

An exploration of nursing professionals' understanding of Autism Spectrum Disorder

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Abstract

The number of children diagnosed with autism spectrum disorder is increasing at an alarming rate. Research indicates that early identification and diagnosis is key in terms of children receiving early intervention. However, many children are not being identified as early as possible by their primary health care providers. This research investigated nursing professional's experiences of working with autism spectrum disorder in a clinic setting. Using phenomenology theory as the epistemological framework, thematic analysis was conducted on ten in-depth interviews with nursing professionals working in the public sector. Three main groupings for the findings emerged from the interpretative analysis: 1) nursing professionals' knowledge, understanding and awareness of autism spectrum disorder, 2) screening practices of nursing professionals; and 3) identified challenges in screening for autism spectrum disorder. Although the majority of the nursing professionals showed a good understanding of some aspects of the condition, there was some confusion about some key facts concerning the disorder, the characteristics of ASD and scientific terminology, and an inaccurate understanding of early intervention treatments. Nursing professionals' screening efforts remain poor despite the diagnostic value of routine screening for early childhood developmental delays. Limited services and resources, a lack of communication between primary and secondary systems, time restrictions, work pressure and inadequate training are all barriers that prevent nursing professionals from conducting routine screening during child wellness visits, resulting in missed opportunities for detecting autism spectrum disorders in the early months or years. This research highlights the urgent need to look into strategies that would improve and support efforts for conducting early screening in primary health care clinics. Implications for future research in this area are also addressed.

Key words: autism spectrum disorder, phenomenology, thematic analysis, screening, nursing professionals, primary healthcare

Declaration

I declare that **An exploration of nursing professionals' understanding of autism spectrum disorder** is my own work, that it has not been submitted for any other degree or examination to any other university, and that all the sources that I have used have been indicated and acknowledged by complete references.

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Table of Contents

Abstract	ii
Declaration	iii
Acknowledgements	iv
CHAPTER ONE	1
Introduction	1
Problem Statement	2
Definition of Terms	3
Thesis Structure	3
CHAPTER TWO	4
Literature Review	4
Diagnostic Statistical Manual IV and DSM 5	5
Prevalence/ Incidence	7
Comorbidity	8
Potential causes	8
Benefits of Early Identification and Intervention	9
Screening practices	10
Barriers to Autism Detection in Primary Healthcare	12
Recommended Screening Instruments for Autism Spectrum Disorders	14
Healthcare delivery in Sub-Saharan Africa and South Africa	17
CHAPTER 3	21
Research methodology	21
Aim	21
Theoretical framework	21
Research design	22
Sample	23
Data collection Tool	25

Procedure	25
Data analysis	26
Reflexivity and Power	27
Ethical considerations	28
CHAPTER FOUR	30
Results	30
Nurses' knowledge, understanding and awareness of Symptoms	30
Conceptions regarding the nature and the prevalence of autism	34
Screening Practices	37
The importance of mothers' reports	39
Identified challenges in screening for ASD	42
Inadequate service provision	42
Lack of communication between primary and secondary systems	43
Time restraints	45
Lack of training; medical training and continuing training	48
CHAPTER FIVE	51
Discussion and Conclusion	51
Limitations	60
Recommendations	60
References	62
Appendices	70
Appendix A: Interview Schedule	71
Appendix B: Participant Information Letter and Consent Form	73
Appendix C: Key on the Transcription System	76

CHAPTER ONE

Introduction

This chapter introduces the study background and focus, starting with a brief description of autism spectrum disorder (ASD), its characteristics, prevalence and the advantages of early detection and diagnosis for more efficacious treatment of children diagnosed with ASD. The importance of accurate and routine screening, as well as the education of primary healthcare providers to be competent diagnosticians in a country such as South Africa is discussed.

Autism spectrum disorder (ASD) is a pervasive developmental disorder characterised by two essential features: a combination of impairments in (1) social interaction and social communication, and (2) restricted, repetitive, and stereotyped patterns of behaviour, interests and activities (American Psychiatric Association, [APA], 2013). Although the aetiology of autism spectrum disorder is currently unknown, the disorder is recognized as a neurological disorder with strong genetic links and one that manifests in social, communication and behavioural deficits during early development (Johnson & Myers, 2007; Baird, Charman, Cox, Baron-Cohen, Swettenham, Wheelwright & Drew, 2001). The number of children diagnosed with ASD is increasing at an alarming rate and the Centre for Disease Control (CDC) have estimated that 1 in 150 children are diagnosed with the ASD (Rice, 2009).

There is no known prevention or cure for autism but early intervention has been reported to show a positive outcome for the ASD diagnosed child's development (Dumont-Mathieu & Fein, 2005; Goin & Myers, 2004), thus making routine testing and early detection key to the process of assessment and diagnosis (Filipek, Accardo, Ashwal, Baranek, Cook, Dawson & Kalle, 2000). The latest publication of a comprehensive set of guidelines for professionals calling for routine screening and early diagnosis provides an algorithm to help primary healthcare professionals to develop a strategy for early identification of children with autism spectrum disorder (Johnson & Myers, 2007, p. 1183). In attempts to identify a child with ASD, it has been suggested by American Academy of Paediatrics (2002) that professionals conduct a general developmental surveillance which includes asking parents about their child's development, monitoring developmental milestones, interacting with a child during examinations, and administering autism specific screening instruments at 18- and -24 month child wellness visits, or when there is an observed or reported concern.

The publication of these guidelines was aimed at encouraging primary health care professionals to perform routine testing in clinical settings to improve the early identification,

detection and diagnosis rates of ASD. However, there is evidence that the majority of primary care providers are either not screening, or incorrectly screening, for developmental disorders (American Academy of Paediatrics, 2001; Sand, Silverstein, Glascoe, Gupta, Tonniges & O'Connor, 2005). One study done in Jamaica in 2008 reported that, although 95% of Jamaican children received their health care from primary care professionals, only 4.6% of referrals to diagnostic centres were made by their health provider (Samms-Vaughan & Franklyn-Banton, 2008). For professionals who did screen for ASD, it was found that primary healthcare workers relied mainly on clinical judgments and a review of developmental milestones, both of which have been shown to be ineffective and to identify only a small number of children with developmental delays (Hix-Small, Marks, Squires & Nickel, 2007; Sices, Feudtner, McLaughlin, Drotar & Williams, 2004).

This suggests that, despite the presence and availability of practice guidelines on the screening for autism, primary health care professionals are not detecting it in their practice. Since international literature indicates a high prevalence of children with autism, it is important for practitioners to be knowledgeable and competent in screening for autism in primary health care settings. It seems clear that further education and training for primary health care professionals regarding routine screening tools and ways to incorporate effective and frequent screening for ASD in their practice is needed. However, in a context like South Africa, where the majority of the population make use of primary health care services, this appears to be a great challenge in terms of the financial implications of the implementation of routine screening in an already overburdened healthcare system.

Problem Statement

The current international literature points to the need for primary care paediatricians to conduct ongoing developmental surveillance for all children during child wellness visits. Guidelines are provided for the use of validated ASD specific tools designed to detect autism at key times in early childhood. However in South Africa little is known about the prevalence and incidence of ASD, and current screening practices of health care professionals, and their knowledge and awareness regarding autism spectrum disorder, is far from adequate. Understanding primary healthcare professionals' experiences of working with autism in a primary setting is the first step in developing educational interventions to teach healthcare providers how to implement routine and accurate autism screening using validated autism screening instruments. Thus identifying factors which can improve the early detection, identification, and timely diagnosis of ASD, and the provision of early intervention, is of great value and significance for public mental health.

Definition of Terms

Autism Spectrum Disorders. Autism Spectrum Disorder (ASD) 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 [APA], 2013).

Early identification. Early identification refers to the detection of ASD and/or other disabilities early on in a child's development.

Screening. A screening is a brief, point-in-time procedure for identifying and deciding which individuals need a referral for further assessment (Filipek et al., 2000).

In summary, this chapter briefly introduced autism spectrum disorder and prevalence rates of the disorder internationally. The chapter highlights the need for professionals to conduct screening at every child wellness visit for early identification and early intervention for children with autism spectrum disorder. As illustrated above, given the resource strapped and overburdened health care system in South Africa, research in efforts for early detection of the disorder is urgently needed.

Thesis Structure

The remaining chapters present information and discussion pertinent to this study. Chapter two provides a review of the available literature on autism spectrum disorders, the process of identification and screening, and the role of primary healthcare providers in the identification of ASD. Chapter three details the methodology that was used in the study, including the research design, sample, data analysis, reflexivity and ethical considerations. Chapter four presents the findings of the study. Chapter five concludes the thesis with a detailed discussion of the findings and the implications of the study, and recommendations both for healthcare practitioners and policy-makers in terms of early and accurate diagnosis of ASD and timely intervention.

