Autism Screening in Children:
Using the Social Communication Questionnaire in South Africa

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Abstract

Autism spectrum disorder (ASD) has a global prevalence of approximately one percent of all new births. There is little literature on autism in South Africa, no epidemiological studies and little information on diagnosis and treatment. South African children are waiting years for diagnoses, despite the fact that early diagnosis and subsequent intervention have a positive effect on the outcomes of the intervention. This pilot study aimed to test the viability of an autism screening questionnaire, the Social Communication Questionnaire (SCQ), in a small South African sample. The Social Communication Questionnaire was administered parents of children with and without ASD (N = 50, age range = 2.5-14 years). 18 children also received an Autism Diagnostic Observation Schedule (ADOS) assessment; the current gold standard for diagnosing ASD. Validity of the SCQ was analysed using Pearson's correlation, logistic regressions and receiver operating curves. The optimal cut-off points for the SCQ were explored. SCQ scores were correlated with ADOS scores. The SCQ predicted ASD diagnosis well, indicating that the SCQ may be viable for use in SA. Further research with a larger demographically stratified sample, should be done on the validity of the SCQ.

Autism spectrum disorders (ASDs) have a global prevalence of approximately one percent of all new births. Symptoms of the disorder, such as language difficulties, problems with communication and social interaction, and preoccupation with adherence to routines, become more evident as the child matures. These symptoms can generally be detected in children as young as 2 years old, and, once detected, there are numerous interventions that can help autistic children develop skills and modify their symptom profile. A critical point, however, is that the earlier the interventions are introduced, the better the chance the child and his/her caregivers have of managing the symptoms and reducing the impact they have on everyday functioning.

Despite the fact that ASD is a global problem, there is surprisingly little South African literature on the topic. No epidemiological studies have been done and there is little information on diagnosis and treatment. Furthermore, structured and consistent screening policy for developmental disabilities in South Africa is lacking (Kirsty Donald, personal communication). Due to inconsistent screening policies and under-resourced hospitals, South African children are waiting years for diagnoses, despite the fact that early diagnosis and subsequent intervention impact positively on outcomes. This study aimed to uncover information which can help ameliorate these problems, by testing the viability of using an ASD screening questionnaire, the Social Communication Questionnaire (SCQ), in a South African population. It is hoped that by using screening tools that are cheap and quick to administer, ASD will be diagnosed at an earlier age and thus intervention may be started earlier.

Definition of Autism

Kanner (1943) first brought attention to the developmental neurological disorder that is autism. His paper presented descriptions of 11 children who were physically and cognitively healthy, but who had social-communicative symptoms that, at the time, did not fit the criteria for any specific disorder. Kanner described the main symptoms that were present across the 11 cases, and in doing so gave the first insight into one of the main features of autism: a focus on the inner world, rather than the environment.

Sixty years later, the syndrome Kanner described is known to exist across a spectrum. Autism spectrum disorder (ASD), falls within the category of pervasive developmental disorders (PDD), and is classed by the text revision of the fourth edition of the Diagnostic

and Statistical Manual of Mental Disorders (DSM-IV-TR; American Psychiatric Association [APA], 2000) as a developmental disorder that begins before the age of 3 years. A number of subtypes are currently defined. Symptoms that must be present for a DSM-IV-TR diagnosis of autism are (1) impairments in social interaction, (2) impairments in communication, and (3) repetitive or stereotyped behaviours, restricted interests, and activities. Cases across the spectrum involve varying degrees of the traits of the disorder, such as diminished communication, impaired social behaviours, stereotypical language problems, preoccupations, and observance of routines (Christ, Kanne, & Reiersen, 2010; Pandey et al., 2008). Currently the gold standard instruments used for autism diagnosis are the ADI-R (Autism Diagnostic Interview-Revised; Lord, Rutter, & Le Couteur, 1994) and the ADOS (Autism Diagnostic Observation Schedule; Lord et al., 2000). These diagnostic instruments have been used for several years, and they markedly improve the reliability of diagnoses (Berument et al., 1999; Lee et al., 2007; Witwer & Lecavalier, 2007).

The trend in the past few decades has been to better define and delineate the symptoms of autistic disorder relative to other forms of ASD; and the symptoms of ASD relative to other developmental disorders (Matson, Nebel-Schwalm & Matson, 2007). Over the last three decades, diagnostic criteria for autism have changed. Examples of this are lowered benchmarks for diagnoses on the severe end of the spectrum and the emergence of various new diagnostic categories, such as the inclusion of Asperger's syndrome (AS) and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) as subtypes within autism spectrum disorder (Shattuck & Grosse, 2007).

Recently, controversy has been caused by the suggested revisions of the diagnostic criteria for ASD in the DSM-V (Lord & Bishop, 2010). These revisions consist of decreasing the symptom domains and eliminating subtypes of ASD, rather describing individual variation in terms of severity (Lord & Bishop, 2010). This is seen by some as backsliding, as currently the aim is to separate individuals according to symptom profile and developmental level in an attempt to better understand the deficits related to the various subtypes (Lord & Bishop, 2010). The current method enables families to understand more of their child's disorder and therefore be able to better fulfil their child's needs (Shattuck & Grosse, 2007).

Autism Spectrum Disorder Epidemiology

Due to the lack of ASD prevalence rates for South Africa and other African countries, I examine prevalence rates established in other countries. However, using prevalence data from other countries is problematic as, although ASD is a neurological disorder (Christ et al.,

2010) and studies in various other countries have reported similar data (Baird et al., 2006; Robins, Fein, Barton & Green, 2001), estimated prevalence rates vary markedly both within individual countries and between different studies, ranging from 8 to 40 cases of autism per 10 000 children, and 38.9 cases of ASD per 10 000 children (Baird et al., 2006). A very recent study on the epidemiology of ASD in Korea found a rate of 264 per 10 000 of children in a Korean village (Kim et al., 2011).

The differences present in the epidemiological reports seems to be associated with (a) differences in diagnostic measures used by different studies,(b) between-study differences in definitions of autism, and (c) the question of whether autism specifically, or ASD generally, is being studied. Regardless of these differences, even the low estimates indicate that ASD is relatively frequent; therefore methods of detection should be investigated.

Best Prognosis: Early diagnosis

ASD is difficult to diagnose in very young children who are below the age of three years, due to the fact that symptoms present differently between cases, and language problems cannot be identified until the stage that speech is normally expected to develop (Robins et al., 2001). It has nevertheless been shown that autism can be reliably diagnosed in children of 2 years of age by clinicians (Shattuck & Grosse, 2007). In a survey of 614 parents in the United Kingdom, Howlin and Asgharian (1999) found that the average age that children with autism received their diagnosis was 5 years. There is, however, a large discrepancy between the age of the child when the parents first became worried and the age when the child was diagnosed. On average, parents in this study suspected that their child had developmental problems around the age of one and a half years and sought help when their child was two years old (Howlin & Asgharian, 1999). This indicates that there are signs and symptoms before the age of 5 years and that diagnosis could occur well before this age.

The fact that most children are diagnosed around the age of 5 is of great concern due to the fact that empirical studies have demonstrated that the earlier interventions are implemented, the better the child's prognosis tends to be (and, conversely, that delayed diagnosis can result in a worse prognosis; Canal-Bedia et al., 2011). Early intervention results in decreases in the symptoms of communication problems and social interaction problems, and greater cognitive abilities (Robins, 2008).Such intervention can lead to long-lasting improvements for those affected by ASD (Robins et al., 2001).

Early diagnosis is necessary in order to improve the lives of those affected by ASD and to best use the resources of the government health system (Watson et al., 2007). People with ASD place large costs on the educational, medical, and social sectors (Baird et al.,2006);

better prognosis can reduce these costs (Robins, 2008). A cost analysis study conducted in America compared costs associated with people with autism in an intensive early intervention versus costs of those in intervention at a later stage (Jacobson, Mulick & Green, 1998). The savings for children who took part in the early intervention were between $187,000 and $203,000 per individual from ages 3 to 22 years and from $656,000 and $1,082,000 per individual from ages 3 to 55 years (Jacobson, Mulick & Green, 1998). Early intervention resulted in substantially reduced costs.

