

**The knowledge, understanding and perceptions of professional nurses,
working in Primary Health Care clinics, about autism spectrum disorder**

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Declaration

This is to certify that the work is entirely my own and not of any other person, unless explicitly acknowledged (including citation of published and unpublished sources). The work has not previously been submitted in any form to the Durban University of Technology or to any other institution for assessment or for any other purpose.

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Dedication

I dedicate this dissertation to my son John Nathan Williams, whose daily struggle with autism shows his strength and is the reason for this research which I hope will help other children like him be diagnosed and treated early.

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Abstract

Background

The Centers for Disease Control and Prevention (CDC) in the United States has found that more children than ever before are being classified as having autism spectrum disorders (ASDs) (Chiri and Warfield 2011: 1081). According to Matenge (2014: 1), ASD is a pervasive developmental disorder characterised by two essential features: a combination of impairments in social interaction and social communication, and restricted, repetitive, and stereotyped patterns of behaviour, interests and activities. Malcolm-Smith *et al.* (2013: 4) report that data on the incidence, prevalence, and impact of ASD in South Africa are almost entirely lacking. No epidemiological studies of ASD have been conducted in the country (Malcolm-Smith *et al.* 2013: 4). Diagnostic and intervention services, particularly at state level, are scarce (Malcolm-Smith *et al.* 2013: 4). Hence, those that are in place are heavily overburdened. Of particular concern for South Africa are research findings indicating that ASD is under-identified in low socioeconomic status communities, so in these contexts ASD often goes undiagnosed, or is diagnosed late (Malcolm-Smith *et al.* 2013: 4). Matenge (2014: 19) argues that there is, therefore, a need to assess the level of knowledge, understanding and the experiences of South African nurses regarding autism, as they are usually the first professionals that families of children with autism contact.

Research purpose

The purpose of this research was to determine the knowledge, understanding and perceptions of professional nurses who work in primary health clinics in eThekweni Health District, KwaZulu-Natal, regarding ASD.

Research design

A quantitative, non-experimental, descriptive research survey design was utilised. A self-reporting questionnaire was used to collect data.

Sampling and sample size

Simple random sampling was used to determine which clinics in the eThekweni health district would be part of the study. The sample size for the clinics was thirty four, of those thirty were eThekweni municipality clinics and four KwaZulu-Natal Department of Health clinics. These clinics were utilised and provided the 275 professional nurses needed. The sample was calculated with a margin of error and an alpha value of 0.05; the researcher needed a minimum of 275 respondents. The researcher selected the respondents utilising non-probability, convenience sampling.

Data analysis

Data was analysed with the assistance of the statistician, using SPSS version 22. Descriptive statistics were used to explore differences between or among groups (Grove, Burns and Gray 2013: 217). Inferential statistics are used to draw conclusions regarding the differences between groups in the population from which the samples are drawn and the relationship between the variables in the population (Morgan *et al.* 2015: 84). Both descriptive and inferential statistics were used to analyse data in this study.

Conclusion and findings

It was found that the average professional nurse working in a primary healthcare clinic has 65.8% knowledge and understanding of ASD. Of particular concern is that the majority of respondents 51% (n=141) did not know or understand that the child with autism loves routine which is a key symptom in making a diagnosis of ASD, which may lead to late, or missed diagnosis. Eighty eight percent (n = 242) of respondents felt that they would benefit from further training on the identification and diagnosis of ASD. It was also found that respondents that have completed the Psychiatric Nursing Science course were more knowledgeable about ASD and confident in diagnosing ASD and counselling parents on ASD and available ASD services in the community.

Recommendations

The researcher recommended that: Autism spectrum disorder to be included in the curriculum for nurses training and that regular in-service training be done to keep the

professional nurses up to date with on new information related to ASD. It was also recommended that all children should be screened for ASD at 18 and 24 months at all PHCs in eThekwini district and that posters on the signs and symptoms of ASD should be displayed at primary healthcare clinics in full view of patients, parents and staff.

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List of Acronyms

Acronym	Full term
ASD	Autism Spectrum Disorder
PHC	Primary Healthcare Clinic
KZN	KwaZulu-Natal
SANC	South African Nursing Council
DSM	Diagnostic and Statistical Manual
KCAHW	Knowledge about Childhood Autism among Health Workers

Chapter 1: Overview of the Study

1.1 Introduction and background

More children than ever before are being classified as having autism spectrum disorders (ASDs) (Chiri and Warfield 2011: 1081). According to Matenge (2014: 1), ASD is a pervasive developmental disorder characterised by two essential features: a combination of impairments in social interaction and social communication, and restricted, repetitive, and stereotyped patterns of behaviour, interests and activities. The cause of ASD is unknown, but it is recognised as a neurological disorder with strong genetic links. According to the Centers for Disease Control and Prevention (2014: 4) one in 68 children in the United States of America and one in 100 worldwide are diagnosed with ASD. There is no known prevention or cure for ASD but early intervention has been reported to show a positive outcome for the development of a child diagnosed with ASD (Chiri and Warfield 2011: 1081).

According to recent studies by Kasari *et al.* (2008), Eikeseth (2009), and Dawson *et al.* (2010), early intervention significantly improves developmental outcomes for young children with ASD. Harris and Handleman (2000: 138) suggest that intervention begun before three years of age has a larger impact than intervention begun after age five.

Autism spectrum disorders are lifelong developmental disorders and the earliest symptoms start to manifest overtly from the age of one year onwards (Kamio *et al.* 2014: 18). Since early educational intervention can optimise long-term prognosis (Rogers and Vismara 2008; Kamio, Inada and Koyama 2013), early detection and diagnosis are crucial. The American Academy of Paediatrics recommends that in addition to broad developmental screening at 9, 18, and 24 months, all children should receive autism-specific screening at 18 and 24 months of age (Johnson and Myers 2007: 1213).

While the number of children diagnosed with autism continues to grow worldwide, it is exceedingly important that healthcare professionals have the foundation of knowledge necessary to recognise the characteristics of the disorder for screening, diagnosis and referral, and have the ability to provide quality care to these children,

and/or to provide support to their primary caregivers (Matenge 2014: 20). According to Crais *et al.* (2014: 2311) most primary care providers are not screening for ASD at 18 and 24 months of age.

Malcolm-Smith *et al.* (2013: 4) report that data on the incidence, prevalence, and impact of ASD in South Africa are almost entirely lacking. No epidemiological studies of ASD have been conducted in the country (Malcolm-Smith *et al.* 2013: 4). Diagnostic and intervention services, particularly at state level, are scarce (Malcolm-Smith *et al.* 2013: 4). Those that are in place are heavily overburdened. Standardised assessment tools in multiple languages are not available in South Africa (Malcolm-Smith *et al.* 2013: 4). Of particular concern for South Africa are research findings indicating that ASD is under-identified in low socio-economic status communities. In these contexts, ASD often goes undiagnosed, or is diagnosed late (Malcolm-Smith *et al.* 2013: 4).

1.2 Problem statement

According to the Centers for Disease Control and Prevention (2014: 4) one in 68 children in the United States of America and one in 100 worldwide are diagnosed with ASD. The researcher has observed the inability of many professional nurses, when examining children at primary health clinics, to identify children with ASD. This leads to a delay in diagnosis, referral and early intervention for these children. Of particular concern for South Africa, are research findings by Malcolm-Smith *et al.* (2013: 4) indicating that ASD is under-identified in low socio-economic status communities. In these contexts, ASD often goes undiagnosed, or is diagnosed late. Children who receive interventions at younger ages have improved outcomes in communication, developmental skills, language, and social skills (Dawson and Osterling 1997; Bryson, Rogers and Fombonne 2003; Rogers and Vismara 2008; Lord and Bishop 2010). A late diagnosis therefore means poor outcomes for children with ASD especially in communication, developmental skills, language and social skills, this will lead to a increased financial and emational burden for the parents and family of the child with ASD. Matenge (2014: 19) argues that there is, therefore, a need to assess the level of knowledge, understanding and perceptions of South African nurses regarding autism, as they are usually the first health care professionals that families of children with autism contact.

1.3 Research purpose

The purpose of this research was to determine the knowledge, understanding and perception of professional nurses, who work in primary health clinics in KwaZulu-Natal, regarding ASD

1.4 Research objectives

The objectives of this study were to determine:

- 1) The knowledge of Professional Nurses working in primary health clinics in eThekweni Health District, KwaZulu-Natal regarding autism spectrum disorder.
- 2) The understanding of Professional Nurses working in primary health clinics in eThekweni Health District, KwaZulu-Natal regarding autism spectrum disorder.
- 3) The perception of Professional Nurses working in primary health clinics in eThekweni Health District, KwaZulu-Natal clinics regarding autism spectrum disorder.

1.5 Significance of the study

This study has identified that professional nurses working in primary healthcare clinics in eThekweni Health District lack the knowledge needed to diagnose a child with ASD, which could lead to these professional nurses not correctly diagnosing a child with ASD, leading to delayed treatment and a poor prognosis for that child. The results of this study will be presented to the KZN Department of Health (DoH) and the eThekweni Municipality in the hope that this will convince them to institute some sort of in-service training on ASD for professional nurses. This increased knowledge could help, these professional nurses to diagnose children with ASD early and refer them for early intervention, which will lead to a better prognosis for these children.

1.6 Definitions of key concepts

Autism spectrum disorders

Autism spectrum disorder is a pervasive developmental disorder with persistent deficits in (1) social communication and social interaction and (2) restricted, repetitive patterns of behaviour, interests or characteristics which occur across

multiple contexts. Symptoms must be present in the early developmental period and should cause clinically significant impairments in social, occupational or other important areas of current functioning (American Psychiatric Association 2013: 119).

Professional nurse

A person registered as such in terms of section 31 of Nursing Act 33 of 2005 (South African Nursing Council 2005).

In this study a professional nurse is a person employed by the department of health as a nurse, working at the PHC and do health assessment and examination of children.

Primary healthcare

A basic level of health care that includes programmes directed at the promotion of health, early diagnosis of disease, and disability and prevention of disease (Mosby Medical Dictionary 2009).

In this study primary healthcare is the first health institution in the community that examines parents would take their babies and child to be examined and staffed by professional nurses and administered by the Department of Health.

1.7 Structure of the dissertation

Chapter 1: Introduction and background of the study.

Chapter 2: Literature review.

Chapter 3: Research methodology.

Chapter 4: Presentation of results.

Chapter 5: Discussion of the findings, recommendations and conclusion.

1.8 Conclusion

This chapter introduced and presented an overview of the study and included the problem statement, research purpose, research objectives, definition of terms. In the following chapter a detailed literature review is presented.

Chapter 2: Literature Review

2.1 Introduction

In the ensuing chapter, a detailed review is presented on all relevant literature pertaining to this study. The literature was obtained from the Durban University of Technology library (DUT) and various databases on the DUT library website. The database that was used most often was EBSCO host which has many databases like CINAHL, Medline. The other search engine utilised was Google Scholar. Of the hundreds of articles found, only articles relevant to this study were used. A total of 108 articles were utilised in this literature review. Some of the search terms used were: autism, autism spectrum disorder, screening, etc. The following topics will be discussed in this chapter: History of Autism, history of Autism in Africa, development of communication in relation to ASD, sensory impairments in ASD, medical comorbidities of children with ASD, Screening for ASD, early intervention, Autism internationally (including South African and KwaZulu Natal) and the Theoretical framework.

2.2 History of autism

In 1943 an American psychiatrist, who was working at Johns Hopkins Hospital in Baltimore, Maryland, Leo Kanner, first described autism in a paper titled: "Infantile autism: autistic disturbances of affective contact". Kanner reported his observations made over a period of five years, about 11 children with unifying behavioural features which he termed "infantile autism", his description of infantile autism fits into the current description of the commonest and more severe form of ASD (Bello-Mojeed, Bakare and Munir 2013: 1). Kanner found the following four characteristics present in all 11 children: firstly, they all preferred to be alone and not have contact with the doctors and their parents, which he called being aloof; secondly they had language disorders for example delayed speech development, echolalia, etc.; thirdly, they had an excellent memory for unusual things like the number of pages in an encyclopaedia (Kanner called this mechanical memory); fourthly, all the children insisted on having everything the same and had tantrums if anything was changed without their knowledge and they had restricted interests (Kanner called this mechanical instead of social) (Kita and Hosokawa 2011).

One year later in 1944, an Austrian psychiatrist and paediatrician Hans Asperger released his paper "Die Autistische Psychopathen im Kindersalter". In his report, he identified a pattern of behaviour and abilities that he called "autistic (self) psychopathy (personality disease)". The patterns were: "lack of empathy, little ability to form friendships, one-sided conversation, intense absorption in a special interest, and clumsy movements." These were similar to the characteristics reported by Kanner, except that the patients Asperger reported on had less severe language delays (Coates 2007; Kita and Hosokawa 2011).

The set of characteristics described by Asperger was termed 'Asperger's syndrome' by Lorna Wing, a British researcher, in a paper published in 1981. Later she developed the concept of autistic continuum or autistic spectrum. Wing, like many others, believed that autism and Asperger's syndrome were similar disorders with differences in intellectual ability and the severity of impairment. Asperger's disorder was added to the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) in 1994 as a separate disorder from autism. However, in 2013, the DSM-V replaced autistic disorder, Asperger's disorder and other pervasive developmental disorders with the umbrella diagnosis of 'autism spectrum disorder' (Autism Society of America n.d.; Kita and Hosokawa 2011).

Baker (2013) summarises the history of autism spectrum disorder as follows:

- 1943: Leo Kanner publishes "Autistic Disturbance of Affective Contact" describing 11 socially isolated children who share an obsessive desire for sameness.
- 1950s-1960s: autism widely regarded as a form of "childhood schizophrenia." Psychoanalysts blame emotionally cold mothering.
- 1970s: autism understood as a biological disorder of brain development.
- 1980: DSM-III distinguishes autism from childhood schizophrenia.
- 1987: DSM-III-R lays out a checklist of criteria for diagnosing autism.
- 1994-2000: DSM-IV and DSM-IV-TR expand definition of autism and include Asperger syndrome.
- 2013: DSM-V folds all subcategories into one umbrella diagnosis of autism spectrum disorder (ASD). It is defined by two categories: impaired social

communication and/or interaction and restricted and/or repetitive behaviours (Baker 2013).

2.3 History of autism in Africa

It was widely believed that ASD was an illness peculiar to Western civilization until 1978 when Dr Victor Lotter, a psychology professor at the University of Guelph Ontario, published his paper entitled "Childhood Autism in Africa". Lotter screened children with intellectual disabilities in nine major cities of six African countries, namely, Ghana, Nigeria, Kenya, Zimbabwe, Zambia and South Africa and found that 9 out of the 1,312 children with intellectual disabilities met the eligibility criteria to be classified as having autism, a rate which was 1 in 145 (Lotter 1978; Bakare and Munir 2011a).

Lotter published a second paper, on autism in Africa in 1980 in which he found: firstly, that the combination of behaviours constituting criteria for autism do occur in African children. Secondly, that there was a greater number of boys among children who exhibited such behaviour combination and such presentation tended to be more common among African children with moderate to severe intellectual disabilities. Thirdly, that the majority of children described as having features of autism had parents of high socio-economic class. Fourthly, there were certain differences in frequency of specific behaviours between African children and children from Western Europe and North America, notably the stereotypic range of behaviour which was observed to be less common among African children compared to their counterparts in the West. This is important because stereotypic behaviour is one of the main criteria for diagnosing autism spectrum disorders (Lotter 1980: 133; Bakare and Munir 2011a).

A literature review to date shows no school or community based epidemiological studies of autism spectrum disorders in the African continent. The only available study that is closely related was focused on prevalence of autism spectrum disorder among children with developmental disorders in the Arab countries (Seif Eldin *et al.* 2008: 281). Prevalence of autism spectrum disorders among children with developmental disorders in Egypt and Tunisia were documented to be 33.6% and 11.5% respectively (Seif Eldin *et al.* 2008: 288). The prevalence figures are quite high compared against the earlier finding by Lotter who documented a prevalence of

9 in 1,312 (approximately 0.7%) among intellectually disabled children (Lotter 1978: 238). In a clinic-based population study in south-eastern Nigeria, prevalence of autism spectrum disorders had been noted to be 0.8% of the total population of children that attended the clinic over a one-year period (Pavone *et al.* 2004; Bakare *et al.* 2011).

The findings of many studies in Nigeria show a low level of knowledge and awareness about autism spectrum disorders in Africa, thereby compromising early recognition of the disorder and intervention to alleviate symptom severity (African Network for the Prevention and Protection against Child Abuse and Neglect 2007; Bakare *et al.* 2008; Bakare *et al.* 2009; Bakare, Ebigbo and Agomoh 2009; Igwe *et al.* 2010; Bakare *et al.* 2011)

2.4 Development of communication in relation to ASD

Communication is the process of exchanging information in different forms with other people. It is not limited to language, but includes non-verbal communication and understanding of symbols (Heflin and Alaimo 2007: 5). Essentially, communication is decoding a message and being able to code a message for others. The process is complex, but it happens very rapidly (Noens and van Berckelaer-Onnes 2005: 123). Typically developing (TD) children progress through three phases of communication. Intentional communication is the use of gestures or vocalizations to get attention or to meet a need or a want. Symbolic communication is the use of early language to interact with others, gain attention, and meet needs. Linguistic communication is the final and most sophisticated phase. This is the ability to engage in full discourse with another using many different forms of communication (Brown and Elder 2014: 219).

Development of communication skills begins in infancy. Crying is the very first form of social interaction. Typically developing infants begin to form relationships between people and objects and recognize emotion through eye gaze and observation of facial expression (Brown and Elder 2014: 219). Infants who are later diagnosed with ASD prefer to look at objects over people, notice parts of objects instead of wholes, and fixate on one item instead of gaze at multiple items (Heflin and Alaimo 2007: 10).

At six to seven months, infants begin babbling and using vocal utterances in addition to crying to gain attention from others. Infants with ASD do not babble as much, do not seem to be as aware of language, and are often thought to have hearing impairment. In the final months of infancy, TD infants begin to gesture to express needs or wants. This is a very early form of intentional communication. Infants with ASD tend to use gestures less often and in less meaningful forms of communication. Toddlers and pre-schoolers engage in three types of behaviours that help in development of communication, social, and language skills. Participation in motor imitation, joint attention, and symbolic play are essential for skill development. Motor imitation begins before language skills (Heflin and Alaimo 2007; Brown and Elder 2014: 220).

Children begin to imitate the actions they have observed in other people. In order to imitate actions correctly, precisely, or in the right context, children must be able to ascribe to the other person an intention for them to act. They have to form a concept of the other person's mind. Children with ASD may be slow to imitate or may inaccurately imitate behaviours because they miss the meaning of symbols or behaviours or they attribute intentions inaccurately (Heflin and Alaimo 2007: 11). Joint attention is the ability to engage in interaction with others. Children can see what another is interested in and gain another's attention in that action or activity (Brown and Elder 2014: 220).

Social interaction includes sharing of emotions and reciprocal exchange of information. These continued interactions with peers and adults contribute to language development. The extent that children with ASD engage in joint attention play is thought to be a predictor of future communication skills (Brown and Elder 2014: 220).

Children with ASD are less likely to request joint attention or respond to another's request for joint attention. Symbolic or object play in childhood helps to develop symbol representation and is critical to development of language skills. Pretend play with objects develops naturally and becomes more complex over time for TD children. The understanding of symbols contributes to the comprehension of language (Brown and Elder 2014: 220).