CHAPTER TWO

Literature Review

This chapter presents a review of the available international and sub-Saharan literature on autism spectrum disorder (ASD) and its diagnosis and treatment by primary healthcare professionals in public healthcare systems. In the context of the increasing number of children being diagnosed with the disorder, particularly in the developed world, it focuses on literature highlighting the difficulties of diagnosing autism spectrum disorder in terms of the complexity of the spectrum of ASD, and cites studies which emphasise the importance of early and accurate diagnosis for positive outcomes and treatment of children with ASD. In terms of the focus of the study, the researcher cites literature detailing a worldwide lack of screening and diagnostic knowledge and skills on the part of primary healthcare professionals and, of direct relevance to the study, identifies a gap in literature assessing the knowledge base of nurses in the screening, diagnosis and treatment of ASD in South Africa.

Autism Spectrum Disorder

As was outlined in Chapter one, ASD is a developmental disorder that is characterized by two essential features which become apparent in early childhood: a combination of impairments in (1) social interaction and social communication, and (2) restricted, repetitive, and stereotyped patterns of behaviour, interests and activities (APA, 2013). In order to meet the diagnostic criteria for ASD, impairments in these two domains must be met. Deficits must exist in social interaction, communication and behaviour. There is no single characteristic that identifies all children with ASD. Rather, each child presents with unique characteristics which vary in occurrence and intensity (Daley & Sigman, 2002). It is important to note here that a deficit or impairment does not imply a total lack or absence of a skill, as is often described, but instead means that there is a deficit in the child's ability when compared to typically developing children of the same age (Filipek et al., 2000).

The following detailed description of the characteristics of autism is based on the latest version of the Diagnostic Statistical Manual V (APA, 2013) criteria for ASD as it is the most commonly diagnosed disorder along the spectrum. A brief discussion of the changes in description between the DSM IV and DSM V criteria for autism spectrum disorders will follow to aid an understanding of the recently published diagnostic criteria of autism disorder and to clarify the definition and use of the term in the current study.

Diagnostic Statistical Manual IV and DSM- 5

In editions previous to, and including the DSM-IV, autism spectrum disorders were a broad category of similar developmental disorders which were typically diagnosed in early childhood and characterised by a triad of qualitative impairments in speech, social behaviour and an adherence to a rigid pattern of behaviour and routine (American Psychiatric Association [APA], 2000). There were five disorders, each with different levels of severity, that fall under ASDs: (a) autistic disorder (b) pervasive development disorder not otherwise specified (PDD-NOS) , (c) Asperger syndrome , (d) Rett syndrome , and (e) childhood disintegrative disorder (APA, 2000).

In the current DSM 5, autism spectrum disorder is identified as a pervasive developmental disorder with different levels of symptom severity in communication and social interaction, and restricted, repetitive patterns of behaviour, interests or activities (APA, 2013). There are three levels of severity under each domain, which range from severe deficits, marked deficits and noticeable impairments. Symptoms should be present in early development but it is acknowledged that some developmental deficits may not fully manifest during this time until demands placed on the child exceed capacity (APA, 2013).

Nevertheless, in order to qualify for a diagnosis of ASD, symptoms should cause clinically significant impairments in important areas of functioning and cannot be accounted for by intellectual disability or global delay. The inclusion of autistic disorder, Asperger's syndrome, childhood disintegrative disorder and pervasive developmental disorder—not otherwise specified under an over-arching spectrum of disorders, implies that individuals previously diagnosed for the above disorders will therefore be give an Autism Spectrum Disorder diagnosis (APA, 2013). For the purpose of this literature review, the researcher will use the terms “autism” and Autism spectrum disorder interchangeably.

Developmental characteristics

Contrary to what was believed previously, where autism had an age marker of three years (APA, 2000), recent research and improved identification and diagnosis has indicated that children show signs of atypical development as early as nine months (Samms-Vaughan & Franklyn-Banton, 2008), with some parents reporting developmental and behavioural concerns at the ages of 12 to 18 months (Filipek et al., 2000; Gupta et al., 2007). Other children are described as following a typical developmental trajectory with concerns mainly arising once the child begins to lose previously learnt language skills; a regression in that skill is a presenting concern for 15-20 % of diagnosed autism cases (Baird et al., 2001). Communication impairments may also involve a delay in, or absence of, language, or repetitious or imitative

use of language, such as delayed babbling past nine months (Johnson & Myers, 2007).

In addition, deficits in communication extend beyond a delay in spoken language as receptive language is often affected. Children with autism are often unable to respond to other people's attempts to communicate with them. They lack an awareness of the presence of feelings towards others and show a lack of emotional responsiveness to the messages of other people (Hyman & Johnson, 2012). Typically, these children display poor use of communicative gestures and proto-declarative pointing (pointing to something of interest to bring it to the attention of another). When an ASD diagnosed child is verbal, the quality of their speech includes unusual patterns, such as utterances with certain sounds, or words, or phrases repeated over and over in what is considered to be self-stimulatory behaviour (Ozonoff, Goodlin-Jones & Solomon, 2005). Some children sometimes exhibit what is referred to as "delayed echolalia", where the child repeats a word or phrase in response to something said by another person. For example, if a mother asks the child "Would you like to play" the child may respond "Would you like to play" instead of answering the question (APA, 2013).

Along with impairments in communication and social interaction, children with autism often demonstrate atypical responses to sensory stimuli (APA, 2013). They experience somatosensory disturbances that may include hypersensitivity to sounds, smells, touch, oral or tactile textures, and visual perception distortion (Strunk, 2009). Children with ASD may respond to normal noises such as hooting, washing machines and vacuums by covering their ears or screaming to express their discomfort. They may also find certain clothing painful to wear and refuse to do so.

Behaviourally, these children may display stereotyped body movements, such as hand flapping, and display a limited interest in others and in their environment. Their interests are often fixated on unusual objects such as bicycle wheels, or wind shield wipers or fans (APA, 2013), a pattern of behaviour which parents often find difficult to manage especially in social settings where they may also have to deal with harsh criticism from extended family members such as grandparents, aunts and uncles, as well as the general public. Additionally, because children with autism are often resistant to change and insist on maintaining routines (Nadel & Poss, 2007), families have to make adjustments to their lifestyles in order to accommodate the child's needs. For example, daily activities such as shopping, eating out, family gatherings and holidays are affected as the family cannot be spontaneous and engage in activities that they have not planned for.

Prevalence/ Incidence

Previously, childhood autism was reported as a rare disorder. However, more recently the number of children diagnosed with an Autism Spectrum Disorder (ASD) is increasing at an alarming rate (Rice, 2009). The current estimated number of children diagnosed with an ASD in the USA varies widely, with one study estimating that 1 in 91 children were diagnosed in 2007 (Kogan et al., 2009), while, as has been mentioned, the Centre for Disease Control (CDC) estimated that 1 in 150 children were diagnosed in the same year (Rice, 2009).

The reasons for the increase in the number of children diagnosed with autism have been widely debated; one argument posits the question of whether the overall prevalence rate of autism has increased, or if past prevalence rates reflected poor recognition of the disorder, leading to under-diagnosis (Croen, Grether, Hoogstrate & Selvin, 2002). It has been suggested that the increase in prevalence rates is due in part to improvements in identification and diagnosis among professionals, the development of standardized assessment and screening tools, and an increased flow of referrals to autism-related specialists and services (Croen et al., 2002). A study by Powell and colleagues (2000) has provided incidence estimates that showed an increasing trend over a brief period of time. However, the study neither examined changes in diagnostic criteria nor sensitivity of case detection procedures during this time period (Fombonne, 2003).

In response to this, some authors argue that this staggering increase is solely attributable to the widening diagnostic criteria to include all spectrum disorders in the DSM IV, such as, Asperger's disorder and Pervasive Developmental Disorder-not otherwise specified (Wing & Potter, 2002). In one study it was reported that the broader diagnostic criteria led to the inclusion of milder cases of autism disorders, and was therefore responsible for the high prevalence increase, and it is suggested that further research is needed to better explain the changes in the incidence and prevalence of autism disorder (Fombonne, 2003).

While it remains unclear whether the increase in autism is due to an increase in prevalence, or reflects improved awareness and diagnostic instruments available for autism (Croen et al., 2002), the rise in the number of individuals diagnosed with the disorder has important implications for early identification and detection, diagnosis and intervention practices (Filipek et al., 2000). The noticeable incidence and prevalence of autism has led to increased concerns about the disorder and effective ways to detect such disorders easily and accurately, which would lead to improved interventions for diagnosed children to be able to realise their potential. Autism is approximately three to four times more prevalent in boys than

in girls and the disorder knows no racial, ethnic, or social boundaries (Senders, Freeman, DePaul & Levy, 2002; Fombone, 2003).

