrum disorder; demographic characteristics; families; government-funded schools; identification; intervention; late onset; learners; South Africa

Introduction

With the growing concern over the increased prevalence together with greater awareness, much effort has been directed towards early identification of autism spectrum disorder (ASD)

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(Wiggins, Baio, & Rice, 2006). A growing body of evidence suggests that early identification and diagnosis of ASD is not only important but also possible (Kleinman et al., 2008; Mandell, Novak, & Zubritsky, 2005). In a retrospective study researchers were able to recognise early ASD features in children between the ages of 8-10 months, who were later diagnosed with ASD, utilising data from home video recordings (Werner, Dawson, Osterling, & Dinno, 2000). Similarly, in a prospective, longitudinal study the emergence of early behavioural signs of ASD was evident by 12 months of age (Ozonoff et al., 2010). In the United States (US) ASD can now be diagnosed reliably between the age of 8-14 months (Chawarska, Klin, Paul, Macari, & Volkmar., 2009; Guthrie, Swineford, Nottke, & Wetherby, 2013). In contrast, research in SA (SA) revealed late diagnosis of ASD (authors). A retrospective study conducted in a single school in SA found that the mean age of diagnosis in children with ASD was 76.1 months (authors). Late diagnosis was also revealed in a survey of 1047 caregivers of children with ASD in the United Kingdom (UK) where the mean age of ASD diagnosis was 89 months (Crane, Chester, Goddard, Henry & Hill, 2016). Early identification precedes early diagnosis and intervention and is critical for improving developmental outcomes for children with ASD by capitalising on the sensitive period for language and cognitive development during preschool years (Mazurek et al., 2014).

Background

Certain demographic characteristics and early management factors are often associated with age of identification and diagnosis (Brett, Warnell, McConachie, & Pan, 2016). It appears that factors linked to delayed identification and diagnosis of ASD can be modified or can be targeted for improved management where the ultimate goal is early identification.

A systematic review revealed that a number of diverse child, family and community level factors are associated with late ASD diagnosis: African-American race, immigrant

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status of mother, later parental concern, presence of hearing impairment, co-occurring neurologic and psychiatric conditions in the child, greater number of professionals seen prior to ASD diagnosis, and when an ASD diagnosis was made by a team of professionals in schools (personal communication with the principal; Daniels & Mandell, 2014). Factors associated with early ASD diagnosis included speech and language regression before three years and when the child was referred from hospitals or speciality centres to a service provider for intervention, while no associations between age of diagnosis and gender were found (Daniels & Mandell, 2014).

Due to contradictory findings regarding the age of identification as well as limited research in low and middle-income countries such as SA, the demographic characteristics, early management of ASD and the age at which caregivers became concerned about their children's development should be explored (Springer, Vaughn, Laughton, & Kidd, 2013; authors). Such research may help South Africans understand children with ASD and their families better, identify possible demographic risk factors, promote early identification and diagnosis, identify parental needs, and plan educational support and appropriate services to learners (Musa & Fakher, 2016; Riya et al., 2014). Therefore the study aimed at describing the demographic characteristics and typical early management of learners attending the six autism-specific government-funded schools in SA.

Method

Setting

At the time of data collection, there were only six autism-specific government-funded schools, situated in urban areas, in SA. The learners attending the schools ranged between the ages of 3 and 21. Since the schools are only situated in three provinces, namely Gauteng, Western Cape, and Eastern Cape Provinces, the other six provinces in SA were excluded

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from the study. Independent schools were excluded from the study as they are not all ASD specific. The learner admission requirements for all six schools were twofold: the child had to be diagnosed with ASD and caregivers had to work or live in the school's catchment area. All these schools have long waiting lists, and a child might not be admitted to the school directly. On average the distance which learners had to travel from home to school was 16.4 kilometres (km). After school admission, multi-disciplinary teams assess the child to determine the current level of performance and to prioritise educational needs.