Due to the lack of public health care resources in South Africa, much of the burden of payment falls on parents and caregivers. The costs associated with later intervention are therefore all the more troubling for a South African population. It is therefore of utmost importance that diagnosis occur at the earliest age possible. This could be facilitated through employing a screening device, which could be given to parents at regular paediatric check-up appointments. If the screen indicates that ASD may be present, further diagnostic assessments could be recommended. Screening devices can thus be very useful. However, careful attention must be paid to balancing the predictive power of the instrument with the costs of time, money and skills needed to administer it (Watson et al., 2007). These considerations will be discussed next.

ASD Screening Tools

There are currently no biological markers that can help detect ASD, and so diagnosis must be based on examination of behaviour (Canal-Bedia et al., 2011). Behavioural diagnostic tools (like the ADI-R and ADOS) should attempt to make the process as cost-effective, far-reaching, uncomplicated, and quick as possible. However, full diagnoses require history-taking and careful observation, which may take between several hours and several days and it is therefore not feasible to do these as part of a regular paediatric check-up. Screening measures can help in this regard because they can be done quickly, and therefore routinely, in order to identify children who need the comprehensive diagnostic assessment (Chandler et al., 2007).

A screening process is ideal for ASD for the following reasons: first, the cost of not detecting ASD is high, due to the loss of time in intervention and the resulting financial and developmental costs; second, screening can help identify behavioural symptoms and can therefore be used to determine whether a child is likely to have ASD; third, suitable screening measures are already available, as are interventions to which children can be referred after a diagnosis has been made (Robins, 2008). In short, screening for ASD is a cost-effective

method that enables primary health care professionals to flag cases that require further specialist attention.

A number of screening instruments have been developed for ASD. Some of these, such as the Pervasive Developmental Disorder Screening Test-II (Siegel, 2004, as cited in Watson et al., 2007), have not been validated with a general population. Others, such as the First-Year Inventory (Watson et al., 2007) and the Early Screening for Autistic Traits questionnaire (Dietz, Swinkels, van Daalen, van Engeland, & Buitelaar, 2006), have proven relatively ineffective as they have led false negative diagnoses: i.e. incorrectly classifying children with ASD as not being on the spectrum (Watson et al., 2007). This indicates low sensitivity.

Sensitivity, in the case of an ASD screening device, is the ability to correctly classify children who have ASD as positive for possibly being on the spectrum. Specificity, on the other hand, is the ability to correctly classify typically developing children as negative, that is, as not being on the spectrum. If a test has a low cut-off point (i.e. few points need to be scored in order to be classed as positive) sensitivity is likely to be high. If a test has a high cut-off point (i.e. many points must be scored in order to be classed as positive) specificity will be high. Good levels of sensitivity and specificity are essential in order for a screening measure to be useful. A complication is that when sensitivity is increased, specificity often decreases- it is thus important to achieve an appropriate balance between these two properties. A screening device which has both good sensitivity and specificity scores is the Social Communication Questionnaire. This screening measure is discussed below.

Social Communication Questionnaire

The Social Communication Questionnaire (SCQ; Berument, Rutter, Lord, Pickles, & Bailey, 1999) is a 40-item self-report questionnaire developed for use as an ASD screening device. It is based on the ADI-R (Lord, Rutter, & Le Couteur, 1994) and the ADOS (Lord et al., 2000).The SCQ requires that the child's primary caregiver fill out questions that are based on the child's behaviour, such as language abilities and social interaction skills. The SCQ takes less than 10 minutes to complete, and less than 5minutes to score. Scores can range from 0 to 39, with higher scores indicating a higher chance of the child having ASD.

As discussed above, different cut-off points result in different levels of specificity and sensitivity. If specificity is low, the measure will falsely flag typically developing children as possibly having ASD, which would make the device less cost-effective. If sensitivity is low,

the measure will miss children who possibly have ASD, losing utility. It is therefore essential that a balance is found.

Berument et al. (1999) initially validated the SCQ by screening a sample of 200 individuals between the ages of 4 and 40 years. Of these, 160 were previously diagnosed with ASD and 40 were not on the spectrum. The optimum cut-off score for ASD was found to be 15, which yielded a sensitivity score of 85% and a specificity score of 75%. A cut-off of 22 was used to discriminate individuals with autism from those with other PDDs**.** In summary, the SCQ was found to discriminate very well between ASD and non-ASD cases.

A further validation study was done by Chandler et al. (2007) that also concluded that the SCQ is a valid screening device. They reported sensitivity and specificity scores of .88 and .72 respectively, distinguishing between children with ASD and those without ASD.

Although the above studies found good sensitivity and specificity scores with a cut-off of 15, Berument et al. (1999) warned that optimum cut-off levels may vary with the population being screened. Numerous studies have attempted to validate the use of the SCQ in young children, generally between the ages of 3 and 5 years (see, e.g., Allen, Silove, Williams, & Hutchins,, 2007; Chandler, et al., 2007; Eaves, Wingert, Ho, & Mickleson, 2006; Wiggins, Bakeman, Adamson, & Robins, 2007). The general conclusions reached by these studies were that specificity and sensitivity were compromised in such a young population, and that the SCQ is therefore less effective in identifying ASD in very young children. For instance, an Australian reduced validity of the instrument in this population was not due to some inherent property of the questionnaire, but rather was due to the fact the not all symptoms of ASD, as addressed in the questionnaire, have emerged in younger children (Allen et al.,2007). Repetitive behaviours, a feature of autism which forms the basis of a number of questions in the SCQ, are only clearly noticeable around the age of four to five years of age (Cox et al., 1999).

To illustrate the value of lowering the cut-off score, Snow and Lecavalier (2008) showed, in a study which focused on whether the SCQ could differentiate between children with ASD and those with other developmental disabilities, that specificity and sensitivity were low when the cut-off was15, but rose considerably when it was reduced to 11. This suggestion was reiterated by Lee, David, Rusyniak, Landa, and Newschaffer (2007).

It appears that the SCQ can correctly identify young children with ASD, but the current cut-off score of 15 may be too stringent when used with children under the age of 5. Ways to increase the sensitivity and specificity, and therefore the effectiveness of the tool, would be to lower the cut-off score. As mentioned above, the optimum cut-off score may also

vary depending of the population screened. Hence, the optimum cut-off score and the SCQ's appropriateness for the South African population must be tested before it is disseminated to clinics and hospitals.

Potential for Use of the SCQ in South Africa

Currently, the SCQ is widely used in clinical practice and in research studies in the global north. That use is not replicated in South Africa, a developing-economy country with relatively fewer resources, a struggling health care sector, great disparities in socioeconomic status and a population that is culturally and linguistically diverse. Due to these differences, adaptation of the SCQ for use in this country might present more challenges than in countries such as Australia, for instance. Nevertheless, Robins (2008) points out that the costs in time and money involved in adapting, validating, and using a screening device are insignificant when one takes into account (a) the benefit that early intervention as a result of early detection has on the development and well-being of those affected by ASD, and (b) the costs associated with late intervention and subsequent management.

Due to the lack of literature on the application of the SCQ and similar screening devices in other developing countries similar to South Africa, it is not possible to become aware of difficulties and pre-empt problems that could arise in adapting the SCQ for use in South Africa through comparison. It is therefore useful to consider the additional requirements and complexities that may result in a South African context.

One of these complexities relates to the optimum balance between sensitivity and specificity. This balance is dependent upon the situation in which the screening device is being used. For example, in settings where resources are abundant, much greater emphasis may be placed on sensitivity, in order to capture all possible positives, at the expense of many false positives. In other settings where false positives would waste precious time and resources, one might place a higher emphasis on specificity. South Africa has limited resources; therefore specificity is an important factor to balance sensitivity.

The population being screened also has an effect on the cut-off point, as shown by the differing optimum cut-off points found in various studies. The SCQ would therefore need to be validated for a different population, and the optimum cut-off point found.