Children with ASD are far less likely to participate in symbolic play (Noens and van Berckelaer-Onnes 2005; Heflin and Alaimo 2007). Children with ASD who develop functional communication often display atypical communication styles such as echolalia, contact gestures, pronoun reversals, and neologisms (Brown and Elder 2014: 220). It is likely that these develop because these children have a limited understanding of the meanings and intentions of symbolic forms of language (Noens and van Berckelaer-Onnes 2005; Heflin and Alaimo 2007).

Often, these children have the vocabulary and even have memorized the syntax to pass standardized language screenings, but they struggle in real world communication settings because they lack true understanding of meaning. The impairments in ASD are often described as qualitative impairments (Noens and van Berckelaer-Onnes 2005: 123; Brown and Elder 2014).

Garcia-Perez, Lee and Hobson (2007: 1321) reports that when matched for age and developmental language level to peers with mental retardation, 12 children with ASD were very comparable in objective measures of communication, such as head nodding or shaking while speaking, looks to the interviewer, and total number of smiles, but they scored significantly lower on subjective measures of communication, such as engagement and conversation flow.

Children with ASD may use language to meet needs and respond to questions, but tend to make comments less often (Brown and Elder 2014: 220). They use language as a functional tool, such as for requesting items (Chiang and Lin 2008: 544). In fact, they may not anticipate engagement at all and tend to declare or express their needs or wants without any expectation for others to engage (Noens and van Berckelaer-Onnes 2005: 123). The frustration of being unable to communicate with others can lead to behavioural outbursts in some children. These behaviours have a wide range of expression and can be aggressive physical behaviours, self-harming behaviours, or loud vocalizations.

These challenging behaviours are proposed to be a form of communication when there are breakdowns in the process and the children are not getting their needs met (Brown and Elder 2014: 220).

2.5 Sensory impairments in ASD

Sensory impairments are present in as many as 80% of persons with ASD. The sensory system may be hypersensitive in some areas and hyposensitive in others. Many repetitive behaviours in ASD may actually be adaptive behaviours for the sensory differences that are being experienced. Often, children with ASD are very sensitive to smells. They usually have difficulty with auditory processing and respond best with visual communication methods. Tactile defensiveness may be present and is caused by a very low threshold for tactile stimulation. Vestibular and proprioceptive systems are also affected and may account for the clumsy behaviour often described in individuals with ASD. Due to differences in their brains, they are unable to filter and prioritize sensory signals. For example, blocking out background noise may be difficult, or they may use peripheral vision to focus on people or objects because having the eyes focus directly forward provides too much sensory information at one time (Heflin and Alaimo 2007: 12; Brown and Elder 2014).

Brown and Elder (2014: 222) argues that knowledge of sensory impairments is an important key to communicating successfully with patients with ASD and that these impairments can overwhelm their systems and make it difficult for them to focus on the communication task, and may also exacerbate behaviour problems that further impede effective communication. Reducing the total amount of stimuli that persons have to process during the communication interaction allows them to remain more focused.

Brown and Elder (2014: 222) further explain that one must assess the environment for possible sensory barriers. The following environmental factors may cause sensory overload or be a distraction:

- Lights: especially bright or flashing,
- Noises: any sound level can be distracting, call systems, monitor beeps, ringing phones, or a noisy waiting room.
- Textures: unfamiliar sheets, bandages, paper on exam table, tongue depressor,
- Smells: Alcohol wipes, cleaning solutions, blood;
- Non-verbal behaviour: touching the patient, gesturing, etc.

2.6 Medical comorbidities of children with ASD

Certain conditions are known to be associated with ASD, including seizures, sleep disturbances, gastrointestinal (GI) disorders, and psychiatric disorders (Scarpinato *et al.* 2010: 246). The onset of epilepsy in children with ASD occurs at two peak age ranges: before age five years and again in adolescence. Prevalence rates for epilepsy among children with ASD are estimated to range from 11% to 39%. Children with ASD who have more severe cognitive impairment or motor deficits have a higher risk for epilepsy than children with ASD who are less impaired. Exacerbation of seizure activity may result in an acute admission for evaluation and medication adjustments (Pavone *et al.* 2004; Scarpinato *et al.* 2010: 246).

Sleep disturbances are common among children with ASD and have been found to occur in 44% to 83% of children with autism. These disturbances have been reported to occur in both children and adolescents with ASD, and at all levels of cognitive function. Richdale (1999) identified several specific sleep challenges for children with ASD, including irregular sleep/wake patterns, problems with sleep onset, poor sleep, early waking, and poor sleep routines. While the specific cause of sleep disturbances among children with ASD is not known, theories range from identifiable associated medical conditions such as sleep apnoea or gastroesophageal reflux, to social and communication impairments that may cause the child to miss the routine and social cues that typically denote a regular sleep/wake cycle, and to disturbances in the body's production of melatonin, an important regulator of sleep (Richdale 1999; Myers, Johnson and Council on Children with Disabilities 2007).

Multiple studies have examined the correlation between ASD and GI symptoms (e.g., chronic abdominal pain, diarrhoea, and constipation) and food sensitivities, such as allergies or celiac disease (Pavone *et al.* 1997; Jyonouchi, Sun and Itokazu 2002). While results of these studies have been mixed, leaving unclear implications for practice, it is important to note that the general paediatric population is known to experience GI problems quite frequently. Indeed, the prevalence rate of constipation, the most common digestive complaint in the general population, ranges from 0.7% to 29.6% (Scarpinato *et al.* 2010: 250). However, recent research suggests that there may be a behavioural association between constipation and feeding issues / feeding selectivity in children with autism, rather than an organic cause of GI manifestations

(Scarpinato *et al.* 2010: 250). In practice, it is important to be aware that these feeding and elimination behaviours (rather than organic conditions) can complicate care. For example, a child with specific food aversions may choose not to eat hospital food and then, in turn, develop constipation.

While not a core symptom of ASD, behavioural and, specifically, psychiatric or mental health co-occurrences of mood disorders, aggression, or self-injurious behaviour appear to be more frequent in this population than in the general population (Lecavalier 2006; Ming *et al.* 2008). One study of 487 school children between the ages of 3 years and 21 years, all of whom were receiving educational services for PDD, found that both teachers and parents consistently rated “physically harms self,” or “bites self” and “hits/slaps self,” as being a moderate to severe problem (Lecavalier 2006). Another study found the incidence of co-occurring psychiatric disorders in their sample of 218 children to be 26%, with a mood disorder and or aggressive/self-injurious behaviours in 32% of children (Ming *et al.* 2008: 8). This same study also reported that the most common targets of aggression were mothers and younger siblings, while the most common self-injurious behaviour was biting of the hands/forearms.

Comorbid psychiatric diagnoses often include specific phobia/s, attention-deficit/hyperactivity disorder, obsessive-compulsive disorder, and major depression (Leyfer *et al.* 2006: 854). These comorbidities may either be a direct reason for acute hospital admission or contribute to the problem list affecting the child’s plan of care (Ming *et al.* 2008: 8). Available data about prevalence rates for comorbid conditions in children with ASD are variable with wide ranges reported. Medical management of comorbid conditions may increase the possibility of acute hospitalisation for a child with ASD (Scarpinato *et al.* 2010: 246).

2.7 Screening for ASD

According to Windham *et al.* (2014: 1621) evidence has accumulated supporting the benefits of early developmental screening for autism spectrum disorders (ASD) as part of routine paediatric practice. Children who receive interventions at younger ages have improved outcomes in communication, developmental skills, language, and social skills (Dawson and Osterling 1997; Bryson, Rogers and Fombonne 2003; Rogers and Vismara 2008; Lord and Bishop 2010).

However, lack of time and training have been identified as barriers to implementing routine screening (Windham *et al.* 2014). In a large survey of U.S. paediatricians, only 23% of primary care clinicians reported routine use of a screening tool (Sand *et al.* 2005: 175). In 2006, the American Academy of Paediatrics (AAP) released a policy statement recommending that paediatricians: (1) incorporate developmental surveillance into every well child visit; (2) use a formal developmental screening tool if risks are present; and (3) administer autism-specific screening at 18 and 30 months of age (American Academy of Pediatrics 2006: 415). However, the AAP statement lacks guidance on specific implementation protocols and it is clear that a standard protocol has not been adopted by paediatricians at large (Sices *et al.* 2003; King *et al.* 2010).

Among studies comparing screening instruments, general consensus is that parent-completed screening questionnaires are more time and cost-efficient than those requiring administration by a paediatrician (Dobrez *et al.* 2001). One of the most widely used and studied ASD screening tools is the modified checklist for autism in toddlers (M-CHAT), a 23-item parent checklist, with a recommended staff follow-up for clarification of failed items (Windham *et al.* 2014: 1621). Other self-administered autism screening instruments include the autism behaviour checklist (ABC) for older children, the infant toddler checklist (ITC) for younger children and the checklist for autism in toddlers (CHAT). Two frequently used self-administered general developmental screeners are the Ages and Stages questionnaire (ASQ) and the Parents Evaluation of Developmental Status (PEDS).

2.8 Early intervention

According Koegel *et al.* (2014: 51), in the 1960s and 1970s there were very poor outcomes for children with ASD, this was before numerous comprehensive interventions were available. Koegel *et al.* (2014: 51) goes on to explain that almost all children in that era with ASD were placed in mental institutions by adolescence, with some placed as early as toddlerhood. Koegel *et al.* (2014: 51) further state that anyone who spent time observing the locked wards of these hospitals would attest to the undesirable living conditions these children had to endure.

Each decade has since provided a rich and accumulating database documenting hundreds of effective interventions for children with ASD ranging from parent education to school interventions, behaviour management techniques (Baker-Ericzen, Stahmer and Burns 2007), methods to improve communication (Koegel *et al.* 1998; Smith and Camarata 1999), socialization (Koegel *et al.* 2005; Harper, Symon and Frea 2008), academics (Koegel *et al.* 2003; Koegel, Singh and Koegel 2010; Robinson 2011), and so on. Many researchers feel that ASD is not necessarily a life-long disabling condition (Koegel *et al.* 1999; Koegel and Koegel 2012), and most research clinics report that, with intervention, most children can be included in regular education classrooms, and as many as 25% of children will lose the diagnosis completely (Lovaas 1987; Sallows and Graupner 2005; Cohen, Amerine-Dickens and Smith 2006; Helt *et al.* 2008).

Despite some methodological concerns with the Lovaas (1987) study, most researchers feel that the interventions and resulting outcomes for children with ASD are much improved today over previous methods. In fact, prior to Lovaas (1987), Prizant (1983) showed that, even with the best available interventions, a staggering number (50%) of children diagnosed with autism remained non-verbal throughout their lives. In contrast, more recent research shows that fewer than 10% of individuals with ASD will remain non-verbal with intervention (Koegel 2000). Moreover, data suggest that children who are completely non-verbal who begin intervention in the early pre-school years are far more likely to become verbal than children who begin intervention over the age of five years (Koegel 2000). The majority of experts in the field agree that intervention must start at the earliest point in time (Rogers 1996; Landa 2007; Reichow 2012). The “wait and see” method for early intervention of ASD is likely to have significant negative consequences on children with ASD, according to the National Research Council (2001) of the United States of America.

Whatever the reasons, studies indicate that delays in diagnosis add significantly to parents’ levels of distress and delay earlier intervention for ASD children. Mitchell and Holdt (2014: 50) emphasise that any delay “eliminates a valuable window of treatment opportunity when the brain is undergoing tremendous development”. Jónsdóttir *et al.* (2011: 182) argue that early intervention not only results in gains for

the individual child and family, but may mean long-term cost savings for parents and service systems.

2.9 Autism internationally

2.9.1 Autism in China

Huang, Jia and Wheeler (2013: 1991) report that for centuries educational services for children with disabilities, especially those with severe developmental disabilities such as ASDs, have been absent in the People's Republic of China. Although the beginning of special education can be traced back to the late nineteenth century, when Western missionaries first established special schools in eastern coastal regions, the real development of special education on a nationwide scale didn't begin until the late 1970s when the late President Xiaoping Deng began to carry out the Reform and Open Door policy.

Huang, Jia and Wheeler (2013: 1991) further report that since then, special education in China has experienced significant reform and fast development, together with profound political, economic and social changes. The passage of the 1986 Compulsory Education Law and its succeeding legislation in the early 1990s reinforced further development of the field. However, most children with severe, multiple disabilities, such as profound cognitive impairments and classic autism (i.e., early infantile autism), are still kept away from schools and community life.

Although autism has been identified for more than 60 years by Western countries, the first case of official diagnosis of autism was reported by Tao from Nanjing Brain Hospital in a Chinese journal in the early 1980s, almost four decades after Kanner first published his ground-breaking paper on early infantile autism in 1943. According to Huang, Jia and Wheeler (2013: 1992) Tao introduced his first four cases of Chinese early infantile autism to the world in English in 1987. Since then, a growing number of children with such a disorder have been identified. Especially in recent years, the number of children diagnosed with ASDs has been increasing. However, the prevalence of autism in China seemed to be less than that in other Western countries (Huang, Jia and Wheeler 2013: 1992).

2.9.2 Autism in the United States of America

Recent reports estimate that 1 in 68 children are diagnosed with an ASD in the United States of America (Centers for Disease Control and Prevention 2014: 4). There are increasing public health concerns related to ASD with a concomitant increase in research on interventions, screening, and diagnosis. Within intervention research, recent systematic studies have demonstrated that early intervention significantly improves developmental outcomes for young children with ASD (Kasari *et al.* 2008; Eikeseth 2009; Dawson *et al.* 2010). Harris and Handleman (2000: 138) suggest that intervention begun before three years of age has a larger impact than intervention begun after age five.

Despite the encouraging outcomes from early intervention, children and families cannot take advantage of these interventions without some type of diagnosis. Unfortunately, the average age of diagnosis of ASD in the United States continues to be between five and six years of age. Regardless of whether there were early concerns, for most families with a child later diagnosed with ASD the pathway to such a diagnosis is time consuming. This pathway may include early developmental screening, referral from primary care, early intervention eligibility evaluation, and eventually diagnostic evaluation (Freuler *et al.* 2013). Crais *et al.* (2014: 2311) state that this phase of uncertainty can be stressful and time-consuming for families. Paediatric healthcare professionals (PHPs) are often considered the “first line of defence” for identification, as well as a gateway to early intervention services. Despite the American Academy of Paediatrics (AAP) Guidelines urging early ASD screening and the available evidence for early markers of ASD, Crais *et al.* (2014: 2311) further suggests that most primary care providers are not screening for ASD at 18 and 24 months of age.

2.9.3 Autism in Africa

Following Kanner’s first description of characteristics of infantile autism in a group of children about seven decades ago, documented evidence revealed that identification of ASD in Africa was not made until about three decades afterwards (Bello-Mojeed, Bakare and Munir 2013: 1). The African Network for the Prevention and Protection against Child Abuse and Neglect (ANPPCAN), Nigeria chapter, carried out a survey to determine the level of knowledge and awareness of ASDs among healthcare

workers and the general public. This study's findings showed that there is a very low level of knowledge and awareness among the general populace and a low to average level among various categories of healthcare workers, with the level being highest in healthcare workers in psychiatric facilities (African Network for the Prevention and Protection against Child Abuse and Neglect 2007).

Using the template of findings and observations made during the ANPPCAN study, a standard questionnaire for assessing knowledge of healthcare workers about ASDs, aimed at early recognition, was designed and validated. A subsequent study consistently showed the same trend of low level of knowledge and awareness among healthcare workers. It was further observed that the ability of healthcare workers in psychiatric facilities to recognise symptoms of ASDs was better than that of their counterparts in paediatric units/departments.

This does not bode well for early identification of ASDs in PHC settings. Igwe *et al.* (2010) examined the level of knowledge about ASDs among healthcare workers undergoing training (final-year medical, nursing and psychology students) at the University of Nigeria and found that overall, the level of knowledge of symptoms of ASDs was low in the three groups. Bakare and Munir (2011b: 119) stated that although available literature on the knowledge about ASDs in Africa comes mainly from Nigeria it is probably similar in other Sub-Saharan countries. Education would enhance early recognition and intervention, which has been observed to improve prognosis in individuals with ASDs (Bakare and Munir 2011b: 119), thus education of healthcare workers and the general public in Africa on ASDs should not be ignored.

Bakare and Munir (2011b: 119) surveyed opinions of healthcare workers in south eastern Nigeria on causes of ASDs, finding that significant proportions of 14.2% and 26.9% subscribed to preternatural and supernatural aetiological explanations, respectively. Trends among healthcare workers typically reflect trends among the majority of the general African population. The preternatural and supernatural aetiological explanations for ASDs in this study bear out the spiritual beliefs of Africans in relation to causes of neuropsychiatric disorders in general. Such explanations for neuropsychiatric disorders often negatively influence help-seeking behaviour, help generally first being sought from spiritualists, traditional healers and other non-orthodox practices.

This pattern of behaviour invariably results in delayed presentation to orthodox clinical practice, which is a common observation among African children with ASD. Late presentation of these children to orthodox medical care is also often accompanied by lack of expressive language ability and denies affected children the opportunity for early intervention, especially interventions aimed at improving speech and language development (Bakare and Munir 2011b: 119) .

Child and adolescent psychiatric facilities in Africa are limited and do not meet the needs of the paediatric population (Belfer 2008; Omigbodun 2008; Kleintjes, Lund and Flisher 2010). Njenga (2008) noted that the numbers of personnel such as psychiatrists, clinical psychologists and psychiatric nurses, among others, are inadequate for mental health needs relative to the size of the African population.

A study by Bakare, Ebigbo and Agomoh (2009) of opinions of healthcare workers on availability of facilities and laws supporting the needs and rights of children with ASDs and other developmental disorders in Nigeria also revealed inadequate facilities and personnel. Bakare, Ebigbo and Agomoh (2009) shows that despite two United Nations Conventions, that on the Rights of the Child and on the Rights of Persons with Disabilities, child rights are not supported by law in every state of the country, and where there are laws they are poorly implemented.

There is therefore a need to reach out to the general community and community healthcare workers to raise awareness about childhood neuropsychiatric disorders, which are rarely recognised early. While observations in the available literature are highlighted in this review, it is important to emphasise that there is currently a paucity of literature addressing the issues of age at first presentation to orthodox clinical practice and symptoms related to expressive language ability of African children with ASDs (Bakare and Munir 2011b: 120).

Bakare and Munir (2011b: 120) propose that excess of non-verbal over verbal cases of ASDs presenting to orthodox clinical practice observed in Africa is probably due to poor knowledge and awareness about ASDs, inappropriate help-seeking behaviour, and inadequate child and adolescent psychiatric facilities and trained healthcare personnel, and further suggest that improvements in these areas may change the currently observed trend because they would promote early recognition, diagnosis

and interventions, especially interventions directed at improving speech and language development sufficiently early.

2.9.4 Autism in South Africa

In 2007 the point prevalence of ASD diagnosis in US children was estimated to be 110/10 000. Using this ratio, there could potentially be over 270 000 people with ASD in South Africa, with a predicted 5 000 new cases per year (Kogan *et al.* 2009: 1400). According to Springer *et al.* (2013: 98), epidemiological surveys in the United States of America since the early 1980s have revealed that increasing numbers of children are being diagnosed with ASD and a similar trend was described in a South African study that documented an 8.2% increase in the number of children presenting with features of ASD to a developmental clinic in Johannesburg over the period 1996 to 2005.

Hyman and Johnson (2012: 1156) explain that in relatively more developed countries, education and support for primary health care professionals caring for children with ASD has been a targeted area of interest, with the aim being the provision of adequate information and skills to primary care providers on screening for ASD and management of developmental disorders. Hyman and Johnson (2012: 1156) further explain that this points to an urgent need to assess the knowledge and awareness of primary health providers in less developed contexts, such as South Africa, in order to put in place appropriate programmes with the ultimate aim of helping children with ASD as well as their primary care givers.