Participants

The autism-specific government-funded schools in SA provide access to the largest population of school-going children with the disorder in SA and are therefore population-rich ("Autism government funded schools", 2016). The potential participants were all the caregivers of learners attending the participating schools. Non-probability, purposive sampling was used to select the caregivers. Of the total number of 823 self-completion questionnaires that were distributed to all children attending the autism-specific schools, 234 (28.4%) were returned after having been completed by the mothers (85.0%), fathers (11.1%), family members (3.4%) and guardians (0.5%). The caregivers were not necessarily the primary caregivers of the learners. The response rate was not as high as desired. The highest response rate (58.3%) was from a recently established school in a township. Although it is acknowledged that there can be no generalisation beyond the study sample, the study may serve to build an understanding of the demographic characteristics and early management of children with ASD in SA. The majority (85.0%) of the caregivers were mothers. Eighty-eight percent were South African, and 11.5% were from other countries within Africa and the UK. Both mothers (44.4%) and fathers (36.3%) had an educational level of either diploma or degree or postgraduate qualification.

Data gathering and data management

Prior to the main investigation, a pilot study was conducted in one of the autism-specific schools to establish the validity and reliability of the questionnaire. Completed questionnaires of fifteen caregivers were selected and were reviewed. After completing the pilot study, minor amendments were made to the questionnaire. The extensive questionnaire distributed to the caregivers was adapted from questionnaires used in other studies (Amr et al., 2012; Becerra et al., 2014; Musa & Fakher, 2016; Riya et al., 2014; Springer et al., 2013; authors). Questions about gender, population group, home language/s, perinatal history, co-morbidities, medication, speech and language development, age at ASD identification and diagnosis, and intervention services consulted were included. Based on the information obtained from the questionnaire, a structured electronic checklist, with relevant information to be captured from the questionnaire was designed. Completed questionnaires without any missing information were used for analysis. The data were captured into IBM SPSS (Version 22) (IBM Corp, 2013) in order to facilitate analysis. Basic means, frequencies, standard deviations and descriptive tables were constructed to investigate and describe the distribution of the data. Non-parametric tests were used to explore associations and correlations between variables. Only characteristics which were significantly associated ($p < 0.05$) with age of parental concern were included in the second phase of the statistical analysis. As the data (first professional contact regarding concern) were too many to be added into the odds assessment in the categories allied health professionals ($n=128$), government primary healthcare clinic ($n=32$), general practitioner ($n=28$), and specialist professional ($n=18$), they were recategorised into two groups, namely specialist professional and allied health professional, governmental health clinic, and general practitioner. The descriptives in the odds assessment provided insightful results for the reference group.

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Ethical considerations

We obtained written permission from the University of Pretoria (GW20160702HS), the Gauteng Department of Basic Education (D2016/268), Western Cape Department of Education, Eastern Cape Department of Education, and the principals of the autism-specific government-funded schools. Informed consent was obtained from caregivers of the children attending each school at the time of data collection.

Results and discussion

Learner characteristics

The demographic characteristics of the learners ($n=234$) attending the autism-specific government-funded schools are provided in Table 1.

Table 1. Demographic characteristics of learners attending autism-specific government-funded schools (n = 234)

Characteristic	Category	Frequency (n)	Percentage (%)
1.1 Gender	Male	201	85.9%
	Female	33	14.1%
	Male-to-female ratio	6.1:1	
1.2 Age of child (mean age in years = 9.88) (SD = 6.2)	<4 years	10	4.3%
	5-9 years	123	52.6%
	>10 years	101	43.1%
1.3 Population group distribution	Black	182	77.8%
	Coloured	33	14.1%
	White	14	6.0%
	Asian/Indian	5	2.1%
1.4 Primary language at home	English	140	59.8%
	Other (Afrikaans, isiNdebele, isiXhosa, isiZulu, Sesotho sa leboa, Sesotho, Setswana, siSwati, Xitsonga, Shona or French)	94	40.2%
1.5 Term pregnancy	Full term	190	81.2%
	Preterm	44	18.8%
1.6 Birth order of the child	1 st child	108	46.2%
	2 nd child	63	26.9%
	3 rd child	39	16.7%
	4 th -7 th child	15	10.2%
1.7 Siblings diagnosed with ASD	Yes	21	8.9%

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As can be seen in Table 1, the predominant gender of the sample was male. The male-to-female ratio was 6.1:1. The gender disparity in this study was considerably higher than that reported by Fombonne (2009) in an epidemiologic study conducted in fifteen high-and-middle-income countries (UK, Denmark, US, Japan, Sweden, Ireland, Germany, Canada, France, Indonesia, Portugal, Finland, Iceland, Israel and Norway), where the male-to-female ratio was 4.2:1. The male bias could simply reflect the difficulty of diagnosing ASD in females (New, Triebwasser, & Charney, 2008). Evidence suggested that the clinical presentation of ASD is different in males than in females, although available findings are inconsistent (Rivet & Matson, 2011). Females may have more social difficulties and are less able to perform social play and imaginative social play than males (Attwood, 2007; Holtman, Bolte, & Poustka., 2007). Also, some females who present with the relevant symptoms tend to be diagnosed with other disorders such as social phobia or borderline personality disorder, instead of ASD (Van Wijngaarden-Cremers, 2017). These differences could lead to delayed or even missed diagnosis of ASD in females (Van Wijngaarden-Cremers, 2017).