South Africa has many healthcare concerns, such as the HIV/AIDS pandemic and other infectious diseases such as tuberculosis and malaria. Moreover, there are limited funds for healthcare concerns. There is, however, no reason why researchers and policy-makers should neglect the areas of diagnosis and treatment of ASD. ASD is present throughout the

lifespan of those with the disorder, and without intervention and management it negatively affects not only the individuals diagnosed, but also their family and caregivers. ASD prevalence and incidence rates in this country are probably as high as those in other countries, and the fact that the disorder is reportedly becoming more common should raise alarm bells for the healthcare sector in South Africa. The complete lack of studies on ASD prevalence and screening in South Africa shows that there is a real need for an early screening device in this country.

Rationale and Specific Aims

As is clear from the review above, motivation for this study arises from a practical need. There are very long waiting lists for admission into Alpha School for Autism and Vera School for Learners with Autism, the only two public schools in the Western Cape that are specially dedicated toward educating children with ASD. Admission into those schools requires a formal diagnosis to be made, and school staff have to go through the relatively inefficient process of comprehensive behaviour-based assessments of every child on the waiting list. There are also long waiting lists at developmental disorder clinics associated with the Red Cross Children's Hospital and Tygerberg Hospital. Again, appropriate treatment at those clinics is contingent upon a comprehensive diagnostic process, and clinic staff might be overwhelmed by that demand.

Hence, children in the Western Cape who are suspected of having ASD can wait a relatively long time for diagnosis and intervention; but as noted in the review above, outcomes following ASD diagnosis are best when intervention occurs early (Allen et al., 2007). The introduction of the SCQ as a widely-used tool will fulfil two functions. First, it will allow large amounts of data on prevalence to be collected, and, second, it will allow for children who possibly have ASD and are on long waiting lists for diagnosis to be screened. Such screening will save time, money, and resources, and will also serve to put many parents at ease. Furthermore, a screening process will allow schools and clinics to prioritise those children whose results show they have a high likelihood of being diagnosed with ASD, and could lead to earlier intervention and better functional outcomes. Screening devices are a relatively quick, inexpensive, and cost-effective way of determining the likelihood of the presence of certain disorders or illnesses. The SCQ is an ideal screening tool for ASD, as it (a) requires no skills to be taught to those who fill it out or those who administer it, and (b) is cost-effective, in terms of both time and money. Creating a version of the SCQ that is valid and reliable for the South African population would be of great value.

A suitable method of beginning to identify the complexities in a South African population is to conduct a pilot study. Pilot projects can highlight difficulties in the research process and are essential in order to refine plans for major studies, such as validation- and epidemiological studies. These projects use fewer resources and pave the way for major studies to follow.

The primary aim of this study, then, was to act as a pilot project for a study which would determine whether the SCQ is a valid screening measure for ASD in a Western Cape population. A pilot project is a cost- and time- effective way of determining whether the SCQ is at all applicable for a South African population. As a pilot project, this study endeavoured to examine validity in a preliminary manner by checking whether there it can discriminate successfully between typically developing children and children with ASD and whether there is concurrency between SCQ results and results from the gold standard of autism diagnosis, the ADOS, within a small sample. A related aim was to get an idea of an optimum SCQ cut-off point that results in good specificity and sensitivity, to be used in the next phase of the study. This would give an indication as to whether the SCQ is effective in a South African context. If so the SCQ could be translated into popular languages in South Africa and a full evaluation of reliability, predictive power and optimum cut-offs could be conducted. A final aim was to expose problems that arise in validating the SCQ, in order to pre-empt the problems in the next phase of the study.

Methods

Design and Setting

The design of the study used existing groups (children reported to have ASD and children reported to be typically developing). To assess whether the SCQ could reliably discriminate between these groups in a small South African sample. SCQ scores were collected for typically developing children (n = 37) and for children with ASD (n = 13). Analyses were done to determine whether SCQ score could predict group allocation. In order to validate the group allocation, the ADOS was conducted with all children with ASD and with 5 typically developing children. All analyses were also done for this confirmed diagnosis subsample to assess whether results for the full sample (where diagnosis was presumed from parent's report) were reliable. Figure 1 visually depicts this process.

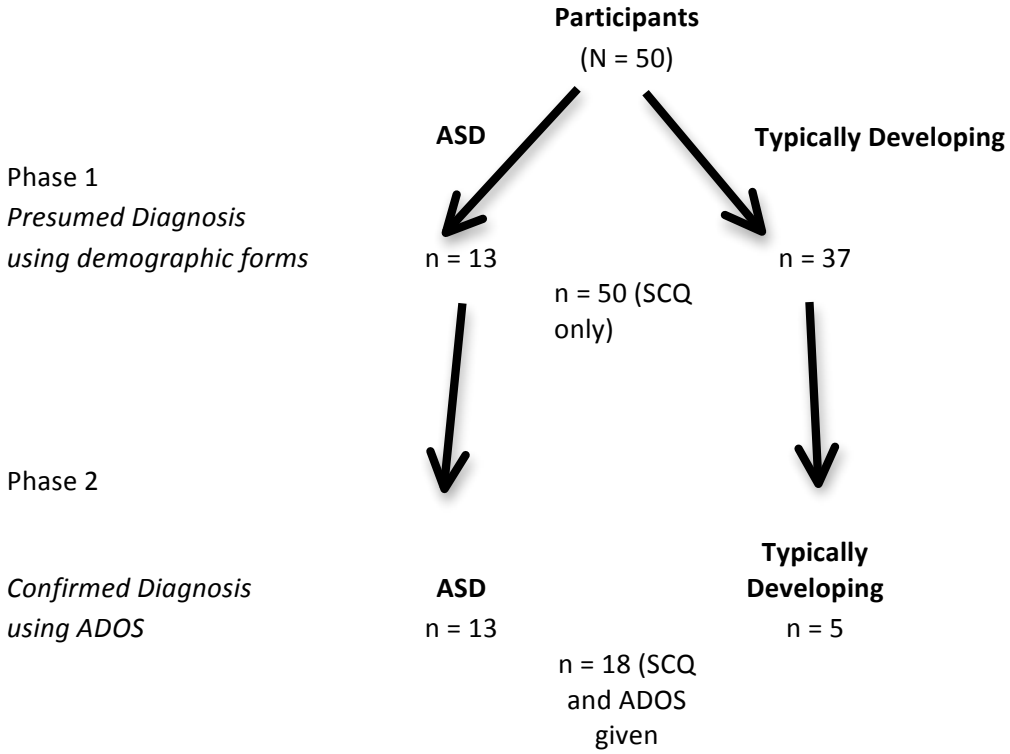

Figure 1. *Diagram showing the breakdown of participant groups according to type of diagnosis and phase of the method.*

Phase 1 - Screening

Participants

To be included in the study, parents had to have children no younger than 2 years old and no older than 15 years old. The cut-off of two years was chosen, as the SCQ is not recommended for children younger than this, as validity is negatively affected (Wiggins et al., 2007). The cut-off of 15 years was chosen, as, although one would hope that ASD would be diagnosed before that time, it is important to extend the cut-off in order to see whether the SCQ can validly screen children of all ages.

A full validation study would feature a full population screening in order to have a representative sample of children. However, as this was a pilot study, the scale of the study and the available resources were smaller. We therefore screened a sample of children (N = 50), some previously diagnosed with ASD (n=13) with the remaining typically developing children acting as control subjects. Convenience sampling was used to access children with ASD: the sample of ASD children was drawn from groups of children who had (a) previously taken part in research on autism (n=2) and/or (b) were taking part in an early intervention study at the UCT Child Guidance Clinic (n=11). Taking this targeted sampling approach

ensured that we obtained a large enough number of cases with ASD, that we could assess the specificity and sensitivity of the SCQ in a South African sample.

Due to a lack of time, resources and Western Cape Education Department ethical clearance, the parents of children acting as controls were recruited through snowball sampling. The researcher e-mailed forms to everyone on her mailing list, asking them to forward on the forms to anyone that they knew with children in the age range needed. Thirteen of the interviews were conducted in person.

The study followed the ethical guidelines for research with human subjects outlined by the Health Professions Council of South Africa (HPCSA) and the University of Cape Town (UCT) Codes for Research. Ethics approval was obtained from the Psychology department of UCT. Informed consent was obtained from the parents. There were no risks associated with participation in the study. Children partaking in the ADOS (see below) were allowed to rest if they experienced fatigue during the assessment. Parents were assured that all responses would be kept confidential and, if desired, they could receive feedback on their child's performance.