Comorbidity

Intellectual disabilities (IDs) which have been reported to have a high association with autism spectrum disorders are characterized by social, cognitive, and adaptive skill deficits (APA, 2013). A study conducted by Simonoff et al. (2008) reported a rate of 71% of children with autism who also presented with IDs of varying degrees (Fombone, 2003). In terms of psychiatric disorders, the study found that the majority of children who had either autism disorder or a pervasive developmental disorder have multiple diagnoses, for example 41% of the children diagnosed with autism which co-occurred with IDs had three or more disorders in addition to the autism (Simonoff et al., 2008). These disorders include attention deficit hyperactivity disorder (ADHD), anxiety, obsessive compulsive disorder, depression, sleep disorders and feeding disorders (Fombone, 2003; Simonoff et al., 2008; Nadon, Feldman, Dunn & Gisel, 2011). In addition to the close link found between autism, intellectual disabilities and psychiatric disorders, there is a reported high rate of autism accompanied by epilepsy and seizures (Fombone, 2003).

Potential causes

The aetiology of autism spectrum disorder is unknown. While no definitive explanations for autism have been found, the search for the aetiology of the disorder, including biological and environmental factors, continues. Previously, primary caregivers especially mothers, were held responsible for the atypical social and emotional functioning of their children, including poor attachment and lack of reciprocity in social interactions (Burkhardt, 2001). However, this belief has since been discredited by research evidence that recognises ASD as a neurological disorder with strong genetic links (Johnson & Myers, 2007). Although evidence is continuing to accumulate for an underlying genetic cause for ASD, more research needs to be conducted in order to determine its aetiology.

Given that there is currently no biological marker or medical tests that can reliably diagnose ASD, evaluation and behavioural methods are utilised for screening. In addition, parents are often excellent sources of information about their children's development, although their concerns are often dismissed or downplayed by medical professionals (Coonrod & Stone, 2004; Filipek et al., 2000). As mentioned earlier, parents find this frustrating as they continue to struggle with their child's atypical development while professionals continue to see their worries as excessive anxiety. In this context, professionals often do not screen children, even though it is known that early detection will lead to earlier and improved interventions (Filipek

et al., 2000).

Benefits of Early Identification and Intervention

Despite the unclear understanding of the reasons for the rising number of children diagnosed with autism and of its aetiology, it is evident that many children are identified. Autism is a life-long pervasive disorder for which a cure does not exist. Although a cure has not been found, we have come to understand the remarkable plasticity abilities of the brains of young children with autism and how early and intensive behavioural intervention can bring about significant and lasting improvements in all domains of social, communication, and adaptive functioning (Bryson, Rogers & Fombonne, 2003; Glascoe, 2005; Goin & Meyers, 2004; Van Tongerloo, Bor & Lagro-Janssen, 2012). The suggestion that symptoms of this disorder can be improved through the use of early intervention practices has led to a significant emergence of research advocating for early diagnosis (Bryson et al., 2003).

Early intervention programs have been found to improve long term outcomes related to language and speech acquisition, social skills and the reduction of stereotyped, ritualistic behaviours found in children with autism (Dietz, Swinkles, Van Daalen, Van Engeland & Buitelaar, 2006; Johnson & Meyers, 2007; Mandell, Listerud, Levy & Pinto-Martin, 2002; Robins & Dumont-Mathieu, 2006). For example, Filipek et al. (2000) found that 75% of children who had been receiving intervention for over two years had developed speech and showed considerable increase in developmental progress and intellectual performance. Some studies (e.g Dawson, 2008; Landa, Holman & Garrett-Mayer, 2007) have reported significant improvements in IQ. It is important to note that, although intervention is beneficial at any age, major gains are found with younger children (Baird et al., 2004). Therefore, the younger the child, the better the chances are to move the child toward a more typical developmental trajectory. Thus it is thus important that children are diagnosed early enough to be able to receive intervention at a young age.

Additional advantages of early intervention include early planning for educational needs and services, improvements in access to interventions, as well as reducing the stress of family members (Filipek et al., 2000; Hyman & Johnson, 2012). Prompt educational interventions can have a positive outcome at a point when typical learning could occur in early childhood. By targeting autism specific symptoms, early identification can also provide considerable financial savings to families and the healthcare system, given the known costs associated with later intervention treatments for the disorder (Mandell, Novak & Zubrisky, 2005). In addition, given the known genetic basis for autism and the increased risk of autism for subsequent children, early identification provides the opportunity to health practitioners to offer timely and accurate

genetic counselling to families regarding subsequent children (Dietz et al., 2006; Nadel & Poss, 2007). It is thus clear that early intervention is the best response to ASD from many points of view, and that the earlier treatment is started, the more favourable treatment outcomes are. Despite this recognition, and the improvements in early diagnosis, there remains a delay in the diagnosis of children with autism, particularly in developing countries and in socio-economically disadvantaged communities (Baird et al., 2001; Coonrod & Stone, 2004; Goin & Meyers, 2004; Robins, Fein, Barton & Green, 2001).

A delay in diagnosis and early intervention compromises the possibilities for ameliorating the negative effects associated with the disorder, which may have a long term deleterious effect on the child (Heidgerken, Geffken, Modi & Frakey, 2005). When an intervention is delayed, children lose the benefits of early intervention and the outcomes tend to be less successful (Dietz et al., 2006; Landa et al., 2007). In addition, delays in identification and diagnosis not only affect the child's development, but the entire family system as well. For example parents reported experiencing more stress when they had numerous specialists to consult when searching for an answer to their child's atypical development (Moh & Magiati, 2012). Thus parental stress would be reduced if the disorder is detected early and they do not have to chase a diagnosis for their child and deal with different professionals and specialists who overload them with new and conflicting information.

Screening practices

The identification and diagnosis of autism is made by a multidisciplinary team including paediatricians, psychologists, psychiatrists and school psychologists (Heidgerken et al., 2005). The diagnosis of autism is often a long and complicated process, characterised by diagnostic confusion, in which healthcare practitioners have to rely on the clinical signs and symptoms presented by the child and described by family members to make a diagnosis (Nadel & Poss, 2007). However, since the deficits associated with autism manifest prior to age 36 months, with some suggesting as early as nine months, paediatricians and family general practitioners are commonly the first health care providers the child and family have contact with through routine infant/toddler wellness check-ups (Samms-Vaughan & Franklyn-Banton, 2008). They are seen as trusted sources on issues related to the health and development of the infant, and in a position to assess and monitor their areas of risk during a period where developmental intervention is possible (Hyman & Johnson, 2012). Therefore, paediatricians, nurses, and family practitioners will be the first medical professionals who receive concerns and worries regarding a child's development from parents (Heidgerken et al., 2005). It would therefore make sense for primary healthcare professional to conduct

screening since it is they who are monitoring children from birth and are also already conducting general developmental screening at different intervals.

However, there is often a lag between the initial period during which parents express their concerns and the time a child finally receives a diagnosis of autism. Parents generally identify their concerns by the age of 12 to 18 months, although recent US data suggest that the average age of diagnosis remains at 4 years and possibly older in socio-economically disadvantaged groups (Filipek et al., 2000). As has been mentioned, it is reported that parents' initial concerns are often dismissed by professionals and a diagnosis is not made until several years later (Baird et al., 2001; Coonrod & Stone, 2004; Goin & Meyers, 2004; Robins et al., 2001). Studies of families with children diagnosed with ASD report that families' accounts of their dissatisfaction with primary healthcare professionals include delays in diagnosis, incorrect information provided and a lack of referrals to specific services (Carbone, Behl, Azor & Murphy, 2010; Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010).

Another study done in Jamaica illustrates this scenario, reporting that, although 95% of Jamaican children receive their health care from primary care medical professionals, only 4.6% of referrals to diagnostic centres were made by primary care health professionals, while 76.2% were largely from paediatricians and other specialist services providing care at secondary or tertiary level (Vaughan, 2005). In a survey of 1300 families done in the UK, fewer than 10% of children whose parents reported concerns were diagnosed at their initial presentation, while another 10% were told to come back at a later stage, having been given the impression by the health care professionals that their children would 'grow out of it' (Howlin & Moorf, 1997). These findings suggest that the majority of children with autism are not being identified by primary health care professionals and are thus losing out on the benefits of early intervention. This is particularly concerning in the context of current research which emphasizes the importance of routine screening of every child at child wellness visits during critical stages of their development. Adding this specific screening to the ongoing developmental check-ups would increase the likelihood of the detection of autism at a younger age, which, as has been mentioned, has potential benefits for both the child and their family (Bryson et al., 2003; Dumont-Mathieu & Fein, 2005).