The mean age of the learners in the six autism-specific schools was 9.8 years. More than half (52.6%) of the learners were between the ages of 5-9 years. The other half of the learners were >10 years (43.1%) and only 4.3 % were younger than four years. A possible explanation why more learners were between the ages of 5-9 years and older than >10 years may be because according to the South African Schools Act (Department of Education [DoE], 1996) children between the ages of seven and fifteen are compelled to attend schools.

The population groups and home languages spoken represent the cultural and linguistically diverse profile of the learners in the schools. The results indicated that while the majority (77.8%) of learners belonged to the black population group, 59.8% of the learners' primary language at home was specified as English and not an African language. Possible explanations may be that English is more frequently spoken by families in urban areas

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(Spaull, 2013) and to assist their children with ASD to learn the Language of Teaching and Learning (LoLT) used in the schools (personal communication with the teachers). However, the primary languages of 40% of the learners were Afrikaans, French, isiNdebele, isiXhosa, isiZulu, Sesotho sa leboa, Sesotho, Setswana, Shona, siSwati, Xitsonga. It therefore appears that the language diversity in SA limits first-language education for learners with ASD in the same measure as for learners without ASD (see e.g. Foley, 2008).

Most (81.2%) learners were full-term infants, with 18.8% born preterm. The preterm birth rate from our study is approximately 4% higher than the 14.17% national preterm birth rate reported in SA (Pattinson, 2013). The findings from the current study corresponded with the results from a population-based study conducted in Denmark between 1980 and 2009 (Atladóttir, Schendel, Hendriksen, Hjort, & Parner, 2016). The researchers found that across all birth year cohorts, the risk of being diagnosed with ASD increased with lower gestational age, although the overall risk for ASD from preterm births had decreased across the years as more children with ASD were born full term (Atladóttir et al., 2016).

Forty-two percent of children from a clinical sample in California were first-born (Fountain, King, & Bearman, 2011). Similarly, 46.2% of learners in the current study were first-born and therefore agree with results from other studies which found that there is an increased risk for ASD if the child was a first-born (Fountain et al., 2011; Gardener, Spiegelman, & Buka, 2009).

Twenty-one of the caregivers in this study indicated that they had more than one child diagnosed with ASD. Fewer families reported having another child with ASD than in a longitudinal study conducted in twelve international network sites by the Baby Siblings Research Consortium (BSRC) (Ozonoff et al., 2011). These researchers indicated that the chances of families with one or more child on the spectrum having another sibling with ASD

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are about 20% (Ozonoff et al., 2011). It remains important that families be counselled about the genetic risk of having another child with ASD.

To conclude, it appears that most of the learners were males from black, English speaking families and were first-born, full-term infants.

Early management of ASD

The early management of learners ($n=234$) attending the autism-specific government-funded schools is provided in Table 2.

Table 2. Early management of learners ($n=234$) attending the autism-specific government-funded schools

Characteristic	Category	Frequency (n)	Mean (SD)	Median	Percentage (%)
2.1 Age (months) when caregivers became concerned about child's development	<47 months	217	25.21 (13.4)	24	92.7%
	>48 months	17			7.3%
2.2 Reason why caregivers became concerned about the child's development	Delayed speech and language	136			58.1%
	Developmental delay	51			21.8%
	No response to name	44			18.8%
	No social interaction with peers	2			0.9%
	Atypical behaviour	1			0.4%
2.3 What caregivers thought was the problem or cause	Developmental causes	164			70.1%
	No idea	45			19.2%
	ASD	9			3.8%
	Medical causes	7			3.0%
	Mental difficulties	6			2.6%
2.4 First professional contact regarding concern	Environmental causes	3			1.3%
	Allied health professionals	128			54.7%
	Government primary healthcare clinic	32			13.7%
	General practitioner	28			12.0%
	None	28			12.0%
	Specialist professional, such as a developmental paediatrician, paediatric	18			7.6%