Measures

Sociodemographic questionnaire. This brief questionnaire (see Appendix A) asked parents to provide information regarding basic demographic data (e.g., the age of their child, family income, race, and home language). It also asked if their child had ever been diagnosed with a developmental disorder, and for details of the clinical presentation, where applicable.

Social Communication Questionnaire (SCQ). The SCQ (Berument at al., 1999) is a self-administered questionnaire that is filled in by the child-in-question's primary caregiver. There are two version; Lifetime and Current. The Current version of the SCQ is for children between the ages of 2 and 5 years, and focuses on the previous 3 months of the child's life. The Lifetime version is for children over the age of 5 years, and focuses on the child throughout his/her lifetime, with specific focus on the period between 4 and 5 years of age (Lee et al., 2007). On each version, the total score ranges from 0 to 39, with higher scores indicating more symptoms connected with ASD (Berument et al., 1999). Both versions were used in this study. The Current version was used by parents with children between the ages of 2 and 5 years. The Lifetime version was used by parents with children over the age of 5 years. Scoring was done by adding up the number of positive answers with regards to the presence of symptoms of ASD.

Procedure

Parents of children who previously or currently took part in research on autism conducted by the University of Cape Town were contacted by e-mail. (They had previously indicated that they would be amenable to taking part in future research, and had supplied their contact details). Parents of control participants were also contacted by e-mail.

Each e-mail contained the socio-demographic questionnaire, a consent form (Appendix B), a letter explaining the study (see Appendix C), and the Lifetime and Current SCQs. Parents were given instructions as to how to fill in the forms and which SCQ to fill in, if they chose to participate, and were asked to e-mail the completed forms back to the research team. They were told that if they had any questions, problems or queries they should e-mail the research team.

Phase 2 – Confirmation of Diagnosis

Participants

A subset of the full sample completed ADOS assessments in order to confirm that allocation to TD and ASD groups in the full sample was valid. Eighteen children underwent formal diagnostic assessment in this phase of the study. All the children with ASD participated (n=13). There were also five control children who underwent formal diagnostic assessment; this group consisted of all the control children whose parents were prepared to bring them in for assessment. A breakdown of the numbers of participants in each group is depicted in figure 1. All of the 50 participants filled out the SCQ, the difference between phase 1 and phase 2 participants, is that phase 2 participants were diagnosed using the ADOS.

Measures

Autism Diagnostic Observation Schedule (ADOS). The ADOS (Lord et al., 2000) is a standardised direct assessment conducted by an individual who has undergone formal training in the use of the instrument. This assessment battery takes the form of specific tasks and playtime for the child, and takes 40-70 minutes to complete. Behaviour is observed by the administrator and rated according to whether it follows autistic patterns within the areas of social, communicative, and repetitive-stereotyped behaviour. Ultimately, the results of this behavioural observation are used to formulate a diagnosis of autistic disorder, other ASD, or unaffected (Lee et al., 2007).

The ADOS validation study (Lord et al., 2000) showed excellent inter-rater reliability and internal consistency. Inter-rater reliability and test-retest reliability were also good for individual items. The ADOS effectively differentiated between autism and other ASDs. Sensitivity and specificity scores were excellent. Specificity ranged from 90-97% across the four modules of the ADOS when differentiating between autism and PDD cases and cases not on the autism spectrum, 87-100% when differentiating between cases of autism and PDD and non-spectrum cases, 80-94% when differentiating between cases of PDD and non-spectrum cases and finally 93-100% when differentiating between cases of autism and non-spectrum cases. Sensitivity scores were slightly lower. They ranged from 87-94% when differentiating between autism and PDD cases and cases not on the autism spectrum, 68-79% when differentiating between cases of autism and PDD and non-spectrum cases, 88-94% when differentiating between cases of PDD and non-spectrum cases and finally 93-100% when differentiating between cases of autism and non-spectrum cases. The ADOS is relied on globally and is seen as the gold-standard of autism diagnostics (Filipek et al., 2000).

A revised algorithm for scoring the ADOS was used in this study, as the developers of this algorithm found better differentiation between diagnoses than when using previous algorithms (Gotham, Risi, Pickles & Lord, 2006).

Procedure

The ADOS diagnostic session took place in a dedicated assessment room at the Child Guidance Clinic at UCT. Before the session began, parents were informed about what the session would entail, and were reminded that they could withdraw at any point without penalty or without affecting their child's future educational or clinical services. At the conclusion of the session parents had an opportunity to ask questions.

The ADOS was administered and scored by two qualified researchers trained in the ADOS instrument, and consensus on the scoring was reached by a group of ADOS trained individuals.

Results

Sample characteristics

Age, race, gender, home language and SES were compared between ASD and typically developing children. Unsurprisingly, given the convenience and snowball sampling methods used, the distribution of demographic variables across the groups was uneven.

Table 1 summarises the spread of the demographic variables across the ASD and control groups. The groups were not well matched. The average age of the TD group was higher than in the ASD group. The distribution of gender was more equal in the TD group than the ASD group, in which there were many more males than females. Race, home language and SES were also very unequally distributed. Most of the control group were White and English speaking, while the majority of the ASD group were Black or Coloured and either English or Xhosa speaking. On average, SES was higher in the TD group than in the ASD group.

Chi squared tests of independence were conducted for the *Presumed diagnosis* and variables *gender*, *race*, *language* and *SES*. An independent *t*-test was conducted for between *presumed diagnosis* and *age*. The differences in group size were found to be significant for all variables besides *SES.* The validity of the results for *SES* was compromised due to the frequencies in the various categories.These results are depicted in Table 1.

Table 1

Demographic Characteristics of the Sample

Variable	Typically Developing (n = 37)	ASD (n = 13)	Test of significant differences betw groups	
			t	***P***
Age (years)	7.14 (3.91)	4.23 (2.13)	41.93	.002
			Pearson Chi-Square	***p***
Gender (male:female)	15:22	12:01	10.38	.001
Race (Black:Coloured:White:Missing)	3:3:29:2	6:7:0:0	27.24	< .001
Home language (Eng:Afrik:Xho:Other:Missing)	28:1:2:4:2	7:4:0:2:0	8.84	.031
SES (low:med:high:missing)	8:7:11:11	3:5:3:2	3.71	.446

Note. For age, means are provided with standard deviations in parentheses.

The ability of the SCQ to predict ASD

In order to determine whether the SCQ can effectively predict whether or not children have ASD a logistic regression analysis was conducted. Due to the small number of TD participants who received an ADOS assessment, two analyses were run. The first tested whether the SCQ was a valid predictor of *Presumed diagnosis.* This analysis used data from the full sample, grouping participants according to the diagnosis that their parents reported on

the demographic questionnaire. Of these participants, 37 were reported to be typically developing, and 13 were reported to be diagnosed with ASD.

The second analysis used *Confirmed diagnosis* as the outcome. The *Confirmed diagnosis* group consisted of only the participants whose diagnoses were tested and confirmed using the ADOS. All 13 children who were reported to have ASD were confirmed to have ASD by the ADOS assessment, while 5 reportedly typically developing children were confirmed by ADOS assessment to be unaffected by ASD.

The analysis run with *Presumed diagnosis* and *SCQ score*, ($N = 50$), was statistically significant, indicating that SCQ score reliably distinguished between ASD and TD participants (chi square = 47.15, $p < .001$ with $df = 1$). Nagelkerke's R^2 of .90 indicated a strong relationship between score and classification. Prediction success overall was 94% (94.6% for TD and 92.3% for ASD). The Wald criterion demonstrated that classification was significantly predicted by SCQ, $p = .011$. The Odds Ratio value indicates that when SCQ score is raised by one unit (one point) the odds ratio is 1.9 times as large and therefore classification of ASD is 1.9 times more likely.