Igwe *et al.* (2010) describe the mode of healthcare delivery in Sub-Saharan Africa as a hierarchical one, where at the bottom of the apex service pyramid is the primary level, which provides services for people at community level. This is followed by the secondary tier, which provides care for cases referred from primary level, and the tertiary level provides specialized care for those referred from secondary level. Igwe *et al.* (2010) therefore postulates that Primary health care providers, specifically nurses in this context, are therefore likely to have the most contact with children coming to public hospitals. Matenge (2014: 17) states that despite the increased prevalence of children with autism, it appears that knowledge and awareness regarding autism and diagnostic screening procedures in Sub-Saharan African countries remains lower than that in developed countries. According to Igwe *et al.*

(2010) the public health care delivery system in South Africa is similar to that in other Sub Saharan countries.

Matenge (2014: 18) suggests that when it comes to the identification and diagnosis of autism at primary healthcare, nurses have a key role to play. Furthermore Matenge (2014: 18) states that no studies investigating the experiences of nurses working with Autism spectrum disorders in primary healthcare in South Africa could be found which is due to a lack of accurate and reliable local data on the prevalence of autism and related issues in South Africa. The majority of autism research originates in developed countries and some of the findings of those studies may not be directly transferable to a South African context. In developed countries, there is a particular view of what autism is and how children behave and interact with adults, whereas in the South African context there may be different expectations around children's behaviour (DeWeerd 2012: 18).

2.9.5. Autism in KwaZulu-Natal

In a study conducted in KwaZulu Natal, Grinker *et al.* (2012) describe the Early Autism Project which recognised that children did not receive services and appropriate intervention at an early age and established a community based early detection program for Zulu speaking children with ASD between the ages of 18-36 months. Findings from this study highlighted some challenges related to early screening and diagnosis (including the use of behavioural diagnostic tests) of autism spectrum disorder in the South African context which are influenced by culture, poverty and the HIV/AIDS epidemic (Matenge 2014: 17). Grinker *et al.* (2012: 205) reported that parents that are not attuned to the early social and communication milestones become alarmed only when a child starts preschool and has difficulties engaging with peers, and may be more concerned about the stigma that the disorder holds and may not disclose their child's early difficulties as a result (DeWeerd 2012: 18; Grinker *et al.* 2012: 205). Matenge (2014: 19) also states that other factors such as poverty diminish the possibility that parents would seek medical care or specialized educational services for children who may not be severely impaired.

The HIV/AIDS epidemic renders many children orphans who have multiple caretakers during a single year which limits the opportunities to observe a child's development over time (Grinker *et al.* 2012: 206). It is well recognised that between

the ages of 18-36 months, there are similarities in the symptomatology of Autism spectrum disorder across cultures but more culturally specific symptoms of autism emerge as children grow up (DeWeerdts 2012: 18). For example, direct eye contact or eye gaze with a peer or adult, one of the diagnostic criteria of ASD, is generally discouraged and seen as disrespectful in Zulu speaking cultures which further points to a culturally nuanced understanding or expression of the disorder in the South African context (Grinker *et al.* 2012: 206). Therefore, recent efforts to develop local capacity through training and research are important starting points to address the challenges of ASD in this country (Grinker *et al.* 2012: 207).

The study conducted by Mitchell and Holdt (2014: 60) found that few ASD diagnoses were being made through the state health system in KwaZulu-Natal, and state funded specialised clinics with a focus on developmental disorders were rare. This makes a diagnosis of ASD inaccessible and extremely difficult for the majority of the South African population. The prevalence of ASD in KwaZulu-Natal children is probably equally dispersed at all levels of society, however, the lack of services precludes diagnosis. The results of the Kim *et al.* (2011) study fuel this concern as they point to the possibility that children with milder symptoms and less impairment are likely to remain undetected in the general education system. Mitchell and Holdt (2014: 60) continued to postulate that there is a critical need to equip medical practitioners, especially paediatricians, in the diagnosis of ASDs and the use of screening and diagnostic tools, and prioritise the need to create facilities and support in terms of ASDs in KwaZulu-Natal. Knowledge of early behavioural signs of ASD in young children should be the focus of educational interventions with practitioners and parents (Moh and Magiati 2012: 295). Mitchell and Holdt (2014: 60) end their study with this suggestion: "It would also be beneficial to conduct research into the knowledge that medical practitioners possess of ASDs, their capacity to diagnose ASDs, and their familiarity and willingness to use early diagnostic tools. This would highlight the extent of the educational interventions required for greater knowledge and awareness of ASDs in parents and medical practitioners, and would prioritise the need for the creation of facilities and support in terms of ASDs."

More studies focusing on the experiences of parents raising children with ASD would also be useful as this would further contribute to our understanding of the disorder and service delivery in South Africa (Mitchell and Holdt 2014: 61). Matenge (2014:

17) posits that in a country with limited services and limited access to information on treatment in the public health care sector, parents may be more dependent on, and bound to, the recommendations and referrals made by their health care provider, and in this context reliable and comprehensive diagnosis becomes critical to treatment. Matenge (2014: 19) argues that there is, therefore, a need to assess the level of knowledge, understanding and the experiences of South African nurses regarding autism, as they are usually the first professionals that families of children with autism contact.

Poor knowledge of autism spectrum disorders among physicians and failure to give further information to caregivers may be a reflection of lack of training in the wide range of behaviours that occur across the autism spectrum and this may delay the average age of diagnosis and subsequent early interventions that have been established as being beneficial. Caring for children with childhood autism and other pervasive developmental disorders requires the services of professionals like psychiatrists, paediatricians, nurses, clinical psychologists and others. Paediatric and psychiatric nurses are usually members of such multidisciplinary teams. The most significant role of a nurse in autism recognition and diagnosis is education. The nurse, the family, and the patient must all be educated on various aspects of autism and autistic disorders. This places nurses at a critical juncture, because they must be increasingly knowledgeable, understanding and supportive of the parents and children afflicted with this condition. Nurses' level of understanding of autism spectrum disorders can have a great impact on the prognosis of children with childhood autism (Igwe *et al.* 2010).

2.10 Theoretical framework: script model

The script theoretical framework was used to guide this study. According to Charlin, Tardif and Boshuizen (2000: 192) medical diagnosis is a categorization task that allows physicians to make predictions about features of clinical situations and to determine appropriate course of action. The script concept, which first arose in cognitive psychology, provides a theoretical framework to explain how medical diagnostic knowledge can be structured for diagnostic problem solving. The main characteristics of the script concept are pre-stored knowledge, values acceptable or

not acceptable for each illness attribute, and default values. Scripts are networks of knowledge adapted to goals of clinical tasks.

The concept of “scripts”, first introduced in medical literature by Feltovich and Barrows and evolving ever since, describes the structure of clinical medical knowledge. The basic principle underpinning the script concept asserts that, to give meaning to a new situation in our environment, we use prior knowledge that contains information about the characteristics and features of the situation and information about the relationships that link those characteristics and features. In other words, incoming information activates a previously acquired network of relevant knowledge and experience – a script – that directs the selection, interpretation, and memorization of that new information. In medicine, when a clinician sees a patient, he or she perceives symptoms, signs, and details from the patient’s environment that activate networks of knowledge that contain those features and their relationships to illnesses. Those networks of knowledge then provide context, and thus meaning, to the new situation (Charlin, Tardif and Boshuizen 2000: 183).

Charlin, Tardif and Boshuizen (2000: 183) further explain that the script concept is a variant of a more general concept, that of schemas. Schemas are goal-directed knowledge structures adapted to perform tasks efficiently. Scripts are schemas associated with sequences of events that occur frequently in a specific order, and knowledge about illnesses includes information about the spatio-temporal sequence of events in illness development. Considering that most of the properties of one concept apply to the other, we use “scripts” to describe properties of both schemas and scripts. Schmidt, Norman and Boshuizen (1990: 61) have described a theory of development of clinical competence that hinges on the concept of illness scripts. Script conceptual framework implies that when clinicians see a patient, they search their memories for an appropriate script, and embody it with the specific information provided by the case (Charlin, Tardif and Boshuizen 2000: 183).

Problem solving, at least in routine cases, is a process of script search, script selection, and script verification. Scripts are pre-stored knowledge structures that are used to actively process clinical information to confirm or eliminate the diagnostic hypotheses the clinician has in mind at a given moment, and collected information is constantly checked with predetermined values to assess for a fit. Scripts are

organized for specific tasks. Because diagnosis is at the core of medical practice, an important part of the acquisition of expertise is related to script construction. The framework offers a model of what kind of knowledge organisation sustains clinical competence (Charlin, Tardif and Boshuizen 2000: 183).

The script theoretical framework applies to this research in the following way: when professional nurses working in primary health clinics examine children, they will diagnose these children based on their pre-stored knowledge or script. If professional nurses examine children with ASD, in order for them to recognise the symptoms or make this diagnosis, they will need to draw on their pre-stored knowledge of ASD. If the professional nurse does not have this pre-stored knowledge of ASD, she/he will, therefore, not suspect or make this diagnosis. The implications of this for the child, is that this child will not receive the much-needed early interventions and support, which will lead to poor prognosis and lifelong disability. This research seeks to determine the knowledge, understanding and perception of professional nurses working in primary health clinics about ASD and in doing so it will indirectly also positively influence the nurses' ability to diagnosis a child with ASD.

2.11 Conclusion

In this chapter, a detailed literature review on the topic was conducted and the theoretical framework for the study was presented and discussed.

Chapter 3: Research Methodology

3.1 Introduction

In this chapter the research methodology is described in detail, namely the research design, the setting of the research, the theoretical framework, population and sample, data collection, data analysis and ethical considerations.

3.2 Research design

In this study, a quantitative, non-experimental, descriptive survey design was utilised. Quantitative research is underpinned by a positivist paradigm. The positivist paradigm assumes that reality is fixed and orderly and can be studied objectively (Polit and Beck 2012: 12). Quantitative research is usually conducted using the traditional, scientific approach which is an orderly, systematic and controlled method of gathering information (Polit and Beck 2012: 13). Quantitative research identifies variables and seeks to answer questions about the relationship between these variables (Polit and Beck 2012: 14). This involves collecting and analysing numeric information (Polit and Beck 2012: 22). Information needed for the study is gathered using formal instruments (Polit and Beck 2012: 726). Deductive, logistical reasoning is used to answer the research question. The findings in quantitative research are based on empirical evidence (Polit and Beck 2012: 738). Empirical evidence is objective evidence, gathered by researchers by means of using their senses (Polit and Beck 2012: 739).

According to Brink, van der Walt and van Rensburg (2012: 112), “non-experimental designs have no manipulation of the independent variable, and therefore no intervention; nor is the setting controlled. The study is carried out in a natural setting and phenomena are observed as they occur.” Brink, van der Walt and van Rensburg (2012: 112) further explain descriptive designs as those concerned with gathering information from a representative sample in the population. The emphasis in the collection of data in descriptive studies is on structured observation, questionnaires and interviews or survey studies. In this research, the data was collected by means of a questionnaire (Annexure A), in the natural work setting of the respondents, i.e.

Primary Healthcare (PHC) facilities, and was used to find out if professional nurses were knowledgeable about screening children for ASD.

3.3 Study setting

The study setting is the location where the research was conducted and may be naturally occurring, partially controlled or highly controlled (Grove, Burns and Gray 2013: 709). This research was conducted at selected PHC clinics in the eThekweni Health District, KwaZulu-Natal (KZN). KwaZulu-Natal is one of the nine provinces of South Africa, with a total population of 10.6 million, accounting for 21,4% of the total population of South Africa. A third of the total population of KZN is within the eThekweni district (Durban) (Dhlomo 2010: 63). There are 11 health districts in the KZN province, hosting 646 clinics (Dhlomo 2009). There are eight Community Health Centres (CHCs); (seven provincial and one shared between the eThekweni municipality and the KZN Department of Health), 102 PHC facilities; 43 provincial and 59 local authorities, three gateway clinics and 28 mobile units (12 provincial and 16 local authorities), in the eThekweni municipality (eThekweni Health District 2015). The KZN Department of Health has some PHC clinics in hospitals which are referred to as gateway clinics, although they are completely managed by the specific hospital.

3.4 Study population

The study population is the whole group of informants that fit the specific criteria that the researcher aims to study (Brink, van der Walt and van Rensburg 2012: 131). The researcher's definition of the population depends on the sample criteria, the similarity of the subjects in the setting, together with which population is accessible and can be best represented by the study sample (Grove, Burns and Gray 2013: 44). The study population in this study were all the professional nurses providing care to children in PHC facilities, in the eThekweni Health District in KZN. There are a total number of 925 professional nurses working in the 102 PHC clinics in the eThekweni district (eThekweni Health District 2015).

3.5 Sampling

Sampling means taking a percentage of a population as representative or having particular characteristics of that total population. Sample involves a subsection of the population considered for inclusion in the study (De Vos *et al.* 2011: 227)

3.5.1 Sampling technique

Simple random sampling was used to determine which clinics in the eThekwini health district were part of the study. According to Brink, van der Walt and van Rensburg (2012: 134), simple random samples are drawn using the basic probability sampling technique. Respondents or elements are drawn in a random way from the sampling frame. Each of the elements in the frame is listed separately and therefore has an equal chance of being included in the sample. The researcher used the “fish bowl” technique as described by Brink, van der Walt and van Rensburg (2012: 134). The names of the 102 primary healthcare clinics in eThekwini district were placed into a bowl and mixed around. The researcher then drew out the number of clinics, as decided upon with the assistance of the statistician, to ensure an adequate sample size. The names once drawn out of the bowl, were placed back in the bowl so that the total number of names remained the same, for probability to remain the same at all times.

3.5.2 Sample size

The researcher drew out 51 clinic names from the bowl as this was 50% of the 102 clinics in KwaZulu-Natal. The researcher contacted the 51 clinics for permission to conduct the study, however only 34 out of the 51 clinics responded positively. Thirty of those were eThekwini municipality clinics and four KwaZulu-Natal Department of Health clinics. These clinics were utilised and provided the number of professional nurses needed. The sample was calculated with a margin of error and an alpha value of 0.05; the researcher needed a minimum of 275 respondents (Annexure J). The total number of professional nurses working at eThekwini Municipality (2015: 107) was 925.

From each of the PHC clinics selected, the researcher selected the respondents utilising non-probability, convenience sampling (also referred to as accidental,

convenience, or availability sampling) (Brink, van der Walt and van Rensburg 2012: 140). This involved the choice of readily available respondents or objects for the study. Participants were included in the sample because they happened to be in the right place at the right time. All professional nurses working at selected PHC clinics were asked to participate in this study, by filling out the questionnaire. The researcher collected data from 100% of the sample, 178 of whom worked for the eThekweni Municipality and 97 for the KwaZulu-Natal Department of Health.

Inclusion criteria:

- All fixed primary healthcare clinics in eThekweni Health District that assess babies and children.
- All professional nurses who assess babies and children as part of their duties.

Exclusion criteria:

- All mobile and primary healthcare clinics in eThekweni Health District.
- All PHC clinics in KwaZulu-Natal that were not examining children, for example specialised clinics such as TB clinics
- All other categories of nurses who are not professional nurses.

3.6 Data collection

Data collection is the process of acquiring subjects and gathering information needed for a study. The researcher must use a research instrument to gather data. The type of instrument can vary from a checklist to a self-report questionnaire to a highly sophisticated physiological measure. The choice of instrument is a major decision that should be made only after careful consideration of the alternatives. A well-designed questionnaire should meet the objectives of the enquiry, demonstrate a fit between its content and the research problem and objectives, obtain the most complete and accurate information possible, and do so within reasonable limits of time and resources (Brink, van der Walt and van Rensburg 2012: 142).

3.6.1 Data collection instrument

In this study, data were collected by means of two questionnaires. Knowledge and understanding was measured with the Knowledge about Childhood Autism among Health Workers (KCAHW) questionnaire. Permission to use the questionnaire was

obtained from Dr Muideen O. Bakare, who is one of the team of psychiatrists and clinical psychologists who developed the questionnaire in 2008 at Enugu, Nigeria (Annexure F). This 19 item questionnaire measures four domains: impairments in social interaction usually found in children with childhood autism (8 items); impairment in the area of communication and language development (1 item); obsessive and compulsive pattern of behaviour found in children with childhood autism (4 items); and knowledge on what type of disorder childhood autism is, possible comorbid conditions and onset of childhood autism in affected children (6 items) (Igwe *et al.* 2010). The KCAHW questionnaire was also used in another study by Igwe *et al.* (2010) and added to the ease of its use by describing the tool in detail as follows: each of the items has three options to choose from, with only one of these three options being correct; The correct option on each item attracts a score of one (1), while the other two options that are incorrect attract a score of zero (0) each. The researcher used 16 of the 19 items because they were relevant to knowledge and understanding of healthcare workers and scored the questionnaire using the same options.

An extensive search found no instrument to measure perceptions of healthcare workers regarding the symptoms of ASD. The researcher developed the perception instrument by identifying relevant items from a search of the literature.

The KCAHW is a self-administered questionnaire that has been established to have good test-retest reliability with good overall internal consistency, Cronbach's alpha = 0.97, (Bakare *et al.* 2008). The entire questionnaire was validated by a statistician and pilot tested.

3.6.2 The Perception Questionnaire

The data collection tool is divided into three sections, namely: section A, this is the section of the questionnaire that collection information on the participants demographics, and section B, collects information on the Knowledge and Understanding of the participants and section C that collects information on the perceptions of the participant. The researcher developed section C of the questionnaire from the sources laid out in Table 3.1:

Table 3.1: Perception questions

Dimension	Question number	Question	Source
Perception Section C	1	I feel confident in my ability to identify features of autism spectrum disorders in a child.	(Hartley-McAndrew, Doody and Mertz 2014)
Perception Section C	2	I feel confident in my ability to counsel parents on autism spectrum disorders	(Hartley-McAndrew, Doody and Mertz 2014)
Perception Section C	3	I feel confident in my ability to counsel parents on available autism spectrum disorder services in the community.	(Hartley-McAndrew, Doody and Mertz 2014)
Perception Section C	4	I would benefit from further training on: Identification and diagnosis of autism spectrum disorders	(Matenge 2014: 20).
Perception Section C	5	ASDs occur more commonly among higher socioeconomic and educational levels	(Hartley-McAndrew, Doody and Mertz 2014)
Perception Section C	6	Autism is caused by poor parenting skills or poor home care.	(Liu <i>et al.</i> 2016)
Perception Section C	7	Autistic children are deliberately negativistic and noncompliant.	(Liu <i>et al.</i> 2016)
Perception Section C	8	Autism is caused by the supernatural (God, being bewitched, etc).	(Bakare and Munir 2011)

The 8-item questionnaire responses ranged from strongly disagree (1) to strongly agree (5).

In addition, demographic (3 items) and nurse-related questions (2 items) were asked.

3.6.3 Pilot study

A pilot study was conducted in one clinic to test the questionnaire. Six questionnaires were administered to the professional nurses on duty. No changes were made to the questionnaire. The clinic and respondents used in the pilot study were not included in the main study.

3.6.4 Data collection methods

Data collection commenced once the proposal was cleared by Durban University of Technology Institutional Research Ethics Committee (REC No: 12/17) and permission obtained from all gatekeepers. The researcher emailed and telephoned nursing service managers and arranged dates and times that suited the clinics, for data collection. The researcher then personally drove to each of the selected PHC clinics and fully explained the research and data collection tool to all the professional nurses on duty and asked them to read the information letter, sign the consent form if they agreed to participate in the study and then complete the questionnaire. The questionnaire took on average of seven minutes to complete and the researcher was present to clarify questions if necessary and collect the questionnaires after they had been completed. This was done to ensure a high return rate of questionnaires. Data collection happened over a period of a month from 15th June 2017 to 15th July 2017. The data were collected during week days. During this period the researcher had to go back to some clinics because staff were off sick. The researcher made appointments with the nursing service managers of each clinic and the questionnaires were completed by the staff at the appointed times. Most clinics preferred appointments from 07:30 to 08:00 in the morning prior to commencement of work or after 14:00 in the afternoon when the clinics were quieter. In most of the clinics, the nursing manager assembled the professional nurses in her office or tea lounge and all professional nurses completed the questionnaire at the same time. The researcher collected data at a total of 34 clinics from a total of 275 respondents.