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2.5 Age (months) when child was first assessed by a professional	neurologist or a child psychiatrist				
	<47 months	183	34.75 (16.9)		78.2%
	>48 months	51			21.8%
2.6 Age (months) when child was diagnosed with ASD	<47 months	128	46.69 (22.3)		54.7%
	>48 months	106			45.3%
2.7 Professional involved with ASD diagnosis	Paediatric neurologist	97			41.5%
	Multi-disciplinary team	82			35.0%
	Child psychiatrist	54			23.1%
	Developmental paediatrician	1			0.4%
2.8 Age (years) when child was adm/itted to autism-specific school	<3.9 years	18	6.80 (6.1)	6	7.6%
	>4.0 years	216			93.1%

Eighty-five percent of the caregivers were mothers who became concerned about their child's development on average at 25.2 months. Studies of parental concerns about children who were later diagnosed with ASD have indicated that caregivers were able to recognise atypical development between the ages of 8 and 12 months (Young, Brewer, & Pattison, 2003; Werner et al., 2000). Significant, positive associations were found between the following variables and age when caregivers became concerned about their child's development: respondent ($p\text{-value} = <0.000$), nationality ($p\text{-value} = <0.002$), qualification of the father ($p\text{-value} = <0.027$) and qualification of the mother ($p\text{-value} = <0.016$). The results show that delayed age at parental concern was most likely associated with the respondent being the father, family-caregiver or guardian, being a South-African citizen, and having a lower level of parental education. Therefore, it appears that the lower level of education, the later the father, family-caregiver or guardian became concerned about their child's development. Generally, higher maternal education appears to be associated with more knowledge about child development (Chawarska et al., 2007; Herlihey, Knoch, Vibert &

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Vein, 2015). In our study, it appears that South African caregivers became concerned about their child's development later than caregivers from countries within and outside of Africa. A possible reason why caregivers from Africa became concerned about their child's development earlier than South African caregivers might be that the majority of children with ASD from countries in Africa do not have access to specialised education services (Thomas, Badoe, & Owusu, 2015) and caregivers are therefore compelled to do more research about their child's development in order to find specialised education for them. The delayed age at parental concern could also be due to the limited access to health services in SA (Petersen & Lund, 2011). It further appears from our results that caregivers may lack knowledge about typical developmental milestones in young children and therefore were unable to recognise developmental concerns at an early age. The result has further implications for policy in basic education, social development, and health departments in SA. The findings emphasise the importance of supporting and empowering caregivers using targeted awareness and early identification programmes for infants and young children with special needs.

Children with late language emergence (LLE) usually have an age-appropriate understanding of language and no other delays in the cognitive and motor domains but have limited spoken vocabulary at 24 months (Owens, 2016). In contrast, infants and young children with ASD show many difficulties, in particular, lack of social interaction, limited orientation to child-directed speech, restricted and repetitive behaviours and interests (Webb & Jones, 2009). The main reason why caregivers became concerned about their child's development was delayed speech and language (58.1%) and not about early ASD symptoms. The findings show that LLE in their children raised the alarm for caregivers (on average at 25.2 months), close to the age at which LLE is recognised as a missed language learning milestone. The current results are in agreement with those from other studies which also found that the most common parental concern in the case of children with ASD was LLE (De

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Giacomo & Fombonne, 1998; Herlihy et al., 2015; Kozlowski, Matson, Horovitz, Worley, Neal, 2011). It appears that caregivers in our study were unaware of early symptoms of ASD, which is confirmed by the findings of the later age at parental concern.

Once the caregivers became concerned about their child's development, less than 4% suspected the cause to be ASD. Seventy percent of the caregivers thought that their child's atypical behaviour was caused by developmental conditions such as hearing impairment, visual impairment, LLE, developmental delay, or attention-deficit-hyperactivity-disorder (ADHD). As mentioned earlier, the majority (85.0%) of the caregivers were mothers, and 87.2% of them thought the atypical behaviour was caused by developmental conditions. The results from our study indicate that caregivers were unfamiliar with ASD, which symptoms can already be identified during late infancy as indicated by Ozonoff et al. (2000) and Werner et al. (2010).