The analysis run with *Confirmed diagnosis* and *SCQ score*, ($N = 18$) was statistically significant, indicating that SCQ score reliably distinguished between ASD and TD participants (chi square = 21.27, $p < .001$ with $df = 1$).Nagelkerke's R^2 of 1.00 indicated a strong relationship between score and classification. Prediction success overall was 100% (100% for TD and 100% for ASD). The Wald criterion was not significant ($p = .996$).This is likely due to the fact that there is no variance is the model, as prediction by the SCQ of classification is perfect. The Odds Ratio value indicated that when SCQ score is raised by one unit, in this case one out of 39 possible points, the odds ratio is 793.4 times as large and therefore classification of ASD is 793.4 times more likely. This is much larger than the ratio in the previous analysis, which was 1.9.

Table 2.

Summary of Logistic Regression Using SCQ as a Predictor and Diagnosis as the outcome

					95% CI for Odds Ratio	
Variable	***B (SE)***	**Wald criterion**	***P***	**Odds Ratio**	**Lower**	**Upper**
Presumed diagnosis[a] (*N* = 50)						
Constant	8.3 (3.27)	6.46				
SCQ	0.64 (.25)	6.51	.011	1.90	1.16	3.12
Confirmed diagnosis[b] (*N* = 18)						
Constant	-56.85 (10857.71)	0.00				

SCQ	6.68 (1193.9)	0.00	1.00	793.39	0.00	-

Note: [a]R^2= .61 (Cox & Snell), .90 (Nagelkerke). Model χ^2 (1) = 47.15, p =.01, [b]R^2= .69 (Cox & Snell), 1.00 (Nagelkerke). Model $\chi^2(1)$= 21.27, p is not significant, due to the fact that it predicts perfectly and there is therefore no variance.

Analysis of the strength of the predictive relationship between SCQ score and ADOS scores

Pearson's correlation was conducted for the variables *SCQ scores* and *ADOS scores* using the *Confirmed diagnosis* group. We hypothesized that SCQ scores (higher scores indicate ASD) would be positively related to ADOS scores (higher scores also indicate ASD), thus the correlations were run as one-tailed tests. *SCQ scores* were strongly positively correlated with *ADOS scores*, $r = .90, p < .001$.

Analyses of the possible cut-off points on the SCQ for optimum sensitivity and specificity

Next, the optimal cut-off score at which the SCQ predicts ASD was examined. Such a cut-off needs to accurately predict ASD when a child scores above it (sensitivity), as well as accurately predict that a child does not have ASD when they score below this value (specificity). In order to determine specificity and sensitivity scores for various cut-off points for SCQ scores, receiver operating curves (ROC) were conducted. ROC curves visually depict the relationship between specificity and sensitivity at various cut off points.

A ROC curve was conducted with *SCQ scores* and *Presumed diagnosis* (Figure 2.). In Figure 2 (N = 50) the area under the curve = .99, p < .001. This is summarised in Table 3. The area under the curve is very high and the SCQ is therefore a very good predictor of ADOS diagnosis and presumed typical development.

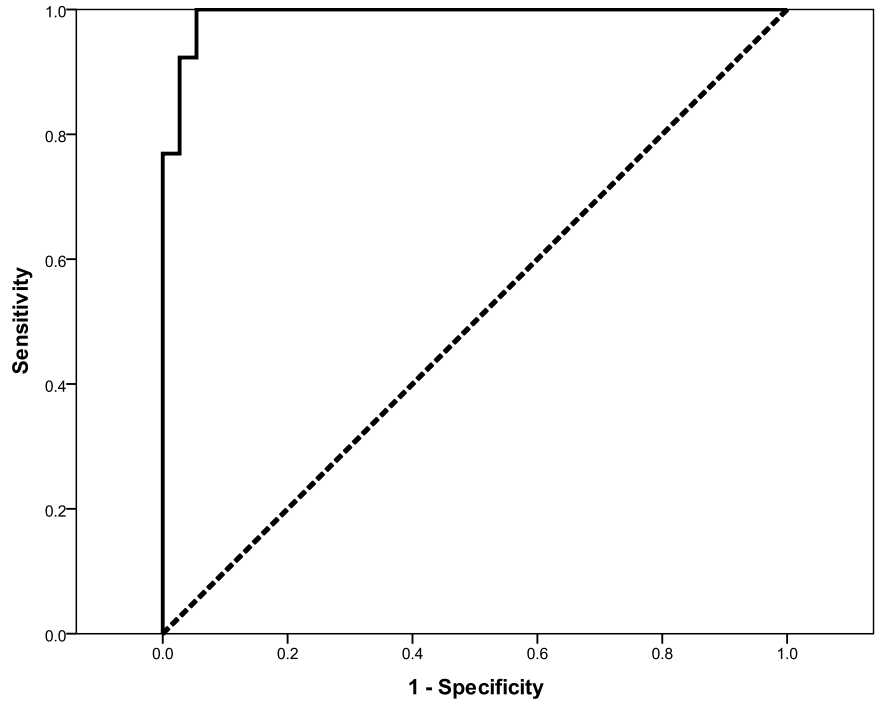

Figure 2. *Receiver Operating Curve for SCQ results and Presumed diagnosis showing specificity and sensitivity values and area under the curve.*

Table 3.
Summary of the Area Under Curve in ROC

			Asymptotic 95% CI	
Variable	**Area (SE)**	**Asymptotic Significance**	**Lower**	**Upper**
Presumed diagnosis	.99 (.01)	< .001	.98	1
Confirmed diagnosis	1.00 (0)	.001	1	1

Table 4 summarises the results of the sensitivity and specificity scores for the ROC curve. Upon examination of Table 4, which analyses the relationship between the SCQ and presumed diagnosis (N = 50), it seems that the best balance between specificity and sensitivity is achieved using a cut-off score between 10 and 12.

Table 4.
Sensitivity and Specificity of the SCQ with Corresponding Cut-Off Scores using Presumed Results

Cut-off Score	Sensitivity	Specificity
7.5	1.00	.87
8.5	1.00	.92
10	1.00	.95
12	.92	.95
13.5	.92	.97

A ROC curve was also conducted for *SCQ scores* and *Confirmed diagnosis* (Figure 3).For Figure 3 (n = 18) the area under the curve = 1.00, p = .001. These figures are summarised in Table 3. The area under the curve is as high as possible and the SCQ is therefore a perfect predictor of ADOS diagnosis.

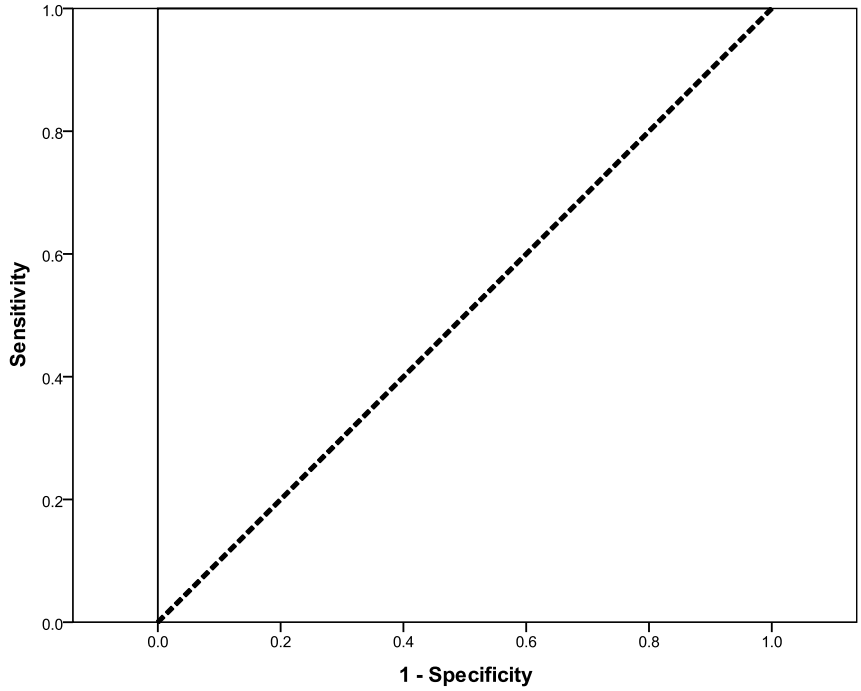

Figure 3. *Receiver Operating Curve for SCQ results and ADOS diagnosis showing specificity and sensitivity values and area under the curve*

Table 5 summarises the results of the sensitivity and specificity scores for each ROC curve. Upon examination of Table 5, it seems that the best balance between specificity and sensitivity is obtained by using a cut-off score between 8.5 and 12.5, which is similar to the finding in Table 4, using presumed diagnosis data, of an optimum cut-off score between 10 and 12.