3.7 Data analysis

Data analysis is the methodical organisation and synthesis of data collected in quantitative research and the testing of hypotheses using this data (Polit and Beck 2012: 725). Data was analysed with the assistance of the statistician, using SPSS version 22. Descriptive statistics were used to explore differences between or among groups (Grove, Burns and Gray 2013: 217). Inferential statistics are used to draw conclusions regarding the differences between groups in the population from which the samples are drawn and the relationship between the variables in the population (Morgan *et al.* 2015: 84). Both descriptive and inferential statistics were used to analyse data in this study. Descriptive statistics including means and standard

deviations, and, where applicable, were used and frequencies represented in tables or graphs. The following tests were used in the analyses of the data:

- ANOVA A which tests for several independent samples that compares two or more groups of cases in one variable. In this study it was used to compare race to average score of the questionnaire and race and perception.
- A binomial test which tests whether a significant proportion of respondents select one of a possible two responses. This can be extended when data with more than 2 response options is split into two distinct groups, in this dissertation it was used to show significance between the correct and incorrect answers to the knowledge and understanding questions.
- Pearson's correlation which measures how variables or rank orders are related; Pearson's correlation coefficient is a measure of linear association. In this study Pearson's correlation was applied to see if there is a significant correlation between scores and age / experience and perception and age / experience.
- One sample t-test which tests whether a mean score is significantly different from a scalar value. This test was used to test if the average score is significantly different from a neutral score of 3, for the perceptions questions in the questionnaire (Section C); which indicated significant agreement or disagreement with the perception questions.
- Independent samples t-test which is a test that compares two independent groups of cases. In this research, independent samples t-test was applied to see if the average score(s) and perceptions differed significantly across categories, such as male and female, or post basic trained and not trained, etc.

3.8 Ethical considerations

This research was only conducted once ethical approval had been received from the Durban University of Technology Institutional Research Ethics Committee REC 12/17 (Annexure G), this was to ensure that it adhered to Durban University of Technology ethical standards. Informed consent to conduct the research was obtained from the KwaZulu-Natal Department of Health Research and Knowledge Management Directorate (Annexure E), eThekweni Health District office (Annexure

H) and the Chief Executive Officers (CEO's) and nursing managers of the various Department of Health clinics (Annexure K). Consent to conduct the research was also obtained from the eThekweni Municipality Health Unit Research Committee (Annexure F) and the various nursing service managers of the eThekweni Municipality clinics. Respondents of the research were informed about the objectives of the research and that participation is completely voluntary and that they may withdraw from the study at any time with no consequences. Each participant received an information letter and signed an informed consent form prior to completing the questionnaire. All participant information was and remains kept completely private and confidential. All questionnaires were anonymous and coded in a way that only the researcher knows in which facility it was completed. Names of institutions have been kept confidential. There are no known risks to those participating in this study.

3.8.1 Informed consent

After obtaining provisional permission from the Durban University of Technology Institutional Research Ethics Committee (IREC) (REC no: 12/17) (Annexure L), the researcher applied for permission from the KwaZulu-Natal Department of Health (Annexure C) and the eThekweni Municipality (Annexure D). After many months permission was granted by both of these authorities (Annexures E and F). The researcher then submitted these approval letters and a report of the pilot study to the IREC which then granted full approval (Annexure G). The researcher was assisted by a deputy director at the eThekweni District Health office to obtain permission from the sub-district managers, hospital and clinic CEO's and the nursing service managers of the clinics belonging to the Department of Health (Annexure K). The eThekweni Municipality Research Committee helped by supplying the researcher with the contact details of the nursing service managers from the various clinics run by the municipality.

3.8.2 Beneficence

Beneficence is the obligation of researchers to minimise harm and maximise the benefits to the respondents (Polit and Beck 2012: 152). There were no known risks of physical harm to respondents involved in the study because they were only required to complete a confidential questionnaire.

3.8.3 Respect for human dignity

Respect for human dignity includes the right to self-determination and the right to full disclosure. The right to self-determination means that prospective respondents may decide of their own free will whether to participate in a study without the risk of prejudice. The right to full disclosure means that the researcher has fully explained what the nature of the study is, that the potential participant has a right to refuse participation, what the researcher's responsibilities are as well as what the risks and benefits are of participating in the study (Polit and Beck 2012: 154). There was full disclosure to the prospective respondents by means of the researcher fully describing the nature of the study, the participants' right to refuse participation, the researcher's responsibilities as well as the risks and benefits of participating in the study. The respondents were informed that their participation was voluntary and that they could withdraw from the study at any time without penalty or prejudice. This disclosure was done in writing. All of the above-mentioned explanations were included in the letter of information and consent form (Annexure B) which the respondents received and signed.

3.8.4 Justice

Polit and Beck (2012: 155) assert that justice involves participants' right to fair treatment. Their right to privacy and participant selection has to be based on study requirements and not on a group's vulnerability. Convenience sampling was utilised which ensured that all available professional nurses would have a fair and equal chance of participating in the research. The questionnaire did not require the name of the clinic or respondent and was therefore completely confidential, which respected the participants' right to privacy.

3.9 Conclusion

In this chapter, the research methodology was described, including: research design, the setting of the research, the theoretical framework, population and sample, data collection, data analysis and ethical considerations.

Chapter 4: Presentation of Results

4.1 Introduction

The previous chapter dealt with the research methodology. This chapter presents the results of the study obtained from the questionnaires. The detailed analysis of findings follows and includes graphs and tables of the results. The study was a quantitative, descriptive study to determine the knowledge, understanding and perceptions of professional nurses, working in PHC clinics in eThekweni Health District, about ASD. A total of 275 questionnaires were completed by professional nurses working in 34 PHC clinics in the eThekweni Health District in KZN. Of this total, 178 worked for the eThekweni Municipality and 97 for KZN DoH. The average professional nurse respondent was female, African, 42 years old, had completed the 4-year nursing diploma, and worked in PHC for 9 years.

4.2 Presentation of the results

A presentation of the results will ensue in the paragraphs below, detailing the findings of this study.

4.2.1 Demographic data (section A of the questionnaire)

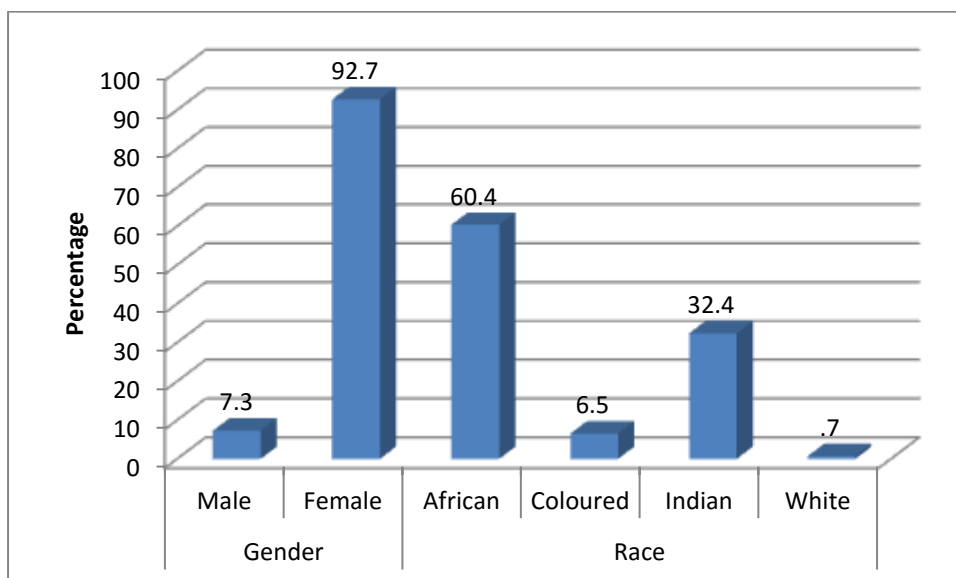


Figure 4.1: Gender and race of respondents

4.2.1.1 Gender and race

Figure 4.1 is a visual description of the demographical data of the research respondents. A total of 275 professional nurses participated in this study, 92.7% (n = 255) were female and 7.3% (n = 20) were male. The sample consisted of respondents of various races namely: African 60.4% (n = 166), Coloured 6.5% (n = 18), Indian 32.4% (n = 89), White 0.7% (n = 2).

4.2.1.2 Age and experience

Table 4.1 presents the age of the respondents and number of years that the respondents have worked in a PHC. The youngest participant was 22 years old and the oldest was 73 years old, with 42 years being the mean age. The respondents' years of experience ranged from zero to 45 years, with the average being 9 years.

Table 4.1: Age of respondents

	Minimum	Maximum	Mean	Std. Deviation
Age	22	73	42.80	10.394
Experience in PHC	0	45	9.65	8.050

4.2.1.3 Correlation of age and experience to the average scores/ percentage

Pearson's correlation was applied to see if there is a significant correlation between scores and age, scores and experience (Table 4.2). There was a significant negative correlation between experience and the score for Domain 4 (Type of disorder), $r = -.143$, $p = .018$. Those with more experience tended to have lower scores for this domain.

Table 4.2: Correlation of age and experience to the average scores/ percentage Correlations

		Total score	Domain 1	Domain 2	Domain 3	Domain 4
Age	Pearson Correlation	.034	.097	.008	.062	-.110
		.571	.108	.900	.304	.068

		275	275	275	275	275
Experience in PHC	Pearson Correlation	-.051	-.023	-.029	.047	-.143*
		.396	.703	.636	.442	.018
		275	275	275	275	275

4.2.1.3 Educational qualifications

The majority of the respondents 55.3% (n = 152) had completed the 4-year nursing diploma, followed by 26.9% (n = 74) having completed their Bachelor's Degree and only 21.1% (n = 58) having completed the bridging course (from Enrolled to Registered Nurse). The majority of the sample 74.9% (n = 206) had a post basic qualification (Figure 4.2).

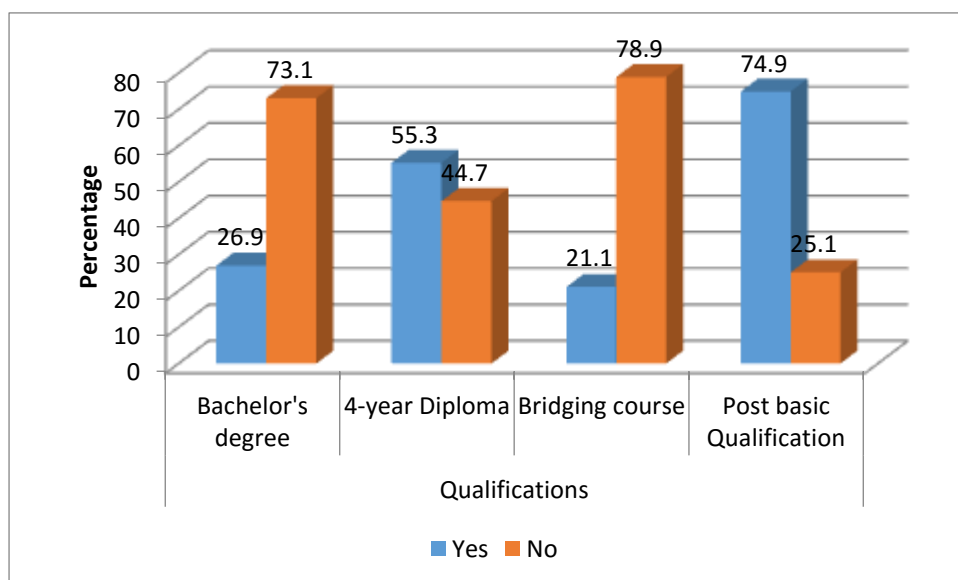


Figure 4.2: Qualifications of respondents

4.2.1.4 Post basic qualifications

Midwifery was the most common post basic qualification 77.7% (n = 160) followed by PHC nursing (clinical nursing science, health assessment, treatment and care) 70.9% (n = 146), Psychiatric Nursing Science 36.9% (n = 76) and lastly Paediatric /Child Nursing Science at 4.4% (n = 9) (Figure 4.3).

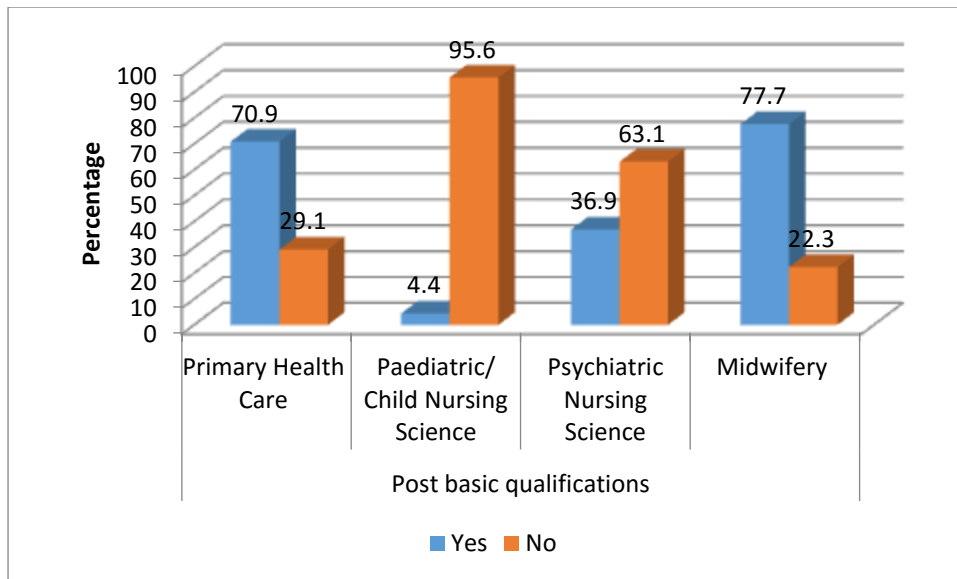


Figure 4.3: Post basic qualifications of respondents

4.2.2 Knowledge and understanding of autism spectrum disorder

Questions 1 to 11 aimed at assessing the knowledge and understanding of nurses on ASD. The results are shown graphically in Figure 4.4.

4.2.2.1 Analysis of questions 1 to 11 knowledge of autism spectrum disorder

For questions 1 to 11 respondents were asked to indicate whether the following behaviours described a child with childhood autism. Yes was the correct answer to all 11 questions.

Question 1: Marked impairment in use of multiple non-verbal behaviours such as eye to eye contact, facial expression, body postures and gestures during social interaction: A significant 84% ($n = 231$, $p < .0005$) of respondents answered this question correctly.

Question 2: Failure to develop peer relationships appropriate for developmental age: A significant 86% ($n = 237$, $p < .0005$) of respondents answered this question correctly.

Question 3: Have a lack of spontaneous will to share enjoyment, interest or activities with other people: A significant 79.3% ($n = 196$, $p < .0005$) of respondents answered this question correctly.

Question 4: Lack of social or emotional reciprocity: A significant 69.8% (n = 192, p < .0005) of respondents answered this question correctly.

Question 5: Stare into open space and not focusing on anything specific: A significant 70.2% (n = 192, p = < .0005) of respondents answered this question correctly.

Question 6: Social smile is usually absent in a child with autism: 44.7% (n = 123, p = .091) of respondents answered this question incorrectly. The p-value shows that there is not a significant difference between the number of correct and incorrect responses to this question.

Question 7: A delay or total lack of development of spoken language: A significant 78.2% (n = 215, p < .0005) of respondents answered this question correctly.

Question 8: stereotyped and repetitive movement (e.g. hand or finger flapping or twisting): A significant 70.2% (n = 193, p < .0005) of respondents answered this question correctly.

Question 9: May be associated with abnormal eating habits: 58% (n = 159, p = .011) of respondents answered this question incorrectly, showing that the majority of the sample do not know that autism may be associated with abnormal eating habits. The p-value shows that there is not a significant difference between the number of correct and incorrect responses to this question.

Question 10: A persistent preoccupation with parts of objects: A significant 71.6% (n = 197, p < .0005) of respondents answered this question correctly.

Question 11: A love for regimented routine activities: 51% (n = 141, p = .718) answered this question incorrectly, showing that the majority of the respondents do not know that autism is associated with a love for regimented routine activities. The p-value shows that there is not a significant difference between the number of correct and incorrect responses to this question.

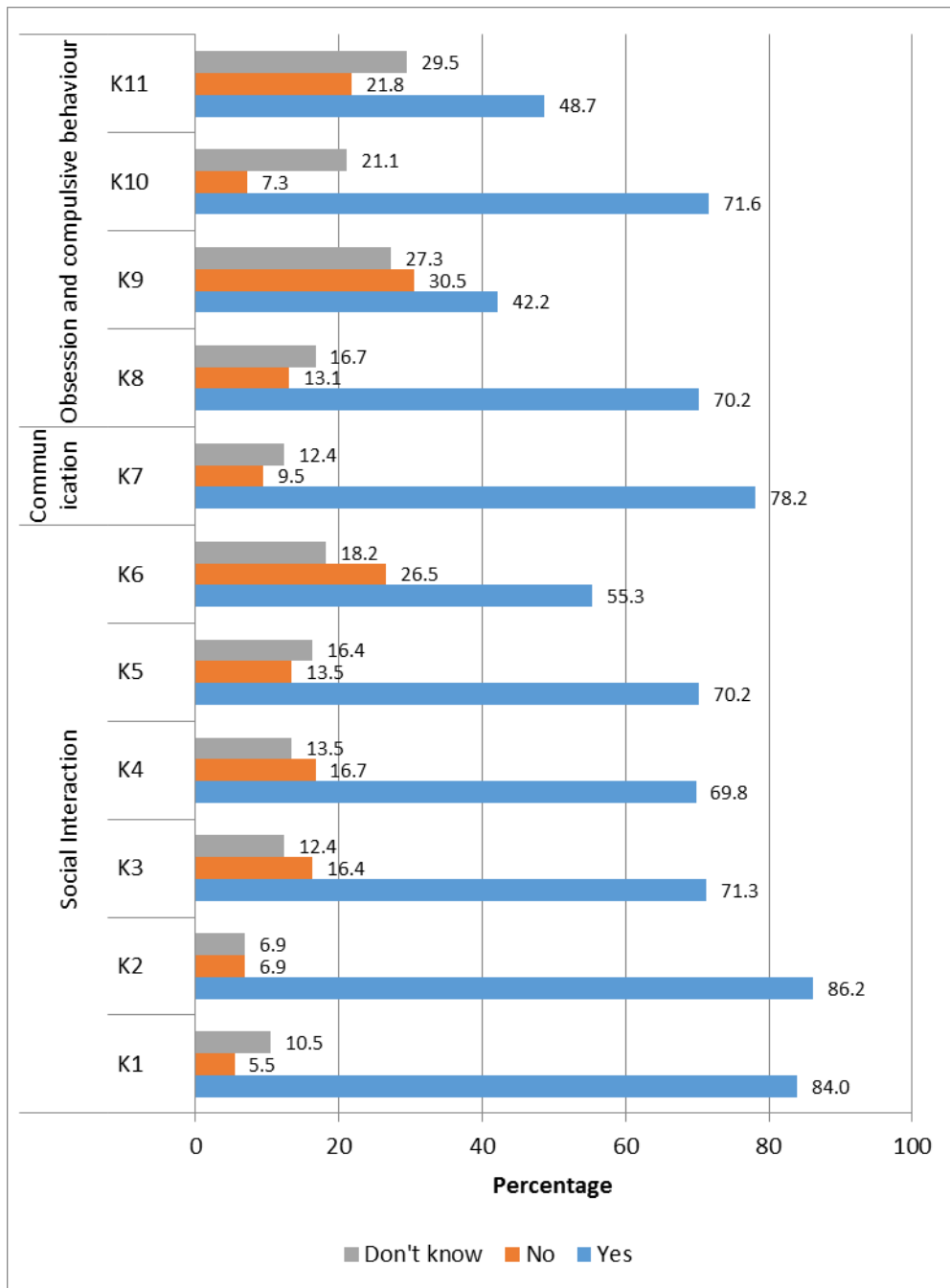


Figure 4.4: Responses to question 1 to 11 knowledge of autism spectrum disorder

4.2.2.2 Analysis of questions 12 to 16 understanding of autism spectrum disorder and associated conditions

The respondents were asked to indicate whether the following statements are True or False. The results are shown graphically in Figure 4.5.