As seen in Table 2 (2.4) the majority (54.7%) of caregivers first consulted allied health professionals regarding their concerns. Furthermore, these caregivers became concerned about their child's LLE on average at age 25.2 months, contrasting sharply with the few caregivers (7.7%) who first consulted specialist professionals (developmental paediatrician, paediatric neurologist or child psychiatrist) at an earlier age of 19.1 months. The fact that allied health professionals, such as speech-language therapists and occupational therapists, were consulted first could indicate that caregivers did not know whom to consult when they first suspected that their child had developmental delays or that their child had a serious developmental condition which warranted specialised attention from the beginning. The result could also mean that there is a shortage of specialist professionals in SA. Therefore, caregivers sought help from the allied health professionals providing intervention for developmental delays first instead of professionals specialising in ASD diagnosis. Our results do not correspond with results from a study conducted in a clinic in the UK where

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general practitioners were the first to be consulted by caregivers of children with ASD (Giacomo & Fombonne, 1998). This may be due to differences in the structure of health services between the two countries. In the UK the first health service contact is the general practitioner (“Autism spectrum disorder”, 2016) and not the allied health professionals, whereas in SA it seems that the allied health professionals in the private sector are contacted first (Fewster & Gurayah, 2015).

The mean age of first assessment by a professional was 34.75 months, almost a year later than when the caregivers became first concerned about their child’s development. The results show that most learners assessed were surprisingly younger than the age of 48 months at first assessment reported for the large metropolitan area of Atlanta (Wiggins et al., 2006). Significant, positive associations were found between age at assessment and the following variables: age at parental concern ($r = .563$; $p\text{-value} = <0.000$), age at diagnosis ($r = .584$; $p\text{-value} = <0.000$) and age at admission to the autism-specific school ($r = .210$; $p\text{-value} = <0.001$). The results show that the later caregivers became concerned, the later the age at first assessment, the age of ASD diagnosis and age at admission to the autism-specific school. Therefore, although caregivers were concerned about their child’s development at 25.2 months already, they consulted a professional about their concern only after some time had passed (on average at 34.7 months of age) and children only received the ASD diagnosis much later (on average at 46.6 months of age) and were also admitted to the autism-specific schools even later (on average 6.8 years). The slow trajectory of delayed intervention may indicate the lack of parental awareness of ASD and limited services available to accelerate the process of admitting a child to an appropriate school in SA. Furthermore, the results reflect the situation approximately eight years ago in SA, as the mean age of the participants in our study was 9.8 years. Increased public awareness may be shown in future studies as

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there is now increased coverage of ASD in mass media in SA (“Autism government funded schools”, 2016.).

The average age at diagnosis in middle-income countries such as Colombia, India, Jamaica, Jordan, and Mexico is 45-57 months (Samms-Vaughan, 2014). Our results correspond with the age of diagnosis reported by Samms-Vaughan (2014) since the mean age at diagnosis was 46.6 months. However, the age of diagnosis in our study is earlier than the age of diagnosis (56.0 months) reported by Springer et al. (2013) in a tertiary hospital developmental clinic in the Western Cape Province of SA over a two-year period (2008-2010). Possible explanations for the earlier age at diagnosis in the current study might be increased awareness of ASD among caregivers and professionals as well as the implementation of effective screening tools.

More (41.5%) learners were diagnosed by paediatric neurologists and fewer by child psychiatrists, developmental paediatricians, and multidisciplinary teams. The results differ from those reported at a Child Neuropsychiatry Clinic in Sweden where comprehensive clinical assessments were primarily conducted by multidisciplinary teams which included a psychologist, psychiatrist, neurologist, speech-language therapist and professionals who are qualified to diagnose ASD (Anderson, Gillberg, & Miniscalco, 2013). This dissimilarity is to be expected due to the difference in both the demographics and the health systems of the two countries involved. In SA the public primary health care system is often inaccessible and overburdened (Petersen & Lund, 2011) and there are only ten central hospitals operating on a national level who provide specialised services, such as paediatric clinics, on a national basis (Department of Health, 2015).