Practitioners, such as Dumont-Mathieu and Fein (2005), suggest that this screening should be implemented during regular 18 and 24 month check-ups and general developmental screening should occur at all ages and development stages. A detailed surveillance and screening algorithm for ASD, together with an updated summary of appropriate standardized screening instruments and their psychometric properties has been stipulated by the

American Association of Psychology in their recent report (American Academy of Pediatrics, 2001). According to this algorithm and screening instrument summary, at first level routine developmental surveillance and screening specifically for autism should be performed for all children. This involves two aspects: firstly identifying children at risk for any type of atypical development, and then identifying those specifically at risk for autism. The second level of screening involves a more in depth investigation of children who have already been identified at the first level, and it is at this point that autism is differentiated from other developmental disorders (Filipek et al., 2000). For the purposes of this study, the discussion of routine screening by primary healthcare professionals refers to the level one recommendations since the focus is on primary health care professionals.

In conclusion, it might reasonable to assume that there exists a number of opportunities for the detection of ASD. The period during which caregivers of children showing atypical development contact primary health professionals in their first year of life is the optimal space for the detection of ASDs. Given the benefits of early diagnosis for the child, the identification of children showing signs of atypical development is critical, it is therefore essential for health practitioners to routinely screen children through monitoring the milestones of development appropriate for specific ages and tracking signs of development in the areas of speech and social and communication skills (Johnson & Myers, 2007). However, it would seem unfair to expect primary health care providers to conduct screening without taking into consideration the possible barriers which would prevent them from conducting autism routine screening in their practice.

Barriers to Autism Detection in Primary Healthcare

Given the research support for the benefits of early identification and intervention, it is crucial that children are identified at an early age as possible. There are several hypotheses as to the reasons for the delay between presence of symptomatology and diagnosis in children with ASD. One hypothesis is that the primary referral sources, such as pediatric healthcare providers, may in many instances be unfamiliar with the early warning signs of ASD and are therefore hesitant to refer these young patients for services (Haflon et al., 2001; Galinat, Barcalow & Krivda, 2005). It is suggested that in many cases healthcare professionals appear to lack the knowledge and competence in understanding the early indicators of autism and how to support these children through screening, referral, diagnosis and early intervention services (Samms-Vaughan & Franklyn-Banton, 2008).

In an earlier study assessing the knowledge and beliefs of several groups of professionals across disciplines and specialisations, Stone (1987) found that participants from four disciplines had varying misconceptions regarding autism. For example, speech-language pathologists

(SLPs) believed that autism was an emotional disorder and professionals from all other disciplines believed individuals with the disorder had special talents and skills. Working with the same group of professionals, Schwartz and Drager (2008) recently found that, although some participants had accurate knowledge about the characteristics of children with autism, they were unsure of the diagnostic criteria for autism. Similarly, in a more recent study, Heidgerken et al. (2005) noted accurate knowledge of the DSM-IV criteria for diagnosis but significant variations between the specialists and primary health care providers on prognosis, course and treatment of autism. Such differences between disciplines and the inability of practitioners to give further information to parents may be a function of the professional training of each profession (Rhoades, Scarpa & Salley, 2007).

Furthermore, Shah (2001) observed that fourth year medical students were significantly likely to respond correctly to questions related to diagnostic criteria and core symptoms. However, for other aspects, such as possible causes, prognosis and treatment, students were unable to offer any answers. Based on these findings, he suggested that more emphasis needs to be placed on more comprehensive and holistic teaching about autism if diagnosis and access to intervention are to be improved (Shah, 2001). Thus I would argue that professionals must be educated in various aspects of autism, given that comprehensive knowledge about childhood autism has been shown to significantly influence the average age of diagnosis.

Another significant barrier to early, comprehensive, and accurate screening and diagnosis includes the anxiety created for parents by a false-positive diagnosis, the negative effects of labelling a child, and the false hope for symptom reversal (Dietz et al., 2006). Furthermore, there are concerns regarding the emotional impact a diagnosis will have on a family as some families continue to hold the belief that ASD carries a long term poor prognosis (AAP, 2001; Oser & Shaw, 2001). In contradiction to this, some authors (e.g Self, Coufal & Parham, 2010) argue that early identification or diagnosis in actual fact allows health practitioners to provide support for parents, which in turn reduces the stress experienced by parents. An early diagnosis enables early acceptance of the diagnosis by parents which will later inform their treatment choices for the child.

Lack of time has also been identified as a significant barrier in conducting screening for autism. Sices, Feudtner, McLaughlin, Drotar and Williams (2003) indicated that less than one-half of physicians in their study agreed that there is adequate time to perform developmental screening during a typical well-child visit. The majority of practitioners in the survey were found to rely on lists of developmental milestones and/or parental concerns to identify children with delays. This practice is not endorsed by some authors who indicate that

autism-specific screening is necessary, as global or general developmental screening may not correctly identify children with ASD (Mandell et al., 2005; Sices et al., 2004; Pizur-Barnekow, Muusz, McKenna, O'Connor & Cutler, 2012; Robins et al., 2001). Additionally, due to the fact that specific recognition of the disorder is difficult because key symptoms that lead to a diagnosis, such as the child's atypical socialisation skills and communication with peers, do not become apparent until the child is older (Crown, 2009), autism-specific screening is of high importance. Therefore, diagnosis of ASD during infancy may be difficult in terms of detecting it, or may present differently from the manifestation of the disorder at later stages (Wetherby, Woods, Allen, Cleary, Dickinson & Lord, 2004). Moreover, because the symptoms and impairments associated with the disorder manifest over a spectrum, autism presentation in the clinical setting is highly complicated, and poses particular challenges for diagnosis (Strunk, 2009; Nadel & Poss, 2007).

Shortening the time period between initial parental concern and diagnosis is an important goal to improve long-term outcome for children with autism as research has indicated that children who are diagnosed with autism earlier show better outcomes (Turner, Stone, Pozdol & Coonrod, 2006). The evidence from recent research thus supports the need for health practitioners to be knowledgeable in the area of symptoms, diagnosis, and treatment, in order to provide support and quality healthcare to families and children with autism (Nadel & Poss, 2007). It is imperative that primary health care professionals are responsive, from initial recognition of symptoms throughout the diagnostic process with initiating intervention services for children with autism. Therefore, first-contact early childhood professionals have tremendous opportunities to reduce diagnostic delays (Samms-Vaughan & Franklyn-Banton, 2008).

Providing basic knowledge to primary health care providers, including paediatricians, nurses and family physicians, will increase their understanding of the disorder and highlight knowledge gaps which together impact on diagnosis and access to early interventions for children with autism and their families. This indicates that, particularly in the South African context, it is critical to develop an adequate understanding of the knowledge base of healthcare professionals in the primary health care sector.

Recommended Screening Instruments for Autism Spectrum Disorders

Currently, there are several screening and diagnostic tools that aid in the diagnosis of autism spectrum disorders. Although these standardized instruments are not 100% accurate, they have been proven to meet the acceptable practice standards in detecting autism spectrum disorder in young children (Filipek et al., 2000; Glascoe, 2005; Goin & Meyers, 2004; Coonrod

& Stone, 2004). A summary of the most widely used validated instruments suitable for Level 1 screening will follow. It should be noted that this summary is not meant to be an exhaustive list of all the available measures, but, an overview of possible screening instruments which are considered to be applicable at Level 1 autism screening in a primary health care setting.

Recent research has recommended that primary health practitioners choose one tool for each age group, become familiar with it, and use it consistently during routine well-child visits (AAP, 2001). In this context, routine developmental surveillance should be conducted by all practitioners at every child wellness visit, and any child who is not pointing or babbling by 12 months, and has not started using single words by 16 months of age, or speaking in two-phrases by 24 months of age, or has experienced any loss of language or social skills at any age, should be specifically screened for ASD (Filipek, 2000; Johnson & Myers, 2007). The following standardized autism screening instruments are recommended to be used for more comprehensive developmental assessment.

The Checklist for Autism in Toddlers (CHAT) is used as an initial autism screening tool during an 18 month developmental visit. It combines parent responses with practitioner observation. The first section comprises of a parent questionnaire which elicits concerns relating to the child's pretend play, motor development, social play, protoimperative pointing (pointing to ask for something), protodeclarative pointing (using index finger to point at something of interest), and social interest. The practitioner section consists of five questions asked during a wellness visit, and recorded observations are scored. A child is considered at high risk for developing autism if he/she fails five key items: pretend play, protodeclarative pointing, ability to follow a point (gaze monitoring), and tower block building (Blackwell & Niederhauser, 2003; Nadel & Poss, 2007). The CHAT requires about 5-10 minutes to administer and is relatively easy to use; however, it has also been criticized for its low sensitivity of 38%. The test has also been shown to differentiate ASD from other developmental delays (AAP, 2001).