Question 12: Autism is childhood schizophrenia: A significant 75.3% (n = 207, p < .0005) of respondents answered False which is the correct answer.

Question 13: Autism is an autoimmune condition: 55% (n = 152, p = .091) of respondents answered False which is the correct answer and 45% (n = 123) of respondents answered incorrectly. The p-value shows that there is not a significant difference between the number of correct and incorrect responses to this question.

Question 14: Autism is a neuro-developmental disorder: A significant 86.2% (n = 237, p = <.0005) of respondents answered True which is the correct answer.

Question 15: Autism could be associated with mental retardation: 56% (n = 154, p = .053) respondents answered True which is the correct answer, and 44% (n = 121) of respondents answered this question incorrectly. The p-value shows that there is not a significant difference between the number of correct and incorrect responses to this question

Question 16: Autism could be associated with epilepsy: A significant 68% (n = 187, p = <.0005) of respondents answered False (48%) or don't know (20%), which is the incorrect answer.

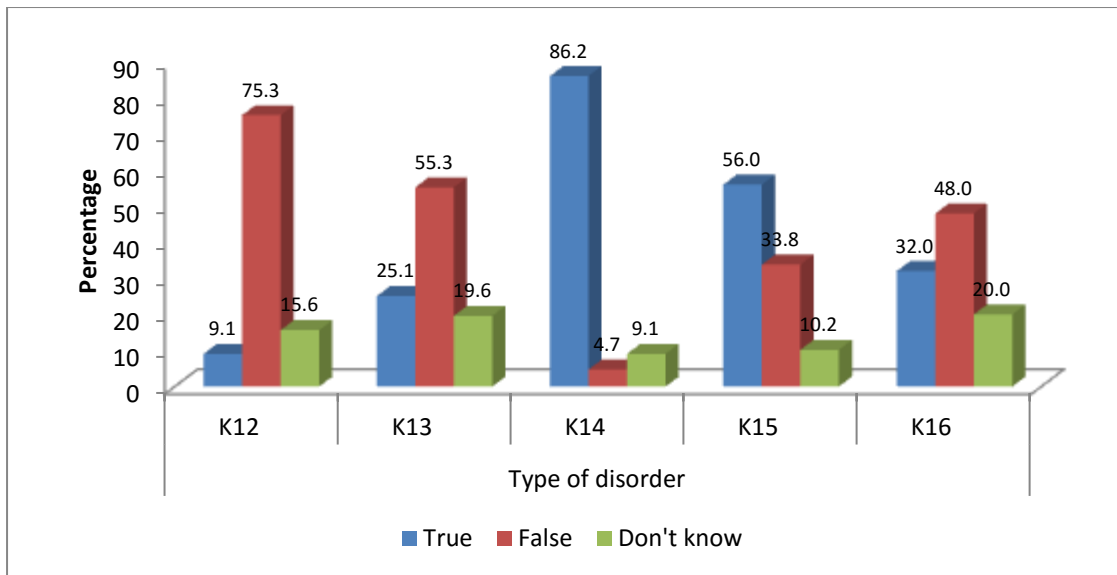


Figure 4.5: Responses to question 12 to 16 understanding of autism spectrum disorder and associated conditions

4.2.2.3 Average scores for the knowledge and understanding sections of the questionnaire

The average total score for all questionnaires was 10.52 out of 16 which is 65.8%. For Domain 1 (social interaction) the average score was 4.37 out of a total of 6 (72.8%). For Domain 2 (communication and language development) for which the average score 0.78 out of 1 (78.2%). For Domain 3 (obsession and compulsive behaviour) the average score was 2.33 out of 4 (58.2%) and lastly for Domain 4 (type of disorder) the average score was 3.05 out of 5 (60.9%) (Table 4.3).

Table 4.3: Average scores for the knowledge and understanding sections of the questionnaire

	Average score	Average Percentage	Minimum	Maximum
Total	10.52	65.8	0	16
Domain 1 – Social interaction	4.37	72.8	0	6
Domain 2 – Communication and language development	.78	78.2	0	1
Domain 3 – Obsession and compulsive behaviour	2.33	58.2	0	4
Domain 4 – Type of disorder	3.05	60.9	0	5

4.2.2.4 Correlation of gender, race and basic education to the average scores/percentage

There were no significant differences found for any of the scores across male ($M = 10.60$, $SD = 3.016$) and female ($M = 10.52$, $SD = 3.167$) or between the different races African ($M = 10.38$, $SD = 3.232$), Coloured ($M = 11.39$, $SD = 2.173$), Indian ($M = 10.65$, $SD = 3.188$), White ($M = 3$, $SD = 0.000$). There was no significant difference in scores between those respondents that did the Bachelor's Degree ($M = 10.46$, $SD = 4.058$), four year diploma ($M = 10.60$, $SD = 2.746$) and bridging course ($M = 10.33$, $SD = 2.964$).

4.2.2.5 Correlation of post basic education to the average scores/percentage

The total knowledge score across all domains differed significantly across those who do and those who do not have a post basic qualification, $t(273) = 3.192$, $p = .002$. Those with this qualification scored significantly higher ($M = 10.87$, $SD = 3.185$) than those without the qualification ($M = 9.49$, $SD = 2.826$).

Respondents that had a Psychiatric Nursing Science qualification scored significantly higher especially in Domain 2, $t(191.737) = 2.174$, $p = .031$ and Domain 4, $t(204) = 3.225$, $p = .001$. The professional nurses that had a Psychiatric Nursing Science scored higher ($M = 0.89$, $SD = 0.309$) than those without this qualification ($M = 0.78$, $SD = 0.413$) in Domain 2 and with the qualification ($M = 3.39$, $SD = 1.244$) and without the qualification ($M = 2.85$, $SD = 1.138$). This indicates that professional nurses who have a Psychiatric Nursing Science qualification have more knowledge about ASD, especially with regard to communication and language development (Domain 2) and type of disorder (Domain 4), which correlates with the findings of Igwe *et al.* (2010) who found that healthcare workers in psychiatric facilities scored higher than those working in paediatric settings.

The only other significant difference $t(132.842) = -2.986$, $p = .003$ found was that those respondents who had a midwifery qualification scored lower ($M = 4.41$, $SD = 1.717$) in Domain 1 (social interaction) than those who did not have a midwifery qualification ($M = 5.00$, $SD = 0.966$). This can be interpreted as showing that professional nurses that are midwives know less about social interaction in ASD.

4.2.3 Perception of autism spectrum disorder

The portion of the questionnaire that deals with perceptions will now be discussed. The results are shown graphically in Figure 4.6.

4.2.3.1 Analysis of Responses to question 1 to 8 on perceptions of autism spectrum disorder

Question 1: I feel confident in my ability to identify features of autism spectrum disorders (ASD) in a child: 35.3% (n = 97) of respondents felt neutral, 31.3% (n = 86) agreed, 18.5% (n = 51) disagreed, 9.1%(n = 25) strongly disagreed and 5.8% (n = 16) strongly agreed.

Question 2: I feel confident in my ability to counsel parents on ASD: 32.7% (n = 90) respondents felt neutral, 27.6% (n = 76) agreed, 26.5% (n = 73) disagreed, 8.4% (n = 23) strongly disagreed and 4.7% (n = 13) strongly agreed.

Question 3: I feel confident in my ability to counsel parents on available ASD services in the community: 29.1% (n = 80) were neutral, 28% (n = 77) disagreed, 25.5% (n = 70) agreed, 10.9% (n = 30) strongly disagreed and 6.5% (n = 18) strongly agreed.

Question 4: I would benefit from further training on identification and diagnosis of ASD: an overwhelming 60.4% (n = 166) and 27.6% (n = 76) agreed, 5.5% (n = 15) being neutral, 4.7% (n = 13) strongly disagreeing and 1.8% (n = 5) disagreeing. It is therefore evident that the majority of respondents 88% (n = 242) are in agreement that they would benefit from training on identification and diagnosis of ASD.

Question 5: Autism occurs more commonly among those with higher socioeconomic and educational levels: 48.7% (n = 134) of respondents disagreed with this statement, 21.5% (n = 59) strongly disagreed, 17.5% (n = 48) were neutral, 8.4% (n = 23) agreed and 4% (n = 11) strongly agreed. This shows that the majority of respondents 70.2% (n = 193) did not perceive that autism occurs among higher socioeconomic and educational levels.

Question 6: Autism is caused by poor parenting skills or poor home care: 45.1% (n = 124) of respondents strongly disagreed, 40.7% (n = 112) disagreed,

10.5% (n = 29) were neutral, 1.8% (n = 5) both agreed and strongly agreed. This indicates that the majority (84.8%) of the respondents do not believe that poor parenting and home care causes autism. Of concern are the 10 respondents that do believe that autism is caused by poor parenting and home care.

Question 7: Autistic children are deliberately negativistic and noncompliant:

39.6% (n = 109) disagreed with this statement, 29.1% (n = 80) strongly agreed, 21.1% (n = 58) were neutral, 9.1% (n = 25) agreed and 1.1% (n = 3) strongly agreed. It is evident from these responses that most 68.7% (n = 189) of the professional nurses did not think autistic children were deliberately negativistic and noncompliant. Of particular concern to the researcher is the other 31.3% (n = 86) of the respondents who do not know or believe that autistic children are deliberately negativistic and noncompliant, which does not bode well for the treatment of autistic children by these professional nurses.

Question 8: Autism is caused by the supernatural (God, being bewitched, etc.):

the majority of respondents 57.8% (n = 159) strongly disagreed with this belief, followed by 26.5% (n = 73) who disagreed, with 10.9% (n = 30) being neutral, 2.9% (n = 8) agreeing and 1.8% (n = 5) strongly agreeing. These statistics demonstrate that most (84.3%) do not believe that autism is caused by the supernatural, however 4.7% of the professional nurses that participated in this study believed that autism is caused by the supernatural.

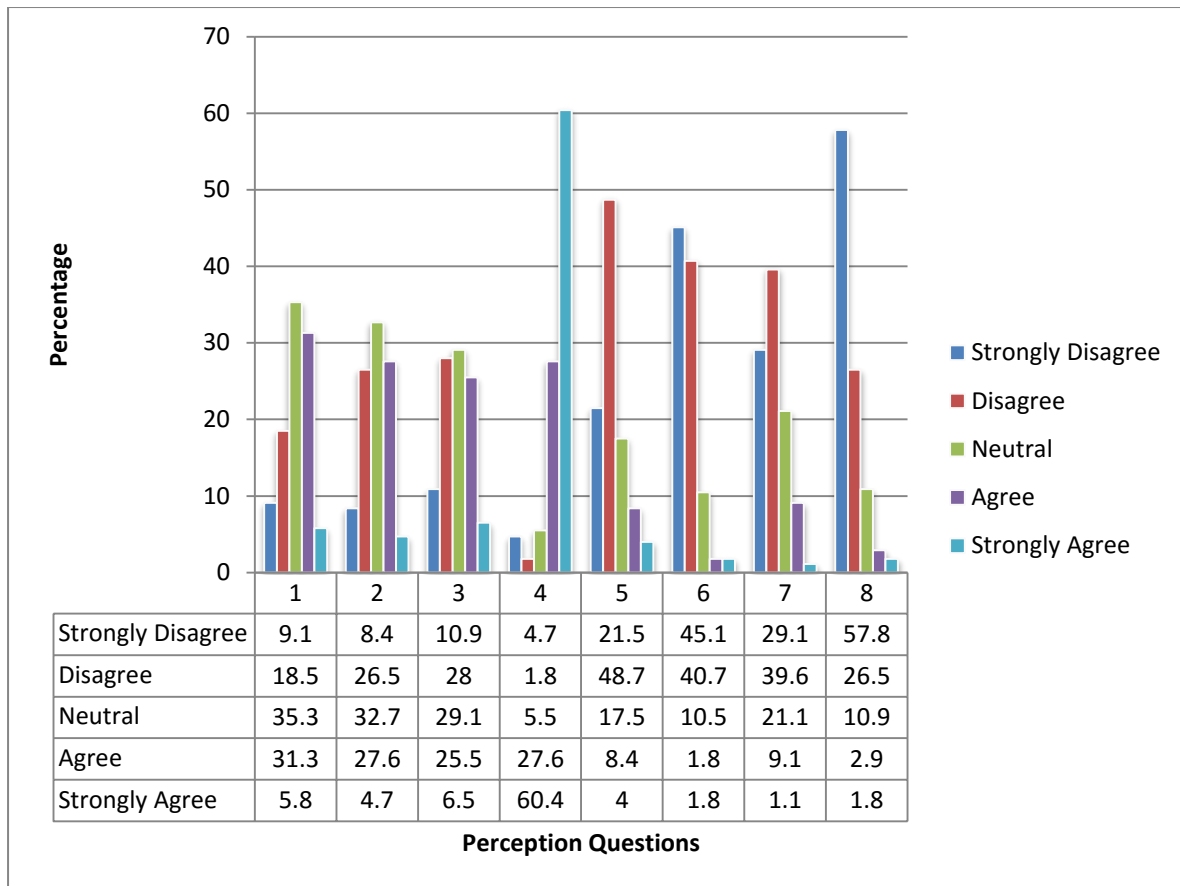


Figure 4.6: Responses to question 1 to 8 on perceptions of autism spectrum disorder

4.2.3.2 Analysis of scores for question 1 to 8 on perceptions of autism spectrum disorder

In analysing Figure 4.7 below it is apparent that there is no significant agreement or disagreement within the first three questions as the mean score is close to 3. However, for Question 4, there is significant agreement ($M = 4.37$, $SD = 1.011$) that benefit would be had from further training on identification and diagnosis of ASD, $t(274) = 22.482$, $p < .0005$. There is significant disagreement ($M = 2.25$, $SD = 1.013$) that autism occurs more commonly among those with higher socioeconomic and educational levels $t(274) = -12.322$, $p < .0005$. There is significant disagreement ($M = 1.75$, $SD = 0.855$) that autism is caused by poor parenting skills or poor home care, $t(274) = -24.340$, $p < .0005$. There is significant disagreement ($M = 2.13$, $SD = 0.974$) that autistic children are deliberately negativistic and noncompliant and finally there is also a significant disagreement ($M = 1.64$, $SD = 0.918$) that autism is caused by the supernatural (God, being bewitched, etc.), $t(274) = -24.493$, $p < .0005$.

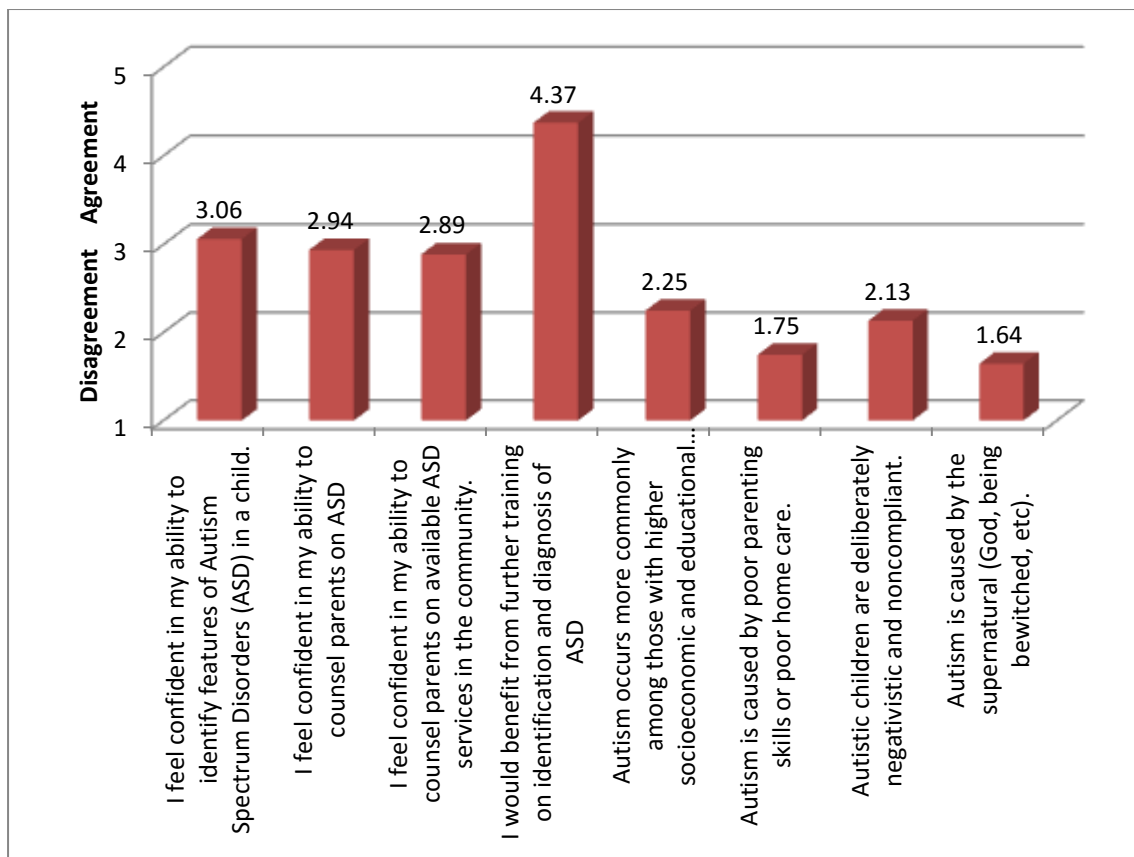


Figure 4.7: The mean scores for question 1 to 8 on perceptions of autism spectrum disorder

4.2.3.3 Analysis of differences between knowledge and understanding about childhood autism and age

The average agreement scores were tested for differences/relationships across the other demographic variables which proved that, with regard to the first three questions, there was a significant correlation between age and agreement with the statement, $r = .122$, $p = .044$ for Question 1, $r = .135$, $p = .025$ for Question 2 and $r = .141$, $p = .019$ for Question 3. The older the participant the more they were in agreement with the statements. This indicated that the older the professional nurse was, the more confident she/he felt in identifying and diagnosing ASD, counselling parents on ASD and available ASD services in the community. There was a significant ($r = -.161$, $p = .007$) negative correlation with age and agreement to the statement in Question 4; which can be interpreted as meaning that the older the respondents were, the less they felt they would benefit from further training on identification and diagnosis of ASD.

4.2.3.4 Analysis of correlation of the average agreement and gender

There was no significant difference found between the genders when agreeing or disagreeing with the statements.