Most (93.1%) of the learners were admitted to school >4.0 years. Significant, positive associations were found when further exploring the underlying linear relationship between age at school admission and the following: age at parental concern ($r = .197$; p -value =

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<0.000); age at first assessment ($r = .210$; p -value = <0.001); and age at diagnosis ($r = .239$; p -value = <0.000). The later the age at parental concern, the later the age at first assessment, age at ASD diagnosis and age at autism-specific school admission. According to the South African Schools Act (DoE, 1996) governing bodies of schools for learners with special educational needs (LSEN) may develop their own admission policies. The governing bodies of the six autism-specific schools where the research was conducted developed an admission policy specifying that learners may be admitted throughout the year. As learners leave classes, openings become available, and these may be filled with other learners of the same level of functionality. It appears that late identification by caregivers set a trajectory of late intervention for the learners. A possible explanation why the learners were not admitted earlier once they are diagnosed may be that there are only a few schools that can accommodate them. These schools are often inaccessible to rural communities or overstretched. There is a need to establish more schools accommodating children with ASD to allow for inclusive education in SA and to relieve the pressure on the existing ones.

As seen in Table 3 (3.1) seventy-one percent of the learners did not have any co-occurring conditions, however almost 30% of the learners had comorbid neurologic conditions which included ADHD, Epilepsy, Tourette syndrome, and visual impairments. Fewer learners from our study had co-occurring conditions than in the study by Springer et al. (2013) who found that 43% of the children with ASD in the tertiary hospital clinic had co-occurring conditions. A possible explanation why fewer learners from our study had co-occurring conditions than reported by Springer et al. (2013) may be because the data were collected at different sites. Springer et al. (2013) collected the data in a tertiary hospital clinic in the Western Cape Province and our data was collected at autism-specific schools. Children with co-occurring conditions such as intellectual disability may not always comply with the schools' admission criteria and therefore not be admitted in the schools (personal

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communication with principals). The current findings highlight the need for further investigation of associated conditions with an ASD diagnosis. Furthermore, it is also possible that in younger children other symptoms or disorders may be masking or obscuring core symptoms of ASD, thereby delaying a diagnosis of ASD (Levy et al., 2010).

Table 3. Selected autistic characteristics of learners attending autism-specific government-funded schools (n = 234)

Characteristic	Category	Frequency (n)	Mean (SD)	Median	Percentage (%)
3.1 Co-occurring conditions	None	167			71.4%
	ADHD	40			17.1%
	Epilepsy	19			8.1%
	Other neurological conditions	8			3.4%
3.2 Medication history	Currently on medication	125			53.4%
	No medication	109			46.6%
3.3 Type of medication	Medication for poor attention	110			47.0%
	Medication to treat Epilepsy	10			4.3%
	Other medications (e.g. for asthma or flu)	3			1.3%
	Medications to treat anxiety	2			0.9%
	Verbal	148			63.3%
3.4 Speech-language developmental history	Age of first words <47 months	92	36.82 (26.8)	26	39.3%
	Age of first words >48 months	56			24.0%
	Non-verbal	86			36.7%
	Speech and language regression	94			40.2%
	Speech and language regressions started at <47 months	79	33.18 (17.2)	30	33.4%
	Speech and language regression started >48 months	16			6.8%

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As further indicated in Table 3 (3.2) more than half (53.4%) of the learners in our study were on medication. Although only 17.1% of the learners had been diagnosed with ADHD as well as ASD, 47.0% of the learners received medication, such as Risperdal, Concerta and Ritalin, typically prescribed to treat poor attention (Damian, Gharai, Sabzali, Darabi, & Javadi, 2017). Therefore some learners in our study received medication to improve their attention, even though they were not diagnosed with ADHD as well. A number of studies have found that tantrums and aggressive and self-injurious behaviours in children with ASD decreased with ADHD medication (McCracken et al., 2002; LeClerc & Easley, 2015; Sharma & Shaw, 2012; Troost et al., 2005).

The mean age when learners said their first words was 36.82 months, much later than typically developing children who are usually able to say their first words at age twelve months and when LLE is identified (Paul, Norbury, & Gosse, 2017; Owens 2016). Twenty-eight percent of the learners at the time of data collection were non-verbal, and 40.1% had experienced speech and language regression. Our results correspond with results from a population-based study which reported that 40% of children with ASD experience regressed speech and language (Hansen et al., 2008). Regressed speech and language usually occurs at 19-21 months and is considered a 'red flag' for ASD (Webb & Jones, 2009).

In summary, it may appear that differences reported represent unique South African characteristics of learners in autism-specific government-funded schools.

Associated odds of single factors predisposing delayed age of parental concern

Odds for the reference group (>48 months) was calculated for all factors associated with age of parental concern. Only one factor was significant and is reported on.