A similar but Modified Checklist for Autism (M-CHAT) is a 23-item parent questionnaire checklist and has been recently developed as an improved screening instrument for ASD for children aged 18-24 months. It has been reported to show an increased sensitivity of 85%, and specificity of 93% (Robins et al., 2001; Dumont-Mathieu & Fein, 2005). Children are considered at risk for ASD if they fail any 3 of the total 23 items, or two of the six "critical items", which means that related behaviours are most likely to indicate an autism spectrum disorder and the child should be immediately referred for further evaluation by a developmental specialist (Nadel & Poss, 2007 ; Dumont-Mathieu & Fein, 2005; Filipek et al., 1999). It is also

recommended that the tool be used for primary care screening purposes as it takes a relatively short time to administer.

Other commonly used tools include the Pervasive Developmental Disorders Screening Test-II (PDDST-II) which consists of a 22- item questionnaire related to symptoms of a pervasive developmental disorder that is completed by the parent or primary caregiver. It is used for infants from birth to three years of age and a 3-tiered approach is followed in which stage 1 is the focus for the primary care clinic setting. This tool has a reported sensitivity of 92% and specificity of 91%, and it takes approximately 10-15 minutes to administer (Blackwell & Niederhauser, 2003; Johnson & Myers, 2007). The Childhood Autism Spectrum Test (CAST) is a 37-item parental questionnaire with behaviours tested listed in the communication, social interactions, restricted range of interest, unusual or atypical body movements, and adaptive functioning (Johnson & Myers, 2007). It is a screening test developed for primary school age children with 100 % sensitivity, specificity of 97 %, and takes approximately 10 minutes to complete (Williams et al., 2005). The Social Communication Questionnaire (SCQ) is a parent report questionnaire with 40 yes/no items with two forms, one for children younger than 6 and one for children aged 6 years and older. Although the SCQ is a level two screening tool, it can be used for clinical surveillance in primary healthcare settings (Al-Qabandi, Gorter & Rosenbaum, 2011). It can be completed and scored by the primary care provider in less than 15 minutes, and is reported to have a sensitivity of 85% and 75% respectively.

As can be seen from the above, there are several general developmental surveillance and screening tools that can be used for routine screening of developmental delays. However, it has also been reported that these general developmental screening tools are not sensitive enough to differentiate children with ASD from children with other developmental delays, and in addition, their sensitivity in identifying children with ASD has not yet been clearly established (Johnson & Myers, 2007). In addition, none of the screening tools have been shown to have a satisfactorily high sensitivity and high specificity in a wide population screening program, and further research is needed in this regard (Al-Qabandi et al., 2011). Nevertheless, AAP lists several age-specific screening tools in their policy statement that can be used with children who are at risk for ASD (Johnson & Myers, 2007). Despite the presence of practice guidelines on the evaluation methods and tools that should be used for assessments, it has been reported that many primary health care providers are unfamiliar with the recommended practices and do not use standardized techniques to screen for developmental problems (American Academy of Pediatrics, 2001).

The implication of the increasing number of children diagnosed with the disorder, and the specialized tools needed to identify affected children, demonstrates the importance of practitioner knowledge and competence in identifying associated behaviours of the disorder using validated screening instruments. Using one of the mentioned screening instruments, along with other sources of information about the child's development, and administering screening tools at child wellness visits, will increase the likelihood that children with autism spectrum disorders are identified at an early age (Robins et al, 2001). Such early identification can only occur if practitioners understand the core deficit areas of a particular child and administer a validated screening tool which is age appropriate. Adhering to these basic principles will ultimately ensure that practitioners appropriately interact with, and effectively provide, the necessary intervention for the child (Hyman & Johnson, 2012).

Healthcare delivery in Sub-Saharan Africa and South Africa

As the previous section demonstrates, in the relatively more developed countries, education and support for primary healthcare 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 & Johnson, 2012). Asian studies have also demonstrated an interest in research pertaining to primary healthcare professionals working with autism spectrum disorders (Iman, Chaundry, Azeem, Chooudhary & Cheema, 2011; Lakic, 2012; Lian, Ho, Yeo & Ho, 2003). This points to an urgent need to assess the knowledge and awareness of primary health providers in less developed contexts, such as sub-Saharan Africa, in order to put in place appropriate programs with the ultimate aim of helping children with ASD as well as their primary care givers (Ingwe, Bakare, Agomoh, Onyeama & Okonkwo, 2010).

The mode of healthcare delivery in Sub-Saharan Africa is a hierarchical one. 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 (Ingwe et al., 2010). Primary health care providers, specifically nurses in this context, are therefore likely to have the most contact with children coming to public hospitals. This implies that, as prevalence rates of children with autism increase in the Western countries, it is unlikely that nurses in the context of primary care in developing countries will encounter lower numbers of children with autism spectrum disorder, with a disorder that knows no status, colour, or nationality (Springer, van Toorn, Laughton & Kidd, 2013). Despite this, it appears that knowledge and awareness regarding autism and diagnostic screening procedures in

Sub-Saharan African countries remains lower than that in developed countries (De Giacomo & Fombonne, 1998).

Bakare and colleagues (2009) found that nurses working in tertiary health institutions in southern regions of Nigeria scored the lowest on knowledge about childhood autism in domains relating to the symptoms of autism. In assessing their knowledge about autism and factors influencing this knowledge, final year undergraduate medical, nursing and psychology students demonstrated discrepancies in their knowledge may be attributed to variations in their training about autism in their undergraduate program (Ingwe et al., 2010). This trend in differential diagnosis and understanding of the disorder in professionals is supported by earlier international studies (e.g. Vaughan, 2005) which conclude that a lack of knowledge and awareness about autism is a major barrier to improving the health and well-being, as well as the long-term outcomes, of both children affected by autism and their primary caregivers. This ultimately limits access to early interventions that are known to improve quality of life and prognosis in children with autism (Ingwe et al., 2010).

Nadel and Poss (2007) suggest that nurses should be educated to respond appropriately to parental concerns around developmental delays in their children, and should be equipped with the knowledge and skills regarding children with autism. These specialized areas of knowledge and skills should be acquired through formal course work and specialized instruction instead of exclusively through in-service training and self- instruction (Heflin & Alaimo, 2007). The task of medical personnel in providing care can often be a difficult and complex one, particularly when there is inadequate knowledge of the disorder, and the special needs and challenges that accompany it are not known (Hyman & Johnson, 2012).

The public health care delivery system in South Africa is similar to that in other Sub-Saharan countries (Ingwe et al., 2010), which suggests that when it comes to the identification and diagnosis of autism at primary healthcare, nurses have a key role to play. No studies investigating the experiences of nurses working with autism spectrum disorders in primary healthcare in South Africa could be found by this researcher, which is not surprising given the lack of accurate and reliable local data on the prevalence of autism and related issues in South Africa. The Early Autism Project however recognized that children did not receive services and appropriate intervention at an earlier age and established a community based early detection program for Zulu speaking children with ASD between the ages of 18-36 months (Grinker et al. 2012). Findings from this study highlighted some challenges of the 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 HIV/AIDS epidemic.

As discussed earlier, the majority of autism research originates in more developed countries and some of the findings of such studies may not be directly transferable to a South African context. In more 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). For example, Grinker et al. (2012) reported that Zulu speakers asserted little knowledge about meaningful differences in development between children from birth to three and had few expectations about social and intellectual milestones.

As such, parents that are not attuned to the early social and communication milestones and become alarmed only when a child starts preschool and has difficulties engaging with peers may be more concerned about the stigma that the disorder holds and may not disclose their child's early difficulties (Deweerd, 2012; Grinker et al. 2012). 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 as orphans who have multiple caretakers during a single year which limit the opportunities to observe a child's development over time (Grinker et al, 2012).

It is well recognized 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 (Deweerd, 2012). 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). Therefore, recent efforts to develop local capacity through training and research are important starting points to address the challenges of ASD in this country (ADOS, Lord et al.2001; Grinker et al. 2012; Malcolm-Smith, Hoogenhout, Ing, Thomas & de Vries, 2013). More studies focusing on the experiences of parents raising children with ASD would also be useful as this further contributes to our understanding of the disorder and service delivery in South Africa (Mitchel & Holdt, 2014).