4.2.3.5 Analysis of correlation of the average agreement post basic qualifications

In Question 1 there was a significant difference between those respondents that have a post basic qualification ($M = 3.16$, $SD = 1.035$) and those respondents that did not have a post basic qualification ($M = 2.77$, $SD = 1.031$), $t(273) = 2.726$, $p = .007$. This can be interpreted as meaning that those respondents with a post basic qualification felt more confident in their ability to identify features of ASD in a child. In Question 2 there was also a significant difference between those respondents that have a post basic qualification ($M = 3.05$, $SD = 1.056$) and those respondents that did not have a post basic qualification ($M = 2.59$, $SD = 0.880$), $t(273) = 3.254$, $p = .001$, which shows that professional nurses with a post basic qualification feel more confident in their ability to counsel parents on ASD. In Question 3 it was also found that there is a significant difference between those respondents that have a post basic qualification ($M = 2.98$, $SD = 1.139$) and those respondents that did not have a post basic qualification ($M = 2.61$, $SD = 0.958$), $t(273) = 2.438$, $p = .015$. Thus, it is evident that the respondents with post basic qualifications are more confident in their ability to counsel parents on available ASD services in the community than those without a post basic qualification. In Question 6 there was a significant difference between those respondents that have a post basic qualification ($M = 1.81$, $SD = 0.911$) and those respondents that did not have a post basic qualification ($M = 1.57$, $SD = 0.630$), $t(273) = 2.035$, $p = .043$, which indicates that those respondents who do not have a post basic qualification are more likely to agree that autism is caused by poor parenting skills or poor home care.

4.2.3.6 Analysis of correlation of the average agreement and specific post basic qualifications

There was no significant correlation found between average agreement score and the post basic qualification in PHC (clinical nursing science, health assessment, treatment and care). There was a significant difference established between those

respondents that have a Paediatric / Child Nursing Science post basic qualification and those that do not $t(12.310) = 3.863, p = .002$, when answering Question 3. Professional nurses with a post basic qualification in Paediatric / Child Nursing Science felt more confident in their ability to counsel parents on available ASD services in the community.

There was no significant correlation found between average agreement score and the post basic qualification in midwifery.

There was a significant difference recognised between those respondents that have a Psychiatric Nursing Science post basic qualification and those that do not $t(204) = 2.664, p = .008$, when answering Question 1. Respondents who have a post basic qualification in Psychiatric Nursing Science felt more confident in their ability to identify features of ASD in a child.

There was a significant difference established between those respondents that have a Psychiatric Nursing Science post basic qualification and those that do not $t(204) = 2.060, p = .041$, when answering Question 2. Respondents who have a post basic qualification in Psychiatric Nursing Science felt more confident in their ability to counsel parents on ASD.

There was a significant correlation difference found between those respondents that have a Psychiatric Nursing Science post basic qualification and those that do not $t(204) = 2.369, p = .019$, when answering Question 3. Respondents who have a post basic qualification in Psychiatric Nursing Science feel more confident in their ability to counsel parents on available ASD services in the community.

A negative correlation was found in Question 5 among those respondents that were Psychiatric Nurses, $t(184.724) = -2.026, p = .044$; respondents with a post basic qualification in Psychiatric Nursing did not believe that autism occurred more commonly among those with higher socioeconomic and educational levels which was an accurate perception. Finally, Question 8 also yielded a negative correlation between those professional nurses who were and were not psychiatrically trained, $t(192.685) = -2.015, p = .045$. Professional nurses with a post basic qualification in Psychiatric Nursing Science correctly did not believe that autism was caused by the supernatural (God, being bewitched, and some such).

4.3 Conclusion

This chapter consisted of the results of the data collected for this study. The data was analysed and presented with the use of tables and graphs. In the chapter that follows the findings of the research are discussed and recommendations presented.

Chapter 5: Discussion of the Results

5.1 Introduction

In this, the concluding chapter, there is a discussion on the interpretation of the findings, the limitations of the study, and recommendations for further research.

5.2 Demographics

A total of 275 professional nurses participated in this study of which the majority (92.7%) were female and only 7.3% were male, which is in-keeping with observation made by Sooruth, Sibiya and Sokhela (2013: 83) that nursing is a predominately female profession. The sample consisted of respondents of various race groups, the racial mix as found in this study is in-keeping with the demographics of the KwaZulu-Natal province, as stated by eThekweni Health District (2015: 13): "The majority are Black (71.9%), followed by Indian/ Asian (16.3%) and Coloured (2.2%)." It is therefore evident that the sample of this study is a good reflection of the demographics of nurses in KwaZulu-Natal and therefore the findings can be generalised. There was no real correlation between gender and knowledge, understanding and perception of ASD. There was also no real correlation found between race group and knowledge and understanding of ASD.

It was also found that the average age of the respondents was 42 years old with an average of nine years of experience working at a PHC. The older the professional nurses were the less they believed that they would benefit from further training on ASD. The findings also indicated that the more experienced the professional nurses were, the less they knew about the type of disorder that ASD was. This could be attributed to a lack of updated knowledge on ASD, but is contrary to the findings of Bakare, Ebigbo and Agomoh (2009) who found that knowledge about childhood autism as measured by scores on KCAHW questionnaire was significantly associated with age group distribution of the healthcare workers, with those of the age group of fourth decade and above being more likely to have a higher mean score ($p = 0.004$) and previous experience of managing children with ASD ($p = 0.000$).

It was also discovered that more than half of the sample (55.3%) had completed the four year integrated diploma in nursing, which means that they would have a qualification in General, Psychiatric and Community Nursing as well as Midwifery. According to Bakare *et al.* (2009: 2), psychiatrically trained healthcare workers have a greater knowledge than other specialities on ASD.

The majority (74.9%) of professional nurses in the sample had a post basic qualification, the most common being Midwifery (basic or advanced) (77.7%) followed by Primary Healthcare (clinical nursing science, health assessment, treatment and care). According to Sooruth, Sibiyana and Sokhela (2013: 84) these additional qualifications improved the knowledge and skills of professional nurses working in the primary healthcare setting. In this study it was found that those with a post basic qualification, specifically in psychiatric nursing, were far more knowledgeable, were much more confident in diagnosing and counselling parents on ASD and on available services in the community. This supports the findings of Bakare *et al.* (2009: 2) who asserted that psychiatrically trained healthcare workers have a greater knowledge than other specialities on ASD.

5.3 The knowledge and understanding of professional nurses working in working in PHC clinics, about autism spectrum disorder

The average score on the KCAHW questionnaire among a particular sample population gives an index level of knowledge about childhood autism in that particular population (Bakare *et al.* 2008). Upon analysis of the knowledge of the professional nurses who participated in this research, it was found that their average score was 10.52, which is a percentage of 65.8%. This means that the average professional nurse working in the primary healthcare clinic has 65.8% knowledge and understanding of ASD. It also showed that the best understood domain was Domain 2 – Communication and language development, followed by Domain 1 – Social interaction and second least understood is Domain 4 – Type of Disorder, with Domain 3 – Obsession and compulsive behaviour, being the least understood domain. Upon further analysis of the responses it was found that the respondents showed a lack of knowledge of the following facts: 1) that in a child with autism the social smile is absent, 2) they have abnormal eating habits, 3) autistic children have a love for routine, 4) autism is not an autoimmune disease, 5) autism could be

associated with mental retardation and 6) that autism could be associated with epilepsy. Of particular concern is that the majority of respondents did not know or understand that the child with autism loves routine, this is of concern because the diagnosis of ASD, in the DSM V (American Psychiatric Association. 2013: 119), is a pervasive developmental disorder with persistent deficits in (1) social communication and social interaction and (2) restricted, repetitive patterns of behaviour, interests or characteristics which occur across multiple contexts. Therefore, if the respondents do not understand this they cannot make a diagnosis of ASD in a child that they examine, which may lead to late diagnosis or misdiagnosis. This is also evident in that the respondents' average scores for Domain 3 (obsession and compulsive behaviour) 58.2% and Domain 4 (type of disorder) 60.9% show a lack of knowledge in these areas of autism.

5.4 The perception of professional nurses working in working in PHCs, about autism spectrum disorder

In analysing the perceptions of the respondents, the following was discovered that the respondents overwhelmingly (88%) agreed that they would benefit from further training on identification and diagnosis of ASD. The majority of the respondents did not believe that autism was caused by poor parenting or the supernatural; they also did not believe that autism occurred more commonly among the higher socioeconomic/ educational groups and they also did not believe that autistic children were deliberately negative and noncompliant.

5.5 Conclusion of findings

Based on the discussion above, the following conclusions can be derived: that gender and race have no bearing on the knowledge of ASD, but the more experienced a respondent was in the PHC setting the less knowledgeable they were about ASD. It was also shown that the older the respondent was, the less they felt they would benefit from further training on the identification and diagnosis of ASD.

The results of the study found that respondents that have completed the Psychiatric Nursing Science course were more knowledgeable about ASD and confident in diagnosing ASD and counselling parents on ASD and available ASD services in the community.

It was also concluded from the discussion above that respondents working in the PHCs in this study lacked knowledge in specific areas of ASD which was necessary in diagnosing a child with ASD.

It was also discovered that the majority of the respondents felt that they would benefit from further training on the identification and diagnosis of ASD.

5.6 Recommendations

It is with the above conclusions in mind that the researcher makes the following recommendations:

- 1 Autism spectrum disorder to be included in the curriculum for nurses training.
- 2 Training on ASD should be specifically designed and implemented for professional nurses working in PHCs regarding the identification and diagnosis of ASD. It is also recommended that this training specifically focuses on domains 3 and 4 as mentioned above, namely, the obsessive and compulsive behaviour associated with ASD and the type of disorder it is as well as the eating habits and associated disorders. This training should target all professional nurses especially those professional nurses that have not completed the Psychiatric Nursing Science course.
- 3 Regular in-service training on ASD to keep professional nurses updated on new information and research on ASD.
- 4 All children should be screened for ASD at 18 and 24 months at all PHCs in eThekweni district. This screening can be done by utilising one of the existing ASD screening checklists and the professional nurses trained on their use.
- 5 Posters on the signs and symptoms of ASD should be displayed at primary healthcare clinics in full view of patients, parents and staff.
- 6 Professional nurses need to be trained on referral and treatment options for children with ASD, and provided with a reference list and network of where to refer parents for further management and treatment.

5.7 Limitations

The one limitation of the questionnaire is that it did not ask about the professional nurses' personal experience with ASD, which should have been included, because

during data collection many respondents verbalised that they have family members who have ASD which meant that their knowledge of ASD was gained from personal and not professional experience.

5.8 Recommendations for further research

The researcher recommends that an epidemiological study be done to determine the rate of ASD in South Africa and KwaZulu-Natal, as this would show the prevalence of the disease in South Africa.

Research should also be conducted on the treatments that are available as well as facilities available to treat ASD.

Research should be done on the coping mechanism of parents with children that have ASD.

5.9 Conclusion

In this the ultimate chapter of this dissertation, the objectives of the study were met, in which the knowledge, understanding and perceptions of professional nurses working in primary healthcare clinics on ASD, were ascertained and conclusions and recommendations were made.

References

African Network for the Prevention and Protection against Child Abuse and Neglect (ANPPCAN), Nigeria Chapter. 2007. Communiqué on a project to increase the level of awareness on autism and develop a mechanism for care and support of children with autism in Enugu State, South Eastern Nigeria.

American Academy of Pediatrics. 2006. Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. *Pediatrics*, 118(1): 405-420.

American Psychiatric Association. 2013. *Diagnostic and statistical manual of mental disorders*. 5th ed. Arlington, VA: American Psychiatric Association.

Autism Society of America. n.d. Asperger's Syndrome. Available: <http://www.autism-society.org/what-is/aspergers-syndrome/> (Accessed 15 May 2016).

Bakare, M. O., Agomoh, A. O., Ebigbo, P. O., Eaton, J., Okonkwo, K. O., Onwukwe, J.U. and Onyeama, G.M. 2009. Etiological explanation, treatability and preventability of childhood autism: a survey of Nigerian healthcare workers' opinion. *Annals of General Psychiatry*, 8: 6.

Bakare, M. O., Ebigbo, P. O. and Agomoh, A. O. 2009. Knowledge about childhood autism and opinion among healthcare workers on availability of facilities and law caring for needs and rights of children with childhood autism and other developmental disorders in Nigeria. *BMC Pediatrics*, 9: 12. Available: <http://www.biomedcentral.com/1471-2431/9/12> (Accessed 14 May 2016).

Bakare, M. O., Ebigbo, P. O., Agomoh, A. O. and Menkiti, N. C. 2008. Knowledge about childhood autism among health workers (KCAHW) questionnaire: description, reliability and internal consistency. *Clinical Practice and Epidemiology in Mental Health*, 4: 17.

Bakare, M. O., Igwe, M. N., Odinka, P. C. and Iteke, O. 2011. Neuropsychiatric diagnosis and psychotropic medication prescription patterns in a mental hospital-based child and adolescent psychiatric service in Nigeria. *Journal of Health Care for the Poor and Underserved*, 22(3): 751-755.

Bakare, M. O. and Munir, K. M. 2011a. Autism Spectrum Disorders in Africa. In: M.-R. Mohammadi, M. R. ed. *A comprehensive book on autism spectrum disorders*. InTech, DOI: 10.5772/17469. Available: <https://www.intechopen.com/books/a-comprehensive-book-on-autism-spectrum-disorders/autism-spectrum-disorders-in-africa> (Accessed 14 May 2016).

Bakare, M. O. and Munir, K. M. 2011b. Excess of non-verbal cases of autism spectrum disorders presenting to orthodox clinical practice in Africa: a trend possibly resulting from late diagnosis and intervention. *South African Journal of Psychiatry*, 17(4): 118-120.

Baker-Ericzen, M. J., Stahmer, A. C. and Burns, A. 2007. Child demographics associated with outcomes in a community-based Pivotal Response Training program. *Journal of Positive Behavior Interventions*, 9(1): 52-60.

Baker, J. 2013. Autism at 70: from Kanner to DSM-5. *The New England Journal of Medicine*, 369(12): 1089-1091

Bello-Mojeed, M. A., Bakare, M. O. and Munir, K. 2014. Identification of autism spectrum disorders (ASD) in Africa: Need for shifting research and public health focus. In: Patel, V. B., Preedy, V. R. and Martin, C.R. eds. *Comprehensive guide to autism*. New York: Springer, 2437-2453.

Belfer, M. L. 2008. Child and adolescent mental disorders: the magnitude of the problem across the globe. *Journal of Child Psychology and Psychiatry*, 49(3): 226-232.

Bernier, R., Mao, A. and Yen, J. 2010. Psychopathology, families and culture: Autism. *Child & Adolescent Psychiatric Clinics of North America*, 19(4): 855-867.

Bothma, Y., Greeff, M., Mulaudzi, F. M. and Wright, S. C. D. 2012. *Research in health sciences*. Cape Town: Heinemann.

Brink, H., van der Walt, C. and van Rensburg, G. 2012. *Fundamentals of research methodology for healthcare professionals*. Cape Town: Juta.

Brown, A. B. and Elder, J.H. 2014. Communication in autism spectrum disorder: a guide for pediatric nurses. *Pediatric Nursing*, 40(5): 219-225.

Bryson, S. E., Rogers, S. J. and Fombonne, E. 2003. Autism spectrum disorders: early detection, intervention, education, and psychopharmacological management. *Canadian Journal of Psychiatry*, 48(8): 506-516.

Centers for Disease Control and Prevention (CDC). 2014. Prevalence of autism spectrum disorder among children aged 8 years: autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report, Surveillance Summaries*, 63(2):1-21.

Charlin, B., Tardif, J. and Boshuizen, H. P. A. 2000. Scripts and medical diagnostic knowledge: theory and applications for clinical reasoning instruction and research. *Academic Medicine*, 75(2): 182-190.

Chiang, H. M. and Lin, Y. H. 2008. Expressive communication of children with autism. *Journal of Autism and Developmental Disorders*, 38(3): 538-545.

Chiri, G. and Warfield, M. E. 2011. Unmet need and problems accessing core health care services for children with autism spectrum disorder. *Maternal and Child Health Journal*, 16(5): 1081-1091.

Coates, L. 2007. History of Asperger syndrome. Available: <http://www.asperger-syndrome.me.uk/history.html> (Accessed 14 May 2016)

Cohen, H., Amerine-Dickens, M. and Smith, T. 2006. Early intensive behavioral treatment: replication of the UCLA model in a community setting. *Journal of Developmental and Behavioral Pediatrics*, 27(2): 145-155.

Crais, E. R., McComish, C. S., Humphreys, B. P., Watson, L. R., Baranek, G.T ., Reznick, J.S., Christian, R.B. and Earls, M. 2014. Pediatric healthcare professionals' views on autism spectrum disorder screening at 12-18 months. *Journal of Autism and Developmental Disorders*, 44(9): 2311-2328.

Dawson, G. and Osterling, J. 1997. Early intervention in autism: effectiveness and common elements of current approaches. In: Guralnick, M.J. ed. *The effectiveness of early intervention*. Baltimore, MD: Brookes Publishing.

Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J. and Greenson, J. 2010. Randomized, controlled trial of an intervention for toddlers with autism: the early start Denver model. *Pediatrics*, 125(1): e17-e23.

De Vos, A. S., Strydom, H., Fouche, C. B. and Delpont, C. S. L. 2011. *Research at grass roots*. 4th ed. Pretoria: Van Schaik.

DeWeerd, S. 2012. Culture: diverse diagnostics. *Nature*, 491(7422): S18-S19.

Dhlomo, S. 2009. *Department of Health KwaZulu-Natal budget speech by Dr S. M. Dhlomo MEC for health*. Available: <http://www.kznhealth.gov.za/speeches/2009/budget2009.pdf> (Accessed 27 May 2016).

Dhlomo, S. 2010. *Budget speech presented by the MEC for Health S Dhlomo at the KwaZulu-Natal Legislature House*. Available: Available at: <http://www.search.gov.za/info/previewDocument.jsp?dk=%2Fdata%2Fstatic%2Finfo%2Fspeeches%2F2010%2F10042212551001.htm%40Gov&q=%28+%28%28dhlomo%29%3CIN%3ETitle%29+%29+%3CAND%3E%28+Category%3Cmatches%3Es+%29&t=S+Dhlomo%3A+KwaZulu-Natal+Health+Prov+Budget+Vote+2010%2F11> (Accessed 27 May 2016).

Dobrez, D., Sasso, A. L., Holl, J., Shalowitz, M., Leon, S. and Budetti, P. 2001. Estimating the cost of developmental and behavioral screening of preschool children in general pediatric practice. *Pediatrics*, 108(4): 913-922.

Eikeseth, S. 2009. Outcome of comprehensive psycho-educational interventions for young children with autism. *Research in Developmental Disabilities*, 30(1): 158-178.

eThekwini Municipality. 2011. Integrated Development Plan 2011/2012: 5 year plan 2011-2016. Available: www.durban.gov.za/City_Government/City_Vision/IDP/Documents/201112.pdf. (Accessed 15 May 2016)

eThekwini Health District. Unit, E. h. 2015. *DISTRICT HEALTH PLAN 2015/2016*. Durban: Available: <http://www.kznhealth.gov.za/Strategic/DHP/2015-16/eThekwini.pdf>. (Accessed 15 May 2016)

Freuler, A., Baranek, G. T., Tashjian, C., Watson, L. R., Crais, E. R. and Turner-Brown, L. 2013. Parent reflections of experiences of participating in a randomized control trial of a behavioral intervention for infants at risk of autism spectrum disorders. *Autism: The International Journal of Research and Practice*, 18(5): 519-528.

Garcia-Perez, R. M., Lee, A. and Hobson, R. P. 2007. On intersubjective engagement in autism: a controlled study of nonverbal aspects of conversation. *Journal of Autism and Developmental Disorders*, 37(7): 1310-1322.