The odds of caregivers becoming concerned late (>48 months) was higher ($r = 5.0$; p -value = <0.005) when the first professional contacted regarding the caregivers concern was a

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specialist professional (developmental paediatrician, paediatric neurologist or a child psychiatrist) than when it was an allied health professional, a governmental clinic, or a general practitioner ($r = 0.8$). The finding that allied health professionals were consulted first is in agreement with research by Self, Coufal and Parham (2010) in the US who found that children suspected of ASD are usually referred to speech-language therapists and other allied health professionals after screening. This could mean that they are known to be knowledgeable on ASD as many allied health professionals are trained to identify ASD and contribute to the diagnosis (Self et al., 2010). The odds are in agreement with the earlier reported finding that most caregivers in the study did not link LLE with ASD or recognise the early symptoms of ASD in their children. Furthermore, some caregivers might have suspected ASD but did not know whom to consult first regarding their concern or they did not suspect a serious developmental condition and therefore did not consult a specialist first. Therefore, caregivers sought assistance from allied health professionals providing intervention for developmental delays first instead of professionals specialising in ASD diagnosis.

Limitations

The researchers relied solely on data obtained from the questionnaires completed by the caregivers of the learners in the autism-specific schools. The data from the questionnaires were not validated against direct contact or interviews with the caregivers. Also, The response rate was low and further research using another data collection method than a survey is required to confirm the findings. The survey provides a baseline for further studies. Another limitation was the purposive sampling method due to the small number of completed questionnaires which were returned.

Recommendations and future research

The data obtained in this study can be used as a baseline for similar studies about learners with ASD in autism-specific government-funded schools in order for changes in increasing public awareness of ASD and accessing early intervention to be tracked. It could be helpful to conduct a study similar to the descriptive survey conducted in various autism-specific organisations within Canada and the US (Mercer, Creighton, Holden, & Lewis, 2006), where caregivers were asked specifically about their beliefs concerning the cause of their child's ASD. Among the forty-one caregivers who completed the survey, genetic influences (90.2%), perinatal factors (68.3%), diet (51.2%), prenatal factors (43.9%) and vaccines (40.0%) were implicated as possible causes of the ASD in their child (Mercer, et al., 2006). The research is important in order to systemise local priorities for timely diagnosis and to provide targeted support. Furthermore the research may inform public awareness campaigns on ASD and its causes, support ASD training for allied health professionals, aid in planning for educational and therapeutic services, assist in measuring the efficacy of early identification and intervention programs and identifying possible contributing factors associated with trends in age at parental concern that could be modifiable. Future research should also be conducted on the emotional and attitudinal responses of caregivers following an ASD diagnosis.

Conclusion

This article revealed the complexity of factors contributing to delayed age of diagnosis and intervention of children with ASD in SA. Factors associated with delayed diagnosis and treatment for children with autism may be context-specific but appears to be a complex issue described by authors across the globe (Becerra et al., 2014; Daniels & Mandell, 2014; Fountain et al., 2011; Mandell et al., 2005). Decreasing the age of identification and diagnosis are essential steps towards improving access to early intervention. The current

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findings indicate that caregivers became concerned about their child's development at the advanced age of 25.2 months and the main reason for concern was their child's delayed speech and language development. Also, the results show that delayed age at parental concern may be attributed to the respondent being the father, family-caregiver or guardian, being a South-African citizen, and having a lower level of parental education. Furthermore, caregivers consulted a professional about their concern only after some time had passed (on average at 34.7 months) and this led to the learner being diagnosed (on average at 46.6 months) and admitted to the autism-specific school (on average at 6.8 years) much later. It appears that more learners are diagnosed by single professionals instead of being diagnosed by multi-disciplinary teams. In our study, it appears that two underlying factors may improve early intervention for children with ASD, greater public awareness of ASD and many more facilities for families to have their children assessed, diagnosed and admitted to a school. The current findings highlight the need for further investigation of associated conditions with an ASD diagnosis in SA. Furthermore, it is also possible that in younger children other symptoms or disorders may be masking or obscuring core symptoms of ASD, thereby delaying a diagnosis of ASD. More than half of the learners were receiving medication to treat their challenging behaviours. Also, the findings indicate that there is a need to establish more government-funded early intervention and educational opportunities for children with ASD in all South African provinces to relieve the pressure on the existing ones and to ensure that these schools are accessible for families of learners with ASD.

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