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 (Daley & Sigman, 2002). Thus one

could argue that there exists a need to assess the level of knowledge and understand the experiences of South African nurses regarding autism, as they are usually the first professionals families with children with autism contact, and who act as educators for this group of children as well for their primary caregivers. This study aims to investigate and explore the experiences of nursing professionals when working with autism spectrum disorder in a Western Cape primary healthcare clinic.

Motivation for the study

My argument informing the objectives of this study is that it is necessary that individuals working in health care professions with children be aware of the advances in the knowledge about the complex nature, screening and diagnosis of autism. While the number of children diagnosed with autism continues to grow worldwide, it becomes exceedingly important that healthcare professionals have the foundation of knowledge necessary to recognize 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 to do this. Thus the purpose of this study is to investigate and describe the knowledge base and current autism screening practices of nursing professionals and determine the extent of nursing professionals' knowledge of, and familiarity with, these practices.

In addition, the study aims to identify the barriers preventing nursing professionals from carrying out routine and comprehensive developmental screening at key child wellness visits. It is hoped that the findings will assist in identifying what kinds of training, or supplementary training, regarding autism are needed by nursing professionals. In understanding the nature and extent of the knowledge and awareness that nurses possess in this area, the researcher can highlight the complexities and uncertainties faced by nurses in the clinical setting, and how these inform how they care for children affected by autism.

Conclusion

This chapter reviewed international and local literature on the screening and diagnosis of ASD by primary healthcare professionals, noting the world wide lack of adequate training of primary healthcare providers to implement this process timeously in terms of the development milestones of children with ASD. The gap in South African literature on this phenomenon relates directly to the topic of this study in terms of the researcher attempting to fill this gap. Chapter three outlines the research design and methodology used to investigate the extent of the knowledge of nursing professionals about ASD, screening practices and how this knowledge informs and affects their work with children presenting with this neurodevelopment disorder in the clinical setting.

CHAPTER 3

Research methodology

This chapter begins with the aims of the research project and explicates the research question. Thereafter, the theoretical framework within which the research is situated is described. I then explain the qualitative research design, including the sample, data collection and procedure, and the method of data analysis used. This is followed by a section on power and reflexivity. Lastly, I discuss the ethical considerations of this research.

Aim

This project aimed to investigate and generate information about the knowledge and clinical practices of nursing professionals as well as information about the various challenges encountered by nursing professionals when working with autism spectrum disorders. Exploring and acquiring an understanding of nursing professionals' experiences in this area is important as this information has the potential not only to fill a research gap but to inform future intervention programmes aimed at improving the diagnosis and overall care of children with ASD. To date information on these interventions in South Africa is scanty.

Main Research Question: What is the extent of nursing professionals' knowledge and understanding of autism spectrum disorders and how does this inform their work with children presenting with this disorder in the primary health care setting?

Sub-research Questions:

What features or characteristics help nurses recognize a child with autism?

Commonly, what do nurses notice when examining children presenting with atypical development?

What are the difficulties related to developmental disorders and autism that nurses come across in their work?

What autism screening practices do nurses follow?

What referral system(s) do nurses follow when autism is suspected?

Theoretical framework

The theoretical framework of this study is located within an interpretative phenomenology paradigm. According to Padgett (2008), phenomenology attempts to generate knowledge about individuals' experiences and phenomenological research aims to understand and describe participants' experiences of their everyday world as they see it. This approach represents an attempt to explore personal experience and is concerned with an

individual's perceptions and account of an object or event (Padgett, 2008). This particular theoretical underpinning was deemed appropriate for this research project because it emphasises subjective experiences in the course of deriving knowledge about a particular phenomenon (Willig, 2013).

The phenomenological question posed in this current research is: what does the experience of encountering a child with autism spectrum disorders in the clinic mean or involve for nursing professionals? Using this approach, the researcher was able in this study to explore and identify nursing professionals' experiences of their subjective realities within a specific context, and, using this understanding, to develop interpretations of these experiences. A phenomenological framework was particularly useful for providing the researcher with a method and a way of thinking about the research process, thus empathy with which to guide, understand, interpret and analyse the participants' responses around their experiences.

Research design

Qualitative research involves an interpretative, naturalistic approach to the world and to the ways in which people make sense of their world (Denzin & Lincoln, 2011). It is also an approach suited to social research or any research which explores human beings' experiences. This type of research is not aimed at generalizing findings to other groups or populations; but it is rather concerned with the uniqueness of a particular sample. The qualitative research approach used in the current study emphasises in-depth investigation of the experiences and perceptions of a small number of individuals, and the quality of the data, therefore; the objective of the study was not to maximize numbers but to become "saturated" with information on the topic (Padgett, 2008, p. 52). A qualitative design was considered appropriate for the exploratory nature of this study because it allowed for a detailed exploration of the nurses' experiences of their encounters with autism in the clinical setting, and their interpretations and understandings of the disorder within their social context (Babbie & Mouton, 2006).

The model advocated by Cresswell (2012) for a qualitative research design was used in the current study as it acknowledges that rather than a single perspective, there are multiple truths and perspectives. Thus, by interviewing practitioners who are primary healthcare providers for children, the study helped to elicit the experiences and perceptions of these providers about their real life screening practices and their understandings of ASD within their own context. The truth value in qualitative research is obtained from the discovery of human experiences as they are lived and perceived by individuals and is thus subject-oriented, not pre-determined by the researcher (Denzin & Lincoln, 2011). These authors caution that, when exploring social phenomena, there should be minimal prior expectations on the part of the

researcher. Therefore, in order to develop explanations of these phenomena, the researcher attempted to ensure, as far as possible, that she approached the research with no preconceptions concerning the research question and the findings, in line with Denzin and Lincoln (2011).

Validity is the extent to which the data collection and analysis answer the research question, and in qualitative research, participants become active agents in producing such knowledge (Willig, 2013). They are also allowed to give the kind of feedback on their interviews that can show whether the findings have captured their experiences, which in turn ensures both validity and rigour in qualitative work (Denzin & Lincoln, 2011). In this study, a report of the findings was presented to the participants to ensure that their experiences are recognized and to establish whether they considered the findings to be a true reflection of their experiences. This is a strategy particularly relevant to the researcher who has little knowledge of the primary health care system and for whom it would have been easy to form opinions based on her own assumptions and preconceptions.

To further ensure reliability and validity during the research process, the researcher moved back and forth between the design and implementation to ensure congruence among the research question, literature, sampling, data collection strategies and analysis. This prolonged engagement with the research promoted the trustworthiness, credibility and transferability of the project as it helped the researcher to identify when to continue or stop and modify the research process which resulted in producing quality work (Morse, Barrett, Mayan, Olsen & Spier, 2002).

Most studies in the area of autism have relied mainly on quantitative data to document and analyse practitioners and nurses' experiences and a qualitative design was selected as the researcher was seeking a deeper and more comprehensive understanding of particular aspects of working with children with autism in primary healthcare settings. By exploring nursing professionals' knowledge, perceptions and experiences, the study also focused on some of the important dynamics and challenges facing nursing professionals working in the area of autism spectrum disorder. A qualitative method was considered appropriate for such an exploration and analysis, particularly in a South African context, since relatively little is known about the factors influencing autism knowledge and screening practices. Lastly, the researcher considered that this approach would also contribute methodologically to the existing knowledge which has to date, as mentioned, relied mainly on surveys and quantitative data collection methods to explore the topic.

Sample

A sample of ten nursing professionals from two primary healthcare clinics was invited to

participate in this study. Eligibility for participation in the study was that the nurse worked in mother-child services and had interacted with at least one child who exhibited signs of atypical development. This criterion for participation in the study was determined by the need to ensure minimal exposure to children who may have potentially had an autism spectrum disorder diagnosis. The sample size was determined by the number of healthcare professionals accessible to the researcher. The researcher also interviewed a minimum of five nursing professionals per primary care clinic and not more than that. This was an attempt by the researcher to cause minimum disturbance in the daily routine running of the clinics as interviews were in-depth and required time off the nurses' schedules (Babbie & Mouton, 2006). Additionally, it was with the understanding that such a large number would sufficiently account for all aspects of the phenomenon being investigated as this reflects adequate sampling in phenomenological research (Morse, Barrett, Mayan, Olsen & Spier, 2002).

All of the participants had a basic level of competency in English. All the participants could be classified as 'coloured'. Only nurses in public hospitals were included in the study. Interviewing health practitioners from the private health care system would affect the results given the assumed differences in working conditions and resources which was likely to reflect a different set of experiences and challenges.

Participants were recruited through the use of purposive sampling given the circumscribed issue of interest, i.e. ASD and developmental disorders. A purposive sampling strategy is based on the assumption that in order to gain insight into an experience, one has to select participants from whom one can gain the information which is most relevant to the study (De Vos et al., 2011). Nursing professionals were thus identified as being the most helpful because they are the first contact participants to use as an authority to explore and describe the experiences of working with ASD in a primary healthcare setting. As De Vos et al. (2011) state, a good informant is one who has the knowledge and experience the researcher requires and has the ability to reflect and articulate her or his experiences.