Grinker, R. R., Chambers, N., Njongwe, N., Lagman, A. E., Guthrie, W. and Stronach, S. 2012. "Communities" in community engagement: lessons learned from autism research in South Korea and South Africa. *Autism Research*, 5(3): 201-210.

Grove, S. K., Burns, N. and Gray, J.R. 2013. *The practice of nursing research: Appraisal, synthesis and generation of evidence*. St. Louis, MO: Elsevier.

Harper, C., Symon, J. and Frea, W. 2008. Recess is time-in: using peers to improve social skills of children with autism. *Journal of Autism and Developmental Disorders*, 38(5): 815-826.

Harris, S. L. and Handleman, J. S. 2000. Age and IQ at intake as predictors of placement for young children with autism: a four- to six-year follow-up. *Journal of Autism and Developmental Disorders*, 30(2): 137-142.

Hartley-McAndrew, M., Doody, K. and Mertz, J. 2014. Knowledge of autism spectrum disorders in potential first-contact professionals. *The North American Journal of Medical Science*, 7(3): 97-102.

Heflin, L. J. and Alaimo, D. F. 2007. *Students with autism spectrum disorders: Effective instructional practices*. Upper Saddle River, NJ: Pearson Education.

Helt, M., Kelley, E., Kinsbourne, M., Pandey, J., Boorstein, H. and Herbert, M. 2008. Can children with autism recover? If so, how? *Neuropsychology Review*, 18(4): 339-366.

Huang, A. X., Jia, M. and Wheeler, J. J. 2013. Children with autism in the People's Republic of China: diagnosis, legal issues, and educational services. *Journal of Autism and Developmental Disorders*, 43(9): 1991-2001.

Hyman, S. L. and Johnson, J. K. 2012. Autism and pediatric practice: toward a medical home. *Journal of Autism and Developmental Disorders*, 42(6): 1156-1164.

Igwe, M. N., Bakare, M. O., Agomoh, A. O., Onyeama, G. M. and Okonkwo, K. O. 2010. Factors influencing knowledge about childhood autism among final year undergraduate medical, nursing and psychology students of University of Nigeria, Enugu State, Nigeria. *Italian Journal of Paediatrics*, 36: 44.

Johnson, C. P. and Myers, S. M. 2007. Identification and evaluation of children with autism spectrum disorders. *Pediatrics*, 120(5): 1183-1215.

Jónsdóttir, S. L., Saemundsen, E., Antonsdóttir, I. S., Sigurdardóttir, S. and Ólason, D. 2011. Children diagnosed with autistic spectrum disorder before or after the age of 6 years. *Research in Autistic Spectrum Disorders*, 5(1): 175-184.

Jyonouchi, H., Sun, S. and Itokazu, N. 2002. Innate immunity associated with inflammatory responses and cytokine production against common dietary proteins in patients with autism spectrum disorder. *Neuropsychobiology*, 46(2): 76-84.

Kamio, Y., Inada, N. and Koyama, T. 2013. A nationwide survey on quality of life and associated factors of adults with highfunctioning autism spectrum disorders. *Autism*, 17(1): 15-26.

Kamio, Y., Inada, N., Koyama, T., Inokuchi, E., Tsuchiya, K. and Kuroda, M. 2014. Effectiveness of using the modified checklist for autism in toddlers in two-stage screening of autism spectrum disorder at the 18-month health check-up in Japan. *Journal of Autism and Developmental Disorders*, 44(1): 194-203.

Kasari, C., Paparella, T., Freeman, S. and Jahromi, L.B. 2008. Language outcome in autism: randomized comparison of joint attention and play interventions. *Journal of Consulting and Clinical Psychology*, 76(1): 125-137.

Kim, Y. S., Leventhal, B. L., Koh, Y. J., Fombonne, E., Laska, E., Lim, E. C., Cheon, K. A., Kim, S. J., Kim, Y. K., Lee, H., Song, D. H. and Grinker, R. R. 2011. Prevalence of autism spectrum disorders in a total population sample. *American Journal of Psychiatry*, 168(9): 904-912.

King, T. M., Tandon, S. D., Macias, M. M., Healy, J. A., Duncan, P. M. and Swigonski, N. L. 2010. Implementing developmental screening and referrals: lessons learned from a national project. *Pediatrics*, 125(2): 350-360.

Kita, Y. and Hosokawa, T. 2011. History of autism spectrum disorders: Historical controversy over the diagnosis. *Journal of Japanese Psychiatry*, 59(2): 147-165.

Kleintjes, S., Lund, C., Flisher, A. J. and MHAPP Research Programme Consortium. 2010. A situational analysis of child and adolescent mental health services in Ghana, Uganda, South Africa and Zambia. *African Journal of Psychiatry*, 13(2): 132-139.

Koegel, L., Koegel, R., Ashbaugh, K. and Bradshaw, J. 2014. The importance of early identification and intervention for children with or at risk for autism spectrum disorders. *International Journal of Speech-Language Pathology*, 16(1): 50-56.

Koegel, L. K. 2000. Interventions to facilitate communication in autism *Journal of Autism and Developmental Disorders*, 30(5): 383-391.

Koegel, L. K., Koegel, R. L., Frea, W. and Green-Hopkins, I. 2003. Priming as a method of coordinating educational services for students with autism. *Language, Speech, and Hearing Services in Schools*, 34(3): 228-235.

Koegel, L. K., Koegel, R. L., Shoshan, Y. and McNerney, E. 1999. Pivotal response intervention II: preliminary long-term outcomes data. *Journal of the Association for Persons with Severe Handicaps*, 24(3): 186-198.

Koegel, L. K., Singh, A. K. and Koegel, R. L. 2010. Improving motivation for academics in children with autism. *Journal of Autism and Developmental Disorders*, 40(9): 1057-1066.

Koegel, R. L., Camarata, S., Koegel, L. K., Ben-Tall, A. and Smith, A. E. 1998. Increasing speech intelligibility in children with autism. *Journal of Autism and Developmental Disorders*, 28(3): 241-251.

Koegel, R. L. and Koegel, L. K. 2012. *The PRT pocket guide: pivotal response treatment for autism spectrum disorders*. Baltimore, MD: Brooks Publishing.

Koegel, R. L., Werner, G. A., Vismara, L. A. and Koegel, L. K. 2005. The effectiveness of contextually supported play date interactions between children with

autism and typically developing peers. *Research and Practice for Persons with Severe Disabilities*, 30(2): 93-102.

Kogan, M. D., Blumberg, S. J., Schieve, L. A., Boyle, C. A., Perrin, J. M., Ghandour, R. M., Singh, G. K., Strickland, B. B., Trevathan, E. and van Dyck, P. C. 2009. Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. *Pediatrics*, 124(5): 1395-1403.

Landa, R. 2007. Early communication development and intervention for children with autism. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(1): 16-25.

Lecavalier, L. 2006. Behavioral and emotional problems in young people with pervasive developmental disorders: relative prevalence, effects of subject characteristics, and empirical classification. *Journal of Autism and Developmental Disorders*, 36(8): 1101-1114.

Leyfer, O. T., Folstein, S. E., Bacalman, S., Davis, N. O., Dinh, E., Morgan, J. and Lainhart, J. E. 2006. Comorbid psychiatric disorders in children with autism: interview development and rates of disorders. *Journal of Autism and Developmental Disorders*, 36(7): 849-861.

Liu, Y., Li, J., Zheng, Q., Zaroff, C., Hall, B., Li, X. and Hao, Y. 2016. Knowledge, attitudes, and perceptions of autism spectrum disorder in a stratified sampling of preschool teachers in China. *BMC Psychiatry*, 16: 142-154.

Lord, C. and Bishop, S. L. 2010. Autism spectrum disorders: diagnosis, prevalence and services for children and families. *SRCD Social Policy Report*, 24(2): 1-27.

Lotter, V. 1978 Childhood autism in Africa. *Journal of Child Psychology and Psychiatry*, 19(3): 231-244.

Lotter, V. 1980. Cross cultural perspectives on childhood autism. *Journal of Tropical Pediatrics*, 26(4): 131-133.

Lovaas, O. I. 1987. Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55(1): 3-9.

Malcolm-Smith, S., Hoogenhout, M., Ing, M., Thomas, K. G. F. and De Vries, P. 2013. Autism spectrum disorders: global challenges and local opportunities. *Journal of Child and Adolescent Mental Health*, 25(1): 1-5.

Matenge, B. 2014. An exploration of nursing professionals' understanding of autism spectrum disorder. M.Sc., University of Cape Town.

Ming, X., Brimacombe, M., Chaaban, J., Zimmerman-Bier, B. and Wagner, G. C. 2008. Autism spectrum disorders: concurrent clinical disorders. *Journal of Child Neurology*, 23(1): 6-13.

Mitchell, C. and Holdt, N. 2014. The search for a timely diagnosis: parents' experiences of their child being diagnosed with an autistic spectrum disorder. *Journal of Child and Adolescent Mental Health*, 26(1): 49-62.

Moh, T. and Magiati, I. 2012. Factors associated with parental stress and satisfaction during the process of diagnosis of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 6(1): 293-303.

Morgan, G. A., Leech, N. L., Gloeckner, G. W. and Barrett, K. C. 2015. *IBM SPSS for intermediate statistics: use and interpretation*. 5th ed. New York: Routledge.

Myers, S. M., Johnson, C. P. and Council on Children with Disabilities. 2007. Management of children with autism spectrum disorders. *Pediatrics*, 120(5): 1162-1192.

Mosby's Medical Dictionary. 2009. 9th ed. St Louis, MO: Elsevier.

National Research Council. 2001. *Educating children with autism*. Washington, DC: The National Academies Press.

Njenga, F. 2008. Autism in Africa: a challenge in the management of an important disorder. *Journal of Intellectual Disability Research*, 52(8), 639.

Noens, I. and van Berckelaer-Onnes, I. 2005. Captured by details: sense-making, language, and communication in autism. *Journal of Communication Disorders*, 38(2): 123-141.

Omigbodun, O. 2008. Developing child mental health services in resource-poor countries. *International Review of Psychiatry*, 20(3): 225-235.

Pavone, L., Fiumara, A., Bottaro, G., Mazzone, D. and Coleman, M. 1997. Autism and celiac disease: failure to validate the hypothesis that a link might exist. *Biological Psychiatry*, 42(1): 72-75.

Pavone, P., Incorpora, G., Fiumara, A., Parano, E., Trifiletti, R. R. and Ruggieri, M. 2004. Epilepsy is not a prominent feature of primary autism. *Neuropediatrics*, 35: 207-210.

Polit, D. F. and Beck, C.T. 2012. *Nursing research: generating and assessing evidence for nursing practice*. 9th ed. Philadelphia, PA: Lippincott Williams and Wilkins.

Prizant, B. 1983. Language acquisition and communicative behavior in autism: toward an understanding of the "whole" of it. *Journal of Speech and Hearing Disorders*, 48(3): 296-307.

Reichow, B. 2012. Overview of meta-analyses on early intensive behavioral intervention for young children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42(4): 512-520.

Richdale, A. L. 1999. Sleep problems in autism: prevalence, cause, and intervention. *Developmental Medicine and Child Neurology*, 41(1): 60-66.

Robinson, S. E. 2011. Teaching paraprofessionals of students with autism to implement pivotal response treatment in inclusive school settings using a brief video feedback training package. *Focus on Autism and Other Developmental Disabilities*, 26(2): 105-118.

Rogers, S. 1996. Brief report: Early intervention in autism. *Journal of Autism and Developmental Disorders*, 26(2): 243-246.

Rogers, S. J. and Vismara, L. A. 2008. Evidence-based comprehensive treatments for early autism. *Journal of Clinical Child and Adolescent Psychology*, 37(1): 8-38.

Sallows, G. O. and Graupner, T. D. 2005. Intensive behavioral treatment for children with autism: four-year outcome and predictors *American Journal on Mental Retardation*, 110(6): 417-443.

Sand, N., Siverstein, M., Glascoe, F. P., Gupta, V. B., Tonniges, T. P. and O'Connor, K. G. 2005. Pediatricians' reported practices regarding developmental screening: do guidelines work? Do they help? *Pediatrics*, 116(1): 174-179.

Sanua, V. D. 1984. Is infantile autism a universal phenomenon? An open question. *International Journal of Social Psychiatry*, 30(3): 163-177.

Scarpinato, N., Bradley, J., Kurbjun, K., Bateman, X., Holtzer, B. and Ely, B. 2010. Caring for the child with an autism spectrum disorder in the acute care setting. *Journal for Specialists in Pediatric Nursing*, 15(3): 244-254.

Schmidt, H. G., Norman, G. R. and Boshuizen, H. P. A. 1990. A cognitive perspective on medical expertise: theory and implications. *Academic Medicine*, 65(10): 21-61.

Seif Eldin, A., Habib, D., Noufal, A., Farrag, S., Bazaid, K., Al-Sharbati, M., Badr, H., Moussa, S., Essali, A. and Gaddour, N. 2008. Use of M-CHAT for a multinational screening of young children with autism in the Arab countries. *International Review of Psychiatry*, 20(3): 281-289.

Sices, L., Feudtner, C., McLaughlin, J., Drotar, D. and Williams, M. 2003. How do primary care physicians identify young children with developmental delays? A national survey. *Journal of Developmental and Behavioral Pediatrics*, 24(6): 409-417.

Smith, A. and Camarata, S. 1999. Using teacher implemented instruction to increase language intelligibility of children with autism. *Journal of Positive Behavior Interventions*, 1(3): 141-151.

Sooruth, U. R., Sibiya, M. N. and Sokhela, D. G. 2015. The use of standard treatment guidelines and essential medicines list by registered nurses at primary health care clinics in the Umgungundlovu District, South Africa.. *International Journal of Africa Nursing Sciences*, 3:50-55.

South African Nursing Council (SANC). 2005. *Nursing Act 33 of 2005*. Pretoria: Government Printer.

Springer, P. E., Van Toorn, R., Laughton, B. and Kidd, M. 2013. Characteristics of children with pervasive developmental disorders attending a developmental clinic in the Western Cape Province, South Africa. *The South African Journal of Child Health*, 7(3): 95-99.

Windham, G. C., Smith, K. S., Rosen, N., Anderson, M. C., Grether, J. K., Coolman, R. B. and Harris, S. 2014. Autism and developmental screening in a public, primary care setting primarily serving Hispanics: challenges and results. *Journal of Autism and Developmental Disorders*, 44(7): 1621-1632.

Annexures

Annexure A: Knowledge about Childhood Autism among Health Workers (KCAHW) Questionnaire

Please answer the following question as accurately as possible

Section A: Demographic Data

Q1. Your age in years: ____

Q2. Gender:

Male	
Female	

Q3. Race:

African	Coloured	Indian	White	Other : Please specify-

Q4. Indicate which of the following South African Nursing Council registered qualification/s you have (Tick all that apply):

Bachelor's Degree	4-year Diploma	Bridging Course

Q5. Do you have a post basic qualification

Yes	
No	

Q5.1. If you answered yes to Question 5, indicate which of the following post basic qualifications below, you have. .

Qualification	Yes	No
5.1.1 Primary Health Care (health assessment, treatment and care)		
5.1.2 Paediatric/ Child Nursing Science		
5.1.3 Psychiatric Nursing Science		
5.1.4 Midwifery (Basic or Advanced)		

Q6. Indicate your total number of years of experience working at a Primary Healthcare Clinic:_____

Section B: Knowledge and understanding

Indicate whether you think the following behaviours describe a child with childhood autism

Behaviours	Yes	No	Don't know
1. Marked impairment in use of multiple non-verbal behaviours such as eye to eye contact, facial expression, body postures and gestures during social			
2. Failure to develop peer relationships appropriate for developmental age			
3. Lack of spontaneous will to share enjoyment, interest or activities with other people			
4. Lack of social or emotional reciprocity			
5. Staring into open space and not focusing on anything specific			
6. Social smile is usually absent in a child with Autism			
7. Delay or total lack of development of spoken language			
8. Stereotyped and repetitive movement (e.g. Hand or finger flapping or twisting)			
9. May be associated with abnormal eating habit			
10. Persistent preoccupation with parts of objects			
11. Love for regimented routine activities			

Indicate whether you think the following statements are true or false.

Statements	True	False	Don't Know
12. Autism is Childhood Schizophrenia			
13. Autism is an autoimmune condition			
14. Autism is a neuro-developmental disorder			
15. Autism could be associated with Mental Retardation			
16. Autism could be associated with Epilepsy			

Section C Perception:

Indicate your agreement with the following statements:

Statement	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. I feel confident in my ability to identify features of Autism Spectrum Disorders (ASD) in a child.					
2. I feel confident in my ability to counsel parents on ASD					
3. I feel confident in my ability to counsel parents on available ASD services in the community.					

Statement	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
4. I would benefit from further training on identification and diagnosis of ASD					
5. Autism occurs more commonly among those with higher socioeconomic and educational levels					
6. Autism is caused by poor parenting skills or poor home care.					
7. Autistic children are deliberately negativistic and noncompliant.					
8. Autism is caused by the supernatural (God, being bewitched, etc).					

Thank you for completing this questionnaire

Annexure B: Information letter and consent to respondents



LETTER OF INFORMATION

Dear Sir/Madam,

Thank you for taking part in this study.

Title of the Research Study: The knowledge, understanding and perceptions of professional nurses, working in Primary Healthcare Clinics, about Autism spectrum disorder (ASD)

Principle researcher: Mr. N. A. Williams (BA Nursing)

Supervisors: Dr. P. Basson (PhD) and Dr. D. Sokhela (D Nursing)

Brief Introduction: I was conducting the study determine your understanding about Autism spectrum disorder.

Purpose of the Study: The purpose of this research is to determine the knowledge, understanding and perception of professional nurses, who work in Primary Healthcare Clinics in KwaZulu-Natal, on Autism spectrum disorder.

Outline of the Procedures: Firstly I will ask you to read this information letter, ask questions where you do not understand and I will then ask you to sign the consent agreeing to take part in the study. Secondly I will ask you to fill in a short anonymous questionnaire, which will take about 10 minutes of your time.

Risk or Discomforts to the Subject: You will not experience any risk or discomfort because you was filling in a quick questionnaire.

Benefits: The is no real benefit to you, except that you was able to assess your own knowledge of ASD.

Reason/s why the Subject May Be Withdrawn from the Study: You may decide not to complete the questionnaire if you wish. There was no adverse consequence to you.

Remuneration: You will not be given any money or any reward for participating in the study. You was doing this on your free will.

Costs of the Study: All costs, that is transport, stationery, etc, was borne by myself as the researcher

Confidentiality: The questionnaire you fill in is completely anonymous and cannot be traced back to you or your institution. All information gathered was kept confidential and used only for the purpose of this research.

Research-related Injury: No compensation, however you will not suffer any injuries because you are only completing a questionnaire.

Persons to Contact in the Event of Any Problems or Queries: For any queries please contact me on 0764809130 or the study supervisors: Dr. P. Basson on 0313732687 or Dr. D. Sokhela on 0313732992 or the Institutional Research Ethics administrator on 031 373 2375.

General: Once again you are assured that participation is voluntary. If you are willing to participate in the study may I request that you sign the consent form on the next page.



CONSENT

Statement of Agreement to Participate in the Research Study:

- I hereby confirm that I have been informed by the researcher, Mr. N.A. Williams, about the nature, conduct, benefits and risks of this study Research Ethics Clearance Number: **IREC 014/17**
- I have also received, read and understood the above written information (Participant Letter of Information) regarding the study.
- I am aware that the results of the study, was anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation was made available to me.