Table 5.

Sensitivity and Specificity of the SCQ with Corresponding Cut-Off Scores using ADOS Results

Cut-off Score	Sensitivity	Specificity
5	1.00	.80
8.5	1.00	1.00
12.5	.92	1.00
15	.77	1.00

Analysis of the effects of demographic variables on SCQ scores

A linear regression was conducted in order to determine the effect that key demographic variables had on SCQ score. An example of this is that children whose home language is not English may have scored lower on the questionnaire because their parents did not properly understand the questions, due to their lack of familiarity with English. This analysis and its interpretation were approached with caution, given the uneven distribution of demographic characteristics across the groups, but it seemed important to do some investigation of the influence these variables might have.

A linear regression was initially conducted including all the variables; however, upon inspection of multi-collinearity and tolerance values, it appeared that race and SES were having suppressing effects on one another and other variables. This prevented the true effects of the variables being shown. Therefore, a linear regression was run with only *age, gender* and *language* as predictors and *SCQ score* as the outcome variable. Next, three separate linear regressions were conducted with race Black, race Coloured and SES predicting *SCQ score.* The results of the four separate regressions are given in Table 6.

Table 6.

Summary of Linear Regression for SCQ Scores and Demographic Variables

					95%CI	
Variable	***b (SE)***	***B***	***T***	***p***	**Lower**	**Upper**
Constant	22.14 (2.52)		8.77	< .001	17.05	27.22
Age	-1.00 (.26)	-0.44	-3.89	< .001	-1.52	-0.28
Gender	-5.64 (2.00)	-0.33	-2.83	.007	-9.66	-1.61
Language	-6.11 (2.24)	-0.32	-2.73	.009	-10.63	-1.00
Constant	6.49 (1.14)		5.68	< .001	4.19	8.79
Race Coloured	11.51 (2.70)	0.53	4.27	< .001	6.09	16.93
Constant	6.95 (1.26)		5.53	< .001	4.42	9.48
Race Black	8.05 (2.81)	0.38	2.87	.006	2.40	13.70
Constant	15.31 (3.96)		3.87	< .001	7.27	23.35
SES	-2.64 (1.77)	-0.25	-1.49	.15	-6.24	-0.95

Note: R^2 = 0.45 for Age, Gender & Language, R^2 = 0.15 for Race Coloured, R^2 = 0.28 for Race Black , R^2 = 0.06 for SES

The correlation between *age* and *SCQ* s*core* was moderate and statistically significant, $r = .42$, $p = .001$, as was the correlation between *gender* and *SCQ score*, $r = .41$, $p = .002$, and that between *language* and *SCQ*, $r = .40$, $p = .002$. The resulting regression model was statistically significant, $F(3, 44) = 11.82$, $p < .001$, and the regression equation derived from this model is *SCQ score*= 22.14 -1.00**age* -5.64**gender* -6.11**language*.

The gender result shows that males are likely to score higher on the SCQ than females. This is in part likely due to the fact that the group with ASD had only one female in comparison to twelve males. With regard to language, the analysis shows that people who speak English are likely to score lower than those who speak another language. This could be explained in part by act that a higher majority of English people were in the control group and would therefore have scored lower on the SCQ. Overall, *age, gender* and *language* explained 45% of the variance in *SCQ score* according to the regression.

The correlation between *race Black* and *SCQ score* was moderate and statistically significant, $r = .53$, $F(1, 48) = 18.23$, $p < .001$. This equation shows that Black participants are likely to score higher on the SCQ than White and Coloured participants grouped together. Overall, *race Black* explained 28% of the variance in *SCQ scores* according to the regression.

The correlation between *race Coloured* and *SCQ score* was low and statistically significant, $r = .38$, $F(1, 48) = 8.21$, $p = .006$. This indicates that Coloured participants score higher on the SCQ when compared White and Black races grouped together. This implies that White participants have the lowest SCQ scores, as Coloured participants have higher

SCQ scores than Black and White participants combined, and Black participants have higher SCQ scores than Coloured and White participants combined. This can also be explained in part by the fact that the ratio of Coloured and Black participants in the ASD group was much higher than in the TD group. Overall, *race Coloured* explained 15% of the variance in *SCQ scores* according to the regression. The correlation between *SES* and *SCQ score* was not significant.

Discussion

The main aim of this study was to conduct a preliminary investigation of the utility and validity of the SCQ screening questionnaire in a South African context. Groups of children reported to have or not have ASD were recruited. The SCQ was found to reliably discriminate between these groups. A logistic regression showed that the SCQ was a very powerful predictor of child's diagnosis (as reported by parents).

In order to provide some confirmation that parent reports regarding their child's development (i.e. that the child was diagnosed with ASD, or that s/he was reported to be typically developing) were reliable, ADOS assessments were conducted on a subset of the total sample. The ADOS is currently the gold standard of diagnosis of ASD (Filipek et al., 2000). ADOS assessments confirmed accurate reporting by the parents in this subset, in other words all children reported as having ASD were in the ASD range on the ADOS and; all those reported TD by parents were in the non-ASD range on the ADOS.

Logistic regression using only those children with confirmed diagnoses confirmed that the SCQ could discriminate between the ASD and TD groups. The fact that the results of both analyses (i.e. for the full sample, and for the diagnosis confirmed subset) were similar is a good indication that the presumed (reported) diagnoses were in fact correct.

Overall, all analyses indicated a strong positive relationship between SCQ score and diagnosis. The logistic regressions showed the SCQ to be a powerful predictor of group membership. This was shown in a small sample of both male and female children varying widely in age, socio-economic status and race. The SCQ was found to work as well in this small sample as it does in Western populations.

The strong positive relationships that were found between SCQ and ADOS scores in the logistic regressions, ROC analyses and Pearson's correlation are similar to those found in other validation studies (e.g. Berument et al., 1999; Chandler et al., 2007). This is another good indication that the SCQ may be as useful in a South African population as it is in England.

Another aim was to determine the optimum cut-off score on the SCQ, above which children are identified as potentially having ASD. Sensitivity and specificity of the device at each potential cut-off point was considered. With a screening device, sensitivity should be more important than specificity, as one aims to identify all cases of possible ASD. However, as mentioned, the exact balance is dependent on the context in which the screening measure is used. The recommended cut-off for the SCQ was initially 15 (Berument et al., 1999). Subsequent research indicated that lower cut-off scores result in better sensitivity and specificity scores when screening younger children (Chandler et al., 2007; Lee et al., 2007; Snow & Lecavalier, 2008). These authors suggest that the current recommended cut-off point of 15 should be lowered to 11, especially when autism needs to be discriminated from other developmental disabilities.

The sensitivity and specificity scores in the ROC analyses for both the full sample and the diagnosis confirmed subset suggested a cut-off score between 8.5 and 12.5. Rounded up, this would be a score of between 9 and 13. Cut-off scores of 9 for the *Confirmed diagnosis* group and 10 for the *Presumed diagnosis* group, were the best choices, as sensitivity was perfect, but specificity was still high. This is in line with the cut-off scores recommended by recent research (Chandler et al., 2007; Lee et al., 2007; Snow & Lecavalier, 2008).