Access to participants was gained through contacting the manager of the City Health Clinics in the Western Cape who oversees all research projects conducted in the city's facilities. The manager provided the names of two possible facilities I may conduct the study and the contact details of the managers at each clinic. After explaining my aim to interview nursing professionals who may have worked with children showing atypical development, the managers spoke to the nurses about me. The managers gave me the contact details and availability times of the nursing professionals willing to be interviewed. I contacted these ten nursing professionals and arranged to meet with them at their respective facilities.

Data collection Tool

Data was collected through the use of semi-structured face-to-face interviews. The purpose of this type of interviewing is for the researcher to enter as far as possible the psychological and social world of an interviewee, providing the researcher and participants opportunities to share more and the researcher an opportunity to introduce issues in the course of the interview (Padgett, 2008). According to this process, respondents are regarded as the experiential experts in the relating of their stories and are given the opportunity, space and the assurance of confidentiality to tell their stories (Willig, 2013). According to Padgett (2008), semi structured interviews in phenomenological research also facilitate the development of rapport between interviewer and interviewee, allowing both to venture into new and unforeseen areas while producing rich and meaningful data.

A semi-structured interview schedule (Appendix A) was used to guide the interviews. This provided a guideline for the researcher to think explicitly about what kinds of questions she should or would ask (Babbie & Mouton, 2006). However, the interview schedule merely guided the interview process. The process was not linear or rigidly structured and was adjusted according to each participant's needs and their emerging narratives, to allow for unlimited opportunities for self-expression (De Vos et al., 2011). This type of interviewing positions the participant as an active agent and expert in their experience which therefore validates their knowledge, and is in line with the philosophies of phenomenological research (Gill & Liamputtong, 2009). Although the interview schedule aimed to focus on and answer the research question, it was also designed to explore the complex diagnostic issues that nurses are confronted with, such as the presence of other developmental disorders and intellectual disability that commonly co-occurs with autism. The schedule allowed the interviewer to draw out detailed information and comments from respondents in a relaxed yet semi-structured manner, while maintaining a relatively high degree of flexibility (De Vos et al., 2011).

Procedure

Once having obtained ethical approval from two institutions (University of Cape Town and City of Cape Town), the administration staff and directors of the two clinics were contacted for permission to access and identify nurses for participation in the study. The participants were contacted telephonically to set up appointments. One semi-structured face-to-face interview was conducted with each nursing professional in their offices at a time convenient for them. The familiarity of the place was also likely to contribute to a relaxed and 'natural' atmosphere, enabling open self-expression and engagement with the researcher (Babbie & Mouton, 2006).

The researcher began by introducing herself and explained the nature of the study. An information sheet and informed consent form (Appendix B) was explained and handed to the participant. Once the informed consent form was signed and rapport had been established, the researcher began the interview. The questions asked purposively allowed the participants to reflect on their experiences throughout the interview. Once participants began to understand what the study was about, they offered more information than they had initially done, which helped to facilitate the process (Denzin & Lincoln, 2011). All interviews with participants were recorded by a dictaphone and were conducted in English; which lasted approximately 20-45 minutes. The aim was to cause minimum disruption of their shift work (Cresswell, 2007). However, some of the participants' interviews took up the full 45 minutes as they became more engaged in the process.

Data analysis

The data was analysed using thematic analysis. This is a flexible way of creating meaning from sets of data and allows for thick descriptions to emerge (Braun & Clarke, 2006). Due to the exploratory nature of the research, this approach was considered suitable for this study whose aim is to explore and report on the nurses' experiences with childhood autism spectrum disorder. The researcher followed Braun and Clarke's (2006) guidelines during the analysis process.

The aim of the study, the research question, and the relevant theory determined the methodology of the transcription and interpretation of the interviews. When analysing the interview transcript the interviewee's account becomes the phenomenon with which the researcher engages (Willig, 2013). In qualitative research, the analysis goes beyond what is simply said in the interviews, and thus the meanings attached to the descriptions and accounts by the interviewees during the interviews are explored and analysed beyond what was said, or beyond the surface of the communication. A phenomenological framework positions itself so that the subjectivity of the interviewee is fully acknowledged by the researcher when reading and transcribing the interview. It allows the researcher to look at the different layers of meaning that are presented or suggested in the accounts given by the interviewees, whilst the interviewee's active role in forming and generating these interpretations is acknowledged (Padgett, 2008).

The recorded interviews were transcribed and all identifying data was removed from the transcriptions. Following the transcription process, the researcher read and re-read the transcripts. A standard coding system was developed and the data were coded in a rigorous

fashion in order to generate the initial codes. Interesting extracts from the transcribed interviews were colour-coded which were then grouped together into categories. The relationships between these codes were investigated and thematic connections within and among them were identified in order to produce transcriptions that were organised.

The categories were collated into potential themes, and once the main themes had been identified they were labelled and defined. The themes that gradually emerged were a result of the combined process of becoming intimate with the data, making logical associations with the interview questions, and taking into consideration what had been gleaned from the initial review of the literature (Braun & Clarke, 2006). The themes and sub themes that emerged were grouped into three broad fields of experience resulting in a phenomenological representation of the interviewees' experience. The analysis was interpretative in that it is dependent on the researcher's view of the world (Willig, 2013).

Inductive thematic analysis was used, a process that involves observing themes as they emerge from the data without imposing preconceptions on the process, and allowing for the organisation of themes within the data (Denzin & Lincoln, 2011). Thus, the themes and sub themes that emerged from the field notes, documents and interviews of the current study were not preconceived, assumed or imposed prior to data collection. Additionally, the researcher engaged in a recursive process throughout the analysis which involved constantly moving between the data sets to ensure that themes relevant to the research question were identified.

Reflexivity and Power

In attempting to understand a participants personal world, phenomenological research acknowledges that access to this world depends on, and is complicated by, the researcher's own conceptions, and thus a two-fold interpretation process is involved: "the participants are trying to make sense of their world and the researcher is trying to make sense of the participants trying to make sense of their world" (Padgett, 2008, p. 54). It is imperative that the researcher understands how her role and the inter-subjective elements she carries may impinge on and transform, or distort, the research process; thus the researcher cannot be viewed as an independent or totally objective observer, but should be seen, and throughout the process see herself, as a participant observer (Finlay, 2002). My class, age, occupation and background may have influenced how participants interacted with me and their willingness to share information. This positioning reflects the power dynamics present in the research relationship, together with the broader implications of the study, such as the higher education institution having a stake in the research (Parker, 2005). Thus the letters I provided the nurses informing them of the details of my study, also required that I inform them that I would be representing the University of

Cape Town.

As the University of Cape Town is known to be a leading institution in the dissemination of knowledge, the possibility existed that the nursing professionals would hold the belief that, as the researcher, situated in the Department of Psychology, I would be more 'knowledgeable' in the area of developmental disorders and autism spectrum disorders than they are, or than I in fact am. Although this holds truth in some respects, my work in this field is recent, and my novice undertakings of research in ASDs may very well place me in a different professional location to theirs. The researcher may thus be viewed not only as the expert, having professional knowledge in the area of research (Parker, 2005), but, more importantly, one who can initiate efforts that aim at providing training. As one participant put it:

The purpose of this study, are they [those in charge of knowledge] planning to train us more, and are they going to send somebody to train us more? We would like that because I mean if you do a study there must be a reason for it. Because I mean you want to find out what we know about autism and what we do with a child. (P9)

Another participant, also seeing the potential benefits from the study, asked hopefully:

...if there is training please just let us know. (P4)

This kind of expectation on the part of participants at times caused conflict for me in the role of a researcher. This was mostly resolved by reiterating the aims and scope of the research as well as an honest acknowledgement of my experience in qualitative research and with ASD. In summary, I acknowledge and understand how I may have an influence on the overall research process due both to the differences and similarities between me and the nurses (Parker, 2005), as well as at times identifying sympathetically with their difficulties and expectations.

Ethical considerations

This study followed the guidelines for research with human subjects as outlined by the University of Cape Town. Ethical approval for conducting the study was firstly obtained from the Psychology Department Ethics Committee at the University of Cape Town. Subsequent to this, permission was sought and granted from the City of Cape Town to conduct the study. For the purposes of this study, the following ethical considerations were strictly adhered to:

Informed consent. The research participants were provided with and requested to sign an informed consent form (Appendix B), which provided an accurate description of the nature and aims of the study. The consent form clearly emphasised the voluntary nature of the study, as well as the right of the participants to withdraw from the study at any time without any

consequence for them. Information about how participants' concerns about privacy, anonymity and confidentiality would be addressed was included. Participants were also requested to sign an informed consent form for the interviews to be audio taped.