Full Name of Participant

Date

Signature

I, Neil Williams herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

Neil Williams

Full Name of Researcher

Date

Signature

Annexure C: Letter of request permission to KZN DoH



9 Lofthill Place
Hillgrove
Newlands West
4037

03 November 2016

Health Research and Knowledge Management Secretariat
KwaZulu-Natal Department of Health
Private Bag X9051
Pietermaritzburg
3201

Sir/Madam

REQUEST FOR PERMISSION TO CONDUCT RESEARCH

I am writing this letter as a written request, to conduct research at your(DoH) primary health care facilities in eThekweni district of KwaZulu-Natal. I am registered for the Master of Health Science Degree at the Durban University of Technology and a requirement of this degree is for me to conduct research. The details of my research are below.

The topic is: The knowledge, understanding and perceptions of professional nurses, working in Primary Healthcare clinics, about Autism spectrum disorder (ASD). The purpose of the study is to determine the knowledge, understanding and perception of professional nurses, who work in Primary Healthcare clinics in KwaZulu-Natal, on Autism spectrum disorder. The objectives are to determine: 1) The knowledge of

professional nurses working in clinics regarding Autism spectrum disorder; 2) The understanding of Professional Nurses working in clinics regarding Autism spectrum disorder; 3) The perception of Professional Nurses working in clinics regarding Autism spectrum disorder.

In this study, the quantitative, non-experimental, descriptive research design was utilised. This research study was conducted at Primary Healthcare clinics in specific Primary Healthcare facilities in the eThekweni District, KwaZulu-Natal (KZN). The data was collected by means of the “Knowledge about childhood autism among health workers” (KCAHW) questionnaire, which has already been used in similar studies in Africa. The questionnaire was completed by all Professional Nurses examining children at the above-mentioned Primary Healthcare clinics. Each participant was given full information about this study in writing and asked to sign a consent form, should they wish to participate in the study. The questionnaire is completely anonymous and cannot be traced to any individual or institution. The respondents will not be expected to pay for participating in the study and they will in turn not receive any payment for their participation.

Descriptive and inferential statistics was used to analyse the data in this study, with the assistance of a statistician and computer software and the results was presented in a research report which was made available to you, upon your request.

For more information, you may contact me on 0764809130 or my supervisors: Dr. P. Basson on 0313732687 or Dr. D. Sokhela on 0313732992

Yours Faithfully,
N.A. Williams (Researcher)

Annexure D: Letter of request for permission to the municipality



9 Lofthill Place
Hillgrove
Newlands West
4037

03 November
2016

The Head of Health
EThekwini Municipality Health Unit
9 Archie Gumede Place
Durban
4001

Sir/Madam

REQUEST FOR PERMISSION TO CONDUCT RESEARCH

I am writing this letter as a written request, to conduct research at your(DoH) primary health care facilities in eThekwini district of KwaZulu-Natal. I am registered for the Master of Health Science Degree at the Durban University of Technology and a requirement of this degree is for me to conduct research. The details of my research are below.

The topic is: The knowledge, understanding and perceptions of professional nurses, working in Primary Healthcare clinics, about Autism spectrum disorder (ASD). The purpose of the study is to determine the knowledge, understanding and perception of professional nurses, who work in Primary Healthcare clinics in KwaZulu-Natal, on

Autism spectrum disorder. The objectives are to determine: 1) The knowledge of professional nurses working in clinics regarding Autism spectrum disorder; 2) The understanding of Professional Nurses working in clinics regarding Autism spectrum disorder; 3) The perception of Professional Nurses working in clinics regarding Autism spectrum disorder.

In this study, the quantitative, non-experimental, descriptive research design was utilised. This research study was conducted at Primary Healthcare clinics in specific Primary Healthcare facilities in the eThekweni District, KwaZulu-Natal (KZN). The data was collected by means of the “Knowledge about childhood autism among health workers” (KCAHW) questionnaire, which has already been used in similar studies in Africa. The questionnaire was completed by all Professional Nurses examining children at the above-mentioned Primary Healthcare clinics. Each participant was given full information about this study in writing and asked to sign a consent form, should they wish to participate in the study. The questionnaire is completely anonymous and cannot be traced to any individual or institution. The respondents will not be expected to pay for participating in the study and they will in turn not receive any payment for their participation.

Descriptive and inferential statistics was used to analyse the data in this study, with the assistance of a statistician and computer software and the results was presented in a research report which was made available to you, upon your request.

For more information, you may contact me on 0764809130 or my supervisors: Dr. P. Basson on 0313732687 or Dr. D. Sokhela on 0313732992

Yours Faithfully,

.....

N.A. Williams (Researcher)

Annexure E: Letter of Permission for the DoH



health

Department:
Health
PROVINCE OF KWAZULU-NATAL

DIRECTORATE:

Physical Address: 330 Langalabelele Street, Pietermaritzburg
Postal Address: Private Bag X9051
Tel: 033 395 2805/ 3189/ 3123 Fax: 033 304 3782
Email: hrkm@kznhealth.gov.za
www.kznhealth.gov.za

Health Research & Knowledge
Management

HRKM Ref: 185/17
NHRD Ref: KZ_2016RP55_824

Date: 23 May 2017
Dear Mr NA Williams
DUT

Approval of research

1. The research proposal titled '**The knowledge, understanding and perceptions of professional nurses working in PHC clinics about Autism Spectrum Disorder**' was reviewed by the KwaZulu-Natal Department of Health.

The proposal is hereby **approved** for research to be undertaken at selected clinics listed in the letter from Acting District Director, eThekweni Health District.

2. You are requested to take note of the following:
 - a. Make the necessary arrangement with the identified facility before commencing with your research project.
 - b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.
3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za.

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

Dr E Lutge

Chairperson, Health Research Committee

Date: 25/05/17

Annexure F: Letter of Permission for the eThekweni Municipality



15.05.2017

Dear Researcher,


Subject: Approval of a Research Proposal

The research proposal titled: **The knowledge, understanding and perceptions of Professional Nurses, working in Primary Healthcare Clinics about Autism Spectrum Disorder** was reviewed by the eThekweni Municipal Health Unit Research Committee. The study is hereby approved to be conducted at all Fixed Municipal clinics (excluding all mobile clinics).

The following conditions need to be noted:

- Submission of the indemnity form obtainable from the eThekweni Municipality Health Unit before commencement of the study.
- Prior arrangements to be made with the facility and an assurance that all services will not be disrupted.
- No staff member should be used for collecting data for the researchers.
- Progress reports to be provided and the final report of the study to the eThekweni Municipality Health Unit or emailed to: rochelle.peters@durban.gov.za
- Obtain permission from the eThekweni municipality health department for press releases and release of results to communities/stakeholders.
- The department has to receive recognition for the assistance given.
- Any amendment to the study must be communicated with the eThekweni Municipality Health Unit and the relevant amendment form obtainable from the unit to be submitted.
- Withdrawal of permission to conduct research will be left to the discretion of the eThekweni Municipality Health Unit.

Yours faithfully,


Deputy Head of Health

Annexure G: IREC full approval letter



Institutional Research Ethics Committee
Research and Postgraduate Support Directorate
2nd Floor, Berwyn Court
Gate 1, Steve Biko Campus
Durban University of Technology
P O Box 1334, Durban, South Africa, 4001
Tel: 031 373 2375
Email: lavishad@dut.ac.za
http://www.dut.ac.za/research/institutional_research_ethics
www.dut.ac.za

14 June 2017

IREC Reference Number: **REC 12/17**

Mr N A Williams
9 Lofthill Place
Hillgrove
Newlands West
4037

Dear Mr Williams

The knowledge, understanding and perceptions of Professional Nurses, working in Primary Healthcare Clinics about Autism Spectrum Disorder

The Institutional Research Ethics Committee acknowledges receipt of your notification regarding the piloting of your data collection tool.

Kindly ensure that participants used for the pilot study are not part of the main study.

In addition, the IREC acknowledges receipt of your gatekeeper permission letters.

Please note that **FULL APPROVAL** is granted to your research proposal. You may proceed with data collection.

Yours Sincerely,



Professor J K Adam
Chairperson: IREC



DUT DURBAN UNIVERSITY OF TECHNOLOGY
2017-06-14
INSTITUTIONAL RESEARCH ETHICS COMMITTEE
P O BOX 1334 DURBAN 4001 SOUTH AFRICA

Annexure H: Permission Letter from the eThekweni District

Reccomendation to Coduct Research Williams.doc



health
Department:
Health
PROVINCE OF KWAZULU-NATAL

DIRECTORATE: CORPORATE SERVICES

83 King Cetshwayo Highway
Mayville, Durban, 4001
Tel: 031 240 5512 Email: sean.hamilton@kznhealth.gov.za
www.kznhealth.gov.za

ETHEKWENI HEALTH DISTRICT OFFICE

10 May 2017

Dear Mr. Williams

Re: Permission To Conduct Research at eThekweni District Facilities.

This letter serves to confirm that your application to conduct research on, the knowledge, understanding and perceptions of Professional Nurses, working in Primary Healthcare Clinics about Autism Spectrum Disorder in the eThekweni district at the following health care facilities has been recommended:

1. Addington Gateway Clinic C
2. Amaoti Clinic
3. Beatrice Street Clinic
4. Cato Manor CHC
5. Chesterville Clinic
6. Clermont Clinic
7. Commercial City Clinic
8. Danganya Clinic
9. Ekuphileni (Umlazi L) Clinic
10. Folweni Clinic
11. Fredville Clinic
12. Goodwins Clinic
13. Halley Stott Clinic
14. Inanda C Clinic
15. King Edward Gateway Clinic C
16. KwaMakhutha Clinic
17. KwaSimama Clinic
18. Lindelani Clinic
19. Magabheni Clinic
20. Maphephetheni Clinic
21. Molweni Clinic
22. Mpumalanga Clinic
23. Msunduze Bridge Clinic
24. Nsimbini Clinic
25. Ntshongweni Clinic
26. Ntuzuma Clinic
27. Oakford Clinic
28. Odidini Clinic
29. Osizweni (Umlazi Q) Clinic
30. Peaceville Clinic

Fighting Disease. Fighting Poverty. Giving Hope

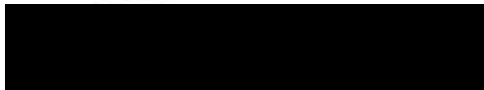
31. Phoenix CHC
32. Qadi Clinic
33. RK Khan Gateway Clinic C
34. Sivananda Clinic
35. Starwood Clinic
36. Umbumbulu Clinic
37. Umlazi D Clinic
38. Umlazi K Clinic
39. Umlazi L Clinic
40. Umlazi U21 Clinic
41. Umlazi V Clinic
42. Umnini Clinic
43. Umzomuhle Clinic
44. Zwelibomvu Clinic

Kindly upload this letter together with your application as required to the Health Research and Knowledge Unit for the KZN Department of Health for Approval.

Please also note the following:

1. This research project should only commence after final approval by the KwaZulu-Natal Health Research and Knowledge Unit, and full ethical approval, has been granted.
2. That you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
3. All research activities must be conducted in a manner that does not interrupt clinical care at the health care facility,
4. Ensure that this office is informed before you commence your research
5. The District Office/Facility will not provide any resources for this research
6. All logistical details must be arranged with the CEO/medical manager /operational manager of the facility,
7. You will be expected to provide feedback on your findings to the District Office/Facility

Yours sincerely



Ms. T. P. Msimango
Chief Director (Acting)
eThekweni Health District

• KINDLY RETURN ALL DOCUMENTATION WHEN REPLYING

Annexure I: Permission to use questionnaire

Bakare, Muideen <mobakare2000@yahoo.com>	Apr 2
to	
me	

Dear Neil,

Thank you for your interest in KCAHW Questionnaire. You are permitted to use the Questionnaire in as much as the following conditions are fulfilled:

1. Original reference of the work should be properly cited.
2. You provide us with adequate information about your study in relation to KCAHW Questionnaire (Sending a short Proposal of the study on what was the use of KCAHW Questionnaire will do).
3. You intimate us about the final publication(s) produced from the study carried out using the KCAHW questionnaire.

In case of Translation of the Questionnaire and Validation of the Translated Version (KCAHW Questionnaire):

1. I would request to have and review copies of forward and back translations of KCAHW Questionnaire.

Thank you for your Interest.

Best,

Muideen

Dr. Muideen Owolabi Bakare, M.B.B.S, FMCPsych, MNIM
Senior Consultant Psychiatrist & Head, Training and Research
Child and Adolescent Unit, Federal Neuro-Psychiatric Hospital,
Upper Chime, New Haven, Enugu, Enugu State, Nigeria

Phones - +234-703-0970-079 +234-703-0970-079, +234-805-2210-933
+234-805-2210-933
Skype: mobakare1
&
Adjunct Lecturer

Department of Internal Medicine
College of Medicine, Enugu State University of Science and Technology
(ESUT),
Enugu, Enugu State, Nigeria

<http://cndinitiatives.com/>

We never know of how much we are capable until we are challenged!!!

Call

Send SMS

Call from mobile

Add to Skype

You'll need Skype CreditFree via Skype

From: neil arnold williams <williams.neilarnold@gmail.com>
To: mobakare2000@yahoo.com
Sent: Saturday, April 2, 2016 11:35 PM
Subject:

Good Evening Dr Bakare

My Name is Neil Williams, I am a masters of health science student at the Durban University of Technology, in Kwazulu-Natal, South Africa.

I am doing my dissertation on the knowledge, understanding and perceptions of professional nurses working in primary health clinics on ASD.

I am therefore humbly requesting to utilise your "Knowledge of childhood autism among health workers" questionnaire in my research.

Thank you very much. Awaiting your positive response

--

Kind

regard

Neil Williams

Annexure J: Letter from Statistician

Gill Hendry B.Sc. (Hons), M.Sc. (Wits), PhD (UKZN)
Mathematical and Statistical Services

Cell: 083 300 9896
email : hendryfam@telkomsa.net

31 July 2017

Re: Assistance with statistical aspects of the study

Please be advised that I have assisted Neil Arnold Williams (Student number 19909436), who is presently studying for a Masters in Health Science (Nursing) at DUT, with the sampling process, questionnaire validation and data analysis for his study.

Yours sincerely

Gill Hendry (Dr)

Annexure K: Permission from CEO's and Nursing managers

 **health**
Department
Health
PROVINCE OF KWAZULU-NATAL

25 Kalandor Road, Cato Manor
PO Box 2443, Durban 4001
Tel: 031 261 4260/508 Fax: 031 251 4746 Email: Glenis.mkhize@kznhealth.gov.za
www.kznhealth.gov.za

DIRECTORATE
Cato Manor CHC

Enquiries: Mrs. G.N. Mkhize

Date: 07 June 2017 ATTENTION: Mr. NA. Williams DUT	From: Mrs. GN. Mkhize Deputy Manager Nursing Cato Manor CHC
------------------------------------------------------------------------	--------------------------------------------------------------------------

RE- PERMISSION TO CONDUCT RESEARCH IN CATO MANOR CHC

I have a pleasure in informing you that permission has been granted to you by Cato Manor CHC to conduct research on THE KNOWLEDGE, UNDERSTANDING AND PERCEPTIONS OF PROFESSIONAL NURSES WORKING IN PRIMARY HEALTHCARE CLINICS ABOUT AUTISM SPECTRUM DISORDER
Please note the following:

1. Ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office (facility) has received confirmation from the Provincial and District Health Research Committees in the KZN Department of Health
3. Please ensure that the facility is informed before you commence your research.
4. The facility will not provide any resources for this research and the research should not interrupt the service delivery
5. You will be expected to provide feedback on your findings to the facility

Yours Faithfully
Mrs. G.N. Mkhize
Deputy Manager Nursing
Acting CEO

Signature: 

Date: 07/06/17

REPLY SLIP:

Date: 1/6/2017

Dear Ms T. P Msimango

Re: Permission To Conduct Research at Phoenix CHC

The request to conduct the research study titled "The knowledge, understanding and perceptions of Professional Nurses, working in Primary Healthcare Clinics about Autism Spectrum Disorder in eThekweni" by researcher **N Williams**, at **Phoenix CHC** has been received.

The researcher is hereby granted /denied site entry.

If denied, specify reason:

Please also note the following:

1. This research project should only commence after final approval by the KwaZulu-Natal Health Research and Knowledge Unit, and full ethical approval, has been granted,
2. That you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
3. All research activities must be conducted in a manner that does not interrupt clinical care at the health care facility.
4. Ensure that the Health Care Facility is informed before you commence your research
5. The Health Care Facility will not provide any resources for this research
6. All logistical details must be arranged with the CEO/medical manager /operational manager of the facility,
7. You will be expected to provide feedback on your findings to the District Office/Health Care Facility

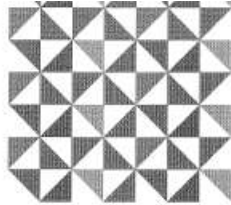
Yours sincerely [Redacted]

Name: [Redacted]

Rank: CEO And medical manager.

• KINDLY RETURN **ALL DOCUMENTATION** WHEN REPLYING

Annexure L: Provisional approval from IREC



Institutional Research Ethics Committee
Research and Postgraduate Support Directorate
2nd Floor, Berwyn Court
Gate 1, Steve Biko Campus
Durban University of Technology
P O Box 1334, Durban, South Africa, 4001
Tel: 031 373 2375
Email: levishad@dut.ac.za
http://www.dut.ac.za/research/institutional_research_ethics
www.dut.ac.za

1 March 2017

IREC Reference Number: **REC 12/17**

Mr N A Williams
9 Lofthill Place
Hillgrove
Newlands West
4037

Dear Mr Williams

The knowledge, understanding and perceptions of Professional Nurses, working in Primary Healthcare Clinics about Autism Spectrum Disorder

I am pleased to inform you that Provisional Approval has been granted to your proposal REC 12/17 subject to:

- Piloting of the data collection tool and
- Obtaining and submitting the necessary gatekeeper permission/s to the IREC.

Full approval is subject to meeting the above conditions.

The Proposal has been allocated the following Ethical Clearance number **IREC 014/17**. Please use this number in all communication with this office.

Approval has been granted for a period of two years, before the expiry of which you are required to apply for safety monitoring and annual recertification. Please use the Safety Monitoring and Annual Recertification Report form which can be found in the Standard Operating Procedures [SOP's] of the IREC. This form must be submitted to the IREC at least 3 months before the ethics approval for the study expires.

Any adverse events [serious or minor] which occur in connection with this study and/or which may alter its ethical consideration must be reported to the IREC according to the IREC SOP's.

Please note that any deviations from the approved proposal require the approval of the IREC as outlined in the IREC SOP's.

Please note that you may continue with validity testing and piloting of the data collection tool. Research on the proposed project may not proceed until IREC reviews and approves the final document. If there are no changes to the data collection tool, kindly notify the IREC in writing.

Yours Sincerely



✓
Professor J K Adam
Chairperson: IREC



Annexure M: Editing certificate

DR RICHARD STEELE

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EDITING CERTIFICATE

Re: Neil Arnold Williams

Master's dissertation: The knowledge, understanding and perceptions of professional nurses, working in Primary Health Care clinics, about autism spectrum disorder

I confirm that I have edited this dissertation and the references for clarity, language and layout. I am a freelance editor specialising in proofreading and editing academic documents. I returned the document to the student with track changes so correct implementation of the changes in the text and references is the responsibility of the student. My original tertiary degree which I obtained at the University of Cape Town was a B.A. with English as a major and I went on to complete an H.D.E. (P.G.) Sec. with English as my teaching subject. I obtained a distinction for my M.Tech. dissertation in the Department of Homeopathy at Technikon Natal in 1999 (now the Durban University of Technology). During my 13 years as a part-time lecturer in the Department of Homoeopathy at the Durban University of Technology I supervised numerous Master's degree dissertations.

Dr Richard Steele

10 October 2017

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