The importance of specificity as opposed to sensitivity depends on the resources of the population and the importance of diagnosis versus a burdening of the diagnostic system and unnecessary worry for the parents must be weighed (Allen et al., 2007). What must be kept in mind is that a screening device is not expected to have a perfect agreement with diagnoses and must be used in conjunction with observation and clinical judgement (Eaves et al., 2006). Early intervention with individuals who have ASD has an exceptionally positive impact on their outcome (Robins, 2008; Robins et al., 2001) and delayed intervention can result in worse prognosis (Canal- Bedia et al., 2011). This means that some false positives are a small price to pay in order to be able to flag all cases of ASD. It is therefore important that a cut-off score be chosen in which sensitivity is as high as possible, while keeping specificity high enough so as to keep the screening device cost-effective. Results from the ROC curve of *SCQ scores* and *ADOS diagnosis* show that using a cut-off point of 8.5, both sensitivity and specificity is perfect. Results from the ROC curve of *SCQ scores* and *Presumed diagnosis* show that using a cut-off score of 10, sensitivity is perfect and specificity is at 95%. This would result in all children with ASD being flagged, however 5% of children seen would be falsely flagged as being at high risk for ASD. These 5% would likely go through a process of

assessment and be found to not have ASD. This excellent sensitivity score and low rate of false positives is evidence that the SCQ would be a very useful screening device.

Unlike the study by Snow and Lecavalier, this study only included typically developing controls and no other disability controls, such as children with a developmental disorder other than ASD. This limited the reliability of the ROC analysis. Firstly, one can only conclude that the SCQ can discriminate well between typically developing children and those with ASD. Secondly, the fact that only typically developing children were used as controls means that the results of the SCQ were likely to be either very low, in controls, or very high, in children with ASD. There would be no "grey" areas, or scores in the middle of the range, which could be depicted in the ROC curves. This limits the reliability of the curve, as only very high and very low values are included. Including children with other developmental disorders would likely result in lower levels of specificity and sensitivity.

Lastly, I wanted to identify potential influences of demographic variables such as age, home language and SES on SCQ scores. However, the lack of demographic similarity between controls and children with ASD was a major limitation. Older children, White individuals, the English language group and the high socio-economic status (SES) group were overrepresented in the control group. Younger children, Coloured and Black individuals, and middle SES group were overrepresented in the group with ASD. This was a result of the snowball and convenience sampling used. As the groups came from different populations, the results of the regression were skewed and therefore did not allow for firm conclusions to be drawn regarding the effect of demographic variables on SCQ score.

Limitations of the Study

There were a number of limitations to the generalisability of results and the conclusions that can be drawn. First, Lee et al. (2007) point out that optimal cut-off points for screening devices may vary due to age and population. Ideally a representative sample of South Africans should have been used. However, due to the lack of time, lack of resources, delays in obtaining ethics approval from external bodies and difficulties in accessing children with ASD, snowball and convenience sampling were used, which resulted in a skewed sample. The fact that participants varied greatly in age and in socio-demographic background may influence conclusions that one can draw about optimal cut-off needed for the South African population. It may be that different cut-off points are needed for different socio-demographic groups within South Africa. Future research should address this.

Second, it was initially planned that ROC analyses would be done by comparing SCQ scores with ADOS diagnosis. However, only certain parents were willing to let their children

take part in the second phase of the study, the ADOS assessment (n = 18). Therefore, diagnosis of the other 32 children was presumed from what their parents had reported on the demographic questionnaire. This presumed diagnosis group was compared with the smaller group who had confirmed diagnoses on the ADOS. The advantage of the ADOS classification analysis was that the diagnoses were definite as they were determined by the gold standard in ASD diagnosis. The group contained only 18 participants; therefore the statistics had less power. The advantage of the presumed classification group was that the sample size was much bigger; however the classification was less reliable, as it was self-report by the parents and relied on the assumption that children who have not received a diagnosis of ASD are not on the autism spectrum. The fact that the logistic regression and ROC curve results for both groups (presumed and confirmed diagnosis) were similar to one another was a positive sign that both analyses were valid.

Third, the importance of specificity as opposed to sensitivity depends on the context in which the SCQ is used; resources of the population and the importance of diagnosis versus a burdening of the diagnostic system and unnecessary worry for the parents must be weighed (Allen et al., 2007). In order to determine what needs in South Africa dictate and what resources allow for, further investigation would be needed.

Lastly, language, cultural and education factors may well have influenced scores on the SCQ. Because the SCQ was only available in English, there may have been misunderstandings by people who speak another home language. This was especially problematic, as the questions in the SCQ are very specific and misunderstandings of a word or the gist of the sentence may result in false positives or false negatives. Even within English groups, misunderstandings may have occurred and these would have had an effect if they were not addressed.

Cultural factors and level of education may also have played a role in this study. For instance, parents' beliefs about 'normal' child development, or their concerns about their child, may be different in certain cultural groups, and may thus affect how parents from those groups fill in the SCQ (Eaves et al., 2006). A parent's level of education may also have played influenced the way the SCQ was understood and therefore whether it truly reflects the child's behaviour (Lee et al., 2000). SCQ answers may also be influenced by emotional states and awareness of ASD and promise of diagnosis (Lee et al., 2000). This must be kept in mind when working with particular populations and generalising to the rest of South Africa.

There were also a number of more general limitations related to the method of data collection that was used. Due to lack of time and lack of ethical approval to conduct research

in schools or clinics, email communication was used to collect most of the data. The drawback of email communication is that participants are less likely to ask for clarification. Unfortunately, despite stating that I was available on phone or e-mail to answer any questions, no one asked any questions regarding the SCQ. This is likely due to the fact that it is a bigger inconvenience to e-mail or phone someone to ask for clarification, than to ask an interviewer for clarification. When conducting a face-to-face interview one can often see when an interviewee is confused and offer clarification or examples. Using e-mails takes away this opportunity, therefore there may be undetected confusion and therefore this could affect validity.

Future research

I propose that a larger project be conducted to test the validity of the SCQ. The limitations of this pilot project should be taken into consideration. Groups of children with ASD and without ASD should be stratified in respect of all demographic variables. Future research should use larger sample sizes in order for the statistical analyses and inferences to be more powerful.

Due to the fact that early diagnosis is so important, a screening device is of great importance. It is therefore vital that questions are understood and answered to the best of the interviewee's ability. The UCT Autism Research Group has had the SCQ, demographic questionnaire and consent form translated into Afrikaans and isiXhosa. This will solve problems of misunderstandings due to language barriers. Information on the accuracy and viability of the SCQ in different languages should be gathered.

The SCQ should be filled out in the presence of a researcher, nurse or an individual who is knowledgeable about the SCQ who can provide clarification or answer any questions that arise. This will ensure that all questions are understood and filled in.

Parents should also be recruited at developmental clinics and at schools for children with ASD or developmental disorders – this will create a more representative sample of the population who need the SCQ. This will also enable testing of whether the SCQ can distinguish between children with ASD and those with other developmental disorders, resulting in more powerful ROC curves and analyses.

Other future projects could distribute the SCQ around the Western Cape, to clinics and paediatricians, to test the viability of the SCQ as a screening device in these settings.

Conclusion

This study found that the SCQ provided a valid screen for ASD in our small sample. The SCQ was found to be a very strong predictor of diagnosis. This shows that the SCQ has potential to work as screening questionnaire in a South African population. Its validity and reliability needs to be further explored in a larger, more representative study, in which groups are matched across demographic variables. And where other developmental disorders are present.

The need for this research is urgent, due to the lack of South African research on ASD epidemiology, diagnosis and intervention. A larger study could investigate whether, from a clinical perspective, the SCQ may be a useful tool that paediatricians or even general practitioners can give to parents who suspect their child may have developmental problems. That child can then be referred to a specialist clinic if the screening suggests the possibility of ASD. Such a process would lessen the diagnostic load on paediatricians and GPs, and would increase the efficiency of specialist clinics, who would only be referred children with a real possibility of having a disorder on the autism spectrum.

More epidemiological information is needed to influence policy considerations regarding diagnosis and intervention in ASD. With more information and with figures at hand of numbers of people affected by ASD, awareness and funds are more likely to be raised and allocated to ASD. This pilot study provides encouraging results suggesting that the SCQ may be a valuable screening tool in our context.

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Appendix A
Sociodemographic Questionnaire

Participant no.: _____ Date: _____

DEMOGRAPHIC QUESTIONNAIRE

A. Child's Information:

1. Name: _____
2. School:_____
3. Age: _____
4. Date of Birth (dd/mm/yy): _____
5. Sex (circle one): Male Female
6. Ethnicity: White Black Indian Coloured Asian
   Other If other please specify: _____
7. Home Language: _____
8. Handedness (circle one): Left Right Ambidextrous
9. Number of siblings: _____
10. Has your child ever had a communication disorder? (For example: Having problems with understanding or producing speech, slow vocabulary development, difficulties recalling words or problems with producing sentences appropriate for his/her age.) YES NO

If yes, please specify:_____

11. Has your child ever been diagnosed with a pervasive developmental disorder (PDD) such as autism, Asperger's syndrome, Rett's disorder or childhood disintegrative disorder?
    (Tick the appropriate block).
    No developmental disorder_____
    Autism_____
    Asperger's Syndrome_____
    PDD – Not Otherwise Specified_____
    Seizures _____
    Head injuries_____

Other (please specify):_____

12. At what age was your child when you noticed that they had developmental difficulties?
    _____
13. At what age was your child when you first sought help?

_____

14. Who or where did you go for help?

_____

B. Parent Information:

1. What is the total monthly income of the household in which you live? (Tick the appropriate block):
[NOTE: This should be total household income, not personal income.]

0-3500:_____3600-7500:_____7600-12500:_____ 12600-17500:_____
17600-22500:_____22600-27500:_____27600-32500:_____32600 or over:_____

2. Highest level of education reachedfor mother, father and/or guardian (please circle appropriate number).

	Biological mother	Biological father	Guardian
1) 0 years (No Grades / Standards) = Never went to school	1. 2.	1. 2.	1. 2.
2) 1-6 years (Grades 1-6 / Sub A-Std 4) = Didn't complete primary school	3. 4.	3. 4.	3. 4.
3) 7 years (Grade 7 / Std 5) = Completed primary school	5.	5.	5.
4) 8-11 years (Grades 8-11 / Stds 6-9) = Some secondary education (didn't complete high school)	6. 7.	6. 7.	6. 7.
5. 12 years (Grade 12 / Std 10) = Completed high school			

6. 13+ years = Tertiary education Completed university / technikon / college 7. Don't know			

3. Parental employment: (Please circle appropriate number)

	Biological mother	Biological father	Guardian
1. Higher executives, major professionals, owners of large businesses	1. 2.	1. 2.	1. 2.
2. Business managers of medium sized businesses, lesser professions (e.g. nurses, opticians, pharmacists, social workers, teachers)	3.	3.	3.
3. Administrative personnel, managers, minor professionals, owners / proprietors of small businesses (e.g. bakery, car dealership, engraving business, plumbing business, florist, decorator, actor, reporter, travel agent)	4. 5. 6. 7.	4. 5. 6. 7.	4. 5. 6. 7.
4. Clerical and sales, technicians, small businesses (e.g. bank teller, bookkeeper, clerk, draftsperson, timekeeper, secretary)	8. 9.	8. 9.	8. 9.
5. Skilled manual – usually			

having had training (e.g. baker, barber, chef, electrician, fireman, machinist, mechanic, painter, welder, police, plumber, electrician) 6. Semi-skilled (e.g. hospital aide, painter, bartender, bus driver, cook, garage guard, checker, waiter, machine operator) 7. Unskilled (e.g. attendant, janitor, construction helper, unspecified labour, porter, unemployed) 8. Homemaker 9. Student, disabled, no occupation			

4. Material and financial resources (please circle appropriate number).

Which of the following items, in working order, does your household have?

Items	Yes	No
1. A refrigerator or freezer	1.	1.
2. A vacuum cleaner or polisher	2.	2.
3. A television	3.	3.
4. A hi-fi or music center (radio excluded)	4.	4.
5. A microwave oven	5.	5.
6. A washing machine	6.	6.
7. A video cassette recorder or	7.	7.

dvd player		

Which of the following do you have in your home?

Items	Yes	No
1. Running water	1.	1.
2. A domestic servant	2.	2.
3. At least one car	3.	3.
4. A flush toilet	4.	4.
5. A built-in kitchen sink	5.	5.
6. An electric stove or hotplate	6.	6.
7. A working telephone	7.	7.

Do you personally do any of the following?

Items	Yes	No
1. Shop at supermarkets	1.	1.
2. Use any financial services such as a bank account, ATM card or credit card	2.	2.
3. Have an account or credit card at a retail store	3.	3.

Appendix B

Informed Consent Document

AUTISM SCREENING IN CHILDREN: USING THE SOCIAL COMMUNICATION QUESTIONNAIRE IN SOUTH AFRICA

Dear Parent(s),

Our study is about whether short questionnaires can be used to help identify autism. Thank you for taking part!

If you take part in our study, you will be asked to give us some basic information about yourself and your family, and to fill out the Social Communication Questionnaire, which asks specific questions about your child's behaviour, the forms are attached in this e-mail. You can e-mail them back as soon as you have filled them in. Please fill in the current version of the SCQ if your child is five years or younger. Please fill in the lifetime version of the SCQ if your child is older than five year.

We may ask if you can bring your child to the clinic so we can watch your child play with toys and do some other simple tasks. We can then give you a formal diagnosis, which will allow your child to get the treatment help interventions that your child needs.

There are no negative effects if you do not fill in the questionnaires
We understand that some of this information may be sensitive, but please be assured that all information will be kept strictly confidential.

Only certain authorized researchers at UCT will be able to view the information. The information will then be saved as part of a dataset that may only include information that cannot directly identify you or your child. For example, the dataset may not include you or your child's name, address, telephone number, ID number or any other photographs, numbers, codes or so forth that link you or your child to the study. If the results of the research are published neither you nor your child will be identified in any way. There are no risks involved. The benefits are that your child may get a formal diagnosis and you will be given advice on what is best to do for your child, and what help you can get. Another benefit is that your child could be ruled out from having autism.

If you have any queries or concerns please feel free to contact our team representative, Faye Bozalek, on 084 607 0788 or faye656@hotmail.com

Thank you for your help!

Autism Research Group

Department of Psychology

University of Cape Town

Please fill in your name to indicate that you have read, understood and accept the above letter:

_____

Appendix C

AUTISM SCREENING IN CHILDREN: USING THE SOCIAL COMMUNICATION QUESTIONNAIRE IN SOUTH AFRICA

Dear Parent(s),

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If you take part in our study, you will be asked to give us some basic information about yourself and your family, and to fill out the Social Communication Questionnaire, which asks specific questions about your child's behaviour, the forms are attached in this e-mail. You can e-mail them back as soon as you have filled them in. Please fill in the current version of the SCQ if your child is five years or younger. Please fill in the lifetime version of the SCQ if your child is older than five year.

After we have looked at the questionnaires, we will let you know the results. These results show how likely it is that your child has autism. We may ask if you can bring your child to the clinic so we can watch your child play with toys and do some other simple tasks. We can then give you a formal diagnosis, which will allow your child to get the treatment help interventions that your child needs.

There are no negative effects if you do not fill in the questionnaires

We understand that some of this information may be sensitive, but please be assured that all information will be kept strictly confidential.

Only certain authorized researchers at UCT will be able to view the information. The information will then be saved as part of a dataset that may only include information that cannot directly identify you or your child. For example, the dataset may not include you or your child's name, address, telephone number, ID number or any other photographs, numbers, codes or so forth that link you or your child to the study. If the results of the research are published neither you nor your child will be identified in any way. There are no risks involved. The benefits are that your child may get a formal diagnosis and you will be

given advice on what is best to do for your child, and what help you can get. Another benefit is that your child could be ruled out from having autism.

If you have any queries or concerns please feel free to contact our team representative, Faye Bozalek, on 084 607 0788

Thank you for your help!

Autism Research Group

Department of Psychology

University of Cape Town

University of Cape Town

Faculty of Humanities

Full name: Faye Bozalek

Student number: BZLFAY001

Course code: PSY4000W

Course Title: Honours in Psychology

Due Date: Thursday, 27 October 2011, 12h00.

Plagiarism Declaration

1. I know that plagiarism is wrong. Plagiarism is to use another's work and to pretend that it is one's own.
2. I have used the APA convention for citation and referencing. Each significant contribution to, and quotation in, this essay from the work, or works, of other people has been acknowledged through citation and reference.
3. This report is my own work.
4. I have not allowed, and will not allow, anyone to copy my work with the intention of passing it off as his or her own work.

_____ _____

Signature Date