Privacy, anonymity and confidentiality of data. Although participants' names were known to the researcher, these did not appear on any data records or analysis sheets or results records. All audiotapes of the research interviews were transcribed and coded to ensure anonymity and confidentiality of the participants and their data. The audiotapes were destroyed upon completion of the research project. Pseudonyms will be provided for any subsequent publication of the research results.

Feedback to participants: A copy of the final report will be submitted to the City of Cape Town's Health department within six months of the completion of the study. A written summary of the main findings of the study was also given to the clinics involved in the study.

Potential risks and benefits. There are no known risks to those participating in this study. However, because of the evaluatory nature of the study, participants may have found the interviewing process as fairly anxiety-provoking as issues of competence were directly implied. It was explained to participants that it is hoped that this study will provide a better understanding of their experiences with children with autism spectrum disorder, and that this in turn will lead to improved training for them in this area. The participants were not offered any monetary gains for their participation in the study, as this was purely on a voluntary basis.

Conclusion

This chapter presented the main and sub- research questions, a rationale for, and description of, the qualitative research design and methodology, including the use of interviews as a data collection tool and a description of the thematic data analysis process. The researcher discussed her rationale for constant reflexivity and described how reflexive processes including power dynamics and participants' expectations may have affected the analysis, all of which allows the reader an understanding of the researcher's position within, and with relation to, the research study. The chapter concluded with a description of the procedure involving ethical considerations and approval. Chapter four will present the findings of the data presented in the interviews.

CHAPTER FOUR

Results

This chapter presents the results of the data analysis and interpretation process outlined in Chapter three. The themes and categories that emerged from the data processing were grouped into three over-arching themes/broad fields of primary health care practitioners' experiences with autism, namely: (1) nursing professional's knowledge, understanding and awareness of symptoms, (2) Screening practices of nursing professionals; and (3) identified challenges in screening for autism.

In terms of participants' knowledge, understanding and awareness of symptoms regarding autism, one sub-theme emerged: conceptions regarding the nature and the prevalence of autism. The second theme relates to the nursing professionals' screening practices and relays the third identified challenge in screening for autism. The impact of a lack of adequate medical and continuing training concludes the discussion based on the views of the participants.

Each of the above themes is reported in the following sections and highlighted by direct quotations from participants' interview transcripts, and by an accompanying reflection on the relevant literature.

Nurses' knowledge, understanding and awareness of Symptoms

All of the participants consistently emphasized that social impairments were often the initial symptoms that stood out for them. These include poor eye contact, lack of emotional responsiveness, a lack of friends as well as a lack of awareness of the presence of feelings towards others. This is in line with Dumont- Mathieu and Fein (2005), who point out that such aspects of social behaviour are some of the earliest features of autism:

Yes here it is just basically, children... umm ... like you can talk to them, they don't, (.) you talk to them but they won't look at you. They will do their own thing. (P2)

I think he's got some degree ((of autism)) because there's very little eye contact, there's very little emotional expression on his face, he doesn't like to be around a lot of people, he doesn't want to be hugged and too many people mustn't say "hello" to him you know, or get close to him, from there he becomes very agitated at times, especially when he's not in his familiar surroundings. (P3)

I would say from the experiences that I got here its withdrawal symptoms; the child is withdrawn from friends... umm ... they don't have a lot of friends, always a loner. The child doesn't want to interact with others, doesn't play with other children. (P5)

Although specific behaviours, such as lack of eye contact and relational difficulties mentioned above are common in most children with autism, Nadel and Poss (2007) indicate that these do not occur in every child with autism. The authors argue that children with autism have the potential to build and maintain supportive relationships with parents, caregivers and peers, and that therefore such generalizations have the potential to compromise both the accuracy of information given to parents, and subsequent intervention.

In addition to social interaction difficulties, language development and speech were symptoms which all of the participants were often concerned about.

The child had difficulty in speech, difficulties in saying if they want something for instance; they have difficulties in those things. (P5)

The child is already two and doesn't make any sounds yet or mustn't try to speak words yet and doesn't speak. (P7)

So that's where I picked up some certain things about autism, and they don't talk. I don't know why they don't talk but they don't talk, they will laugh and fiddle, that's what I picked up with the language. (P8)

In describing the social communication difficulties, participants' comments are particularly consistent with research where a complete absence of speech indicates a severe deficit in verbal communication (APA, 2013). The communication and social interactive difficulties reported above in fact constitute a key characteristic of the disorder. However, symptoms, such as the child's socialization skills and communication with peers which lead to a diagnosis, are even more difficult to recognize because they do not become apparent until the child is older (Crown, 2009). It is encouraging to mention that, even at an age when it is difficult to identify atypical development with any accuracy, the participants in this study were still able to differentiate typical and non-typical development in children.

In addition to communication impairments, most of the participants also spoke about the restricted, repetitive patterns of behaviour, interests or activities of the children they were monitoring, an additional marker of autism:

They will do their own thing...um (.) you know they will just or they will go to their tap now because there is something interesting there and they open and close, and open and close, ((demonstrates)) and you can say 'Don't, don't play with the water! Do you want water? I can give you water,' you know, but they will just do that all the time. For a long time, it's like it sort of intrigues you now, and um (.) behaviours (.) it's like routine to you, when you must like have certain routine, you just don't do things, if you don't do it at a certain time then it's like it throws everything out in your mind, you know that type of thing. (P2)

They look all over and like something that will distract them, like (.) maybe a bright colour, so they will just be focused on that and not really to what you are saying. The child just screams when he is not in his surroundings. (P6)

They are very scared of being touched, they are scared of sudden movements, to turn them to put them on a scale then they are suddenly jumpy. Or the child doesn't respond to anything; you give them an injection then they just sit there, they don't respond to pain. Some of them make jerky movements, some of them do...what do you call it, when you do something over and over again (...) yes stereotypical, they bump their heads the whole time or they shake the whole time. (P7)

Most of the respondents also reported characteristics not specific to autism but that commonly co-exist with the disorder, such as hyper-activity, attention problems and socially inappropriate behaviour, such aggressiveness and soiling:

An autism child is a child you can pick up in the clinic, a child who cannot sit still, shouts in the corner; a disruptive child who breaks things, and throws things. (P1)

He is not focusing; He is not paying attention because he just goes off into his own world. Also...umm (.) bedwetting and... um (.)... um (.)... she soils himself, we couldn't

understand because I mean, why can't he say he wants to go to the toilet. So he just stands there and soils himself, so that's something that is really odd to see. (P2)

They are always like that, aggressiveness in their world, they fiddle here, they fiddle there, they don't concentrate....they are very hyperactive and so they can't sit still in one place. They eat things that we don't eat, like faeces and things like that, or they will spit on your face and think its normal and laugh. (P8)

The above findings reflecting a considerable knowledge of early symptoms of ASD shown by participants however contradict findings of two studies. Samms-Vaughan and Frank-Banton (2008) found that health professionals in their study lacked knowledge and understanding of the early indicators of autism while a study conducted in the southern regions of Nigeria found that nurses scored lowest on symptom knowledge about autism in comparison to other domains.

While participants were able to correctly point out some early indicators of ASD, only a few also reported that the outward 'normal' appearance of a child with autism often left them feeling confused and uncertain, indicating that the children's early behavioural difficulties and developmental delays are difficult to process when a child does not appear on the surface to have any abnormalities:

There was one child specifically, it was a normal looking child but the behaviour is (...) the child is withdrawn, didn't speak much, but the behaviour was like, it's not normal for that child. A boy, but normal looking, just sitting there watching television and all of a sudden it's like he is fiddling with the hands, (.) you know, screaming, but it's not all the times, its episodes.(P9)

A recent study found that health practitioners feelings of confusion and helplessness in the process of trying to make sense of children's presentations of the disorder, was similar to what mothers reported. This 'normal' appearance of a child with autism, and the complete absence of any visible features suggesting the presence of a developmental disorder, which tend to confuse practitioners, extends to other research. Midence and O'Neill (1999) found that mothers report feeling confused by their children's early behavioural difficulties and developmental delays in the context of their normal appearance, and that this contributed to parents deciding to contact health professionals in a search for answers:

Sometimes if the mother will tell you it's a sudden (.) when it's a sudden occurrence,(.) like the child is all of a sudden very quiet or all of a sudden hyperactive then I query if its autism or it's a psychological problem or something that happened to the child, maybe abuse or something. (P7)

Like if the mother says the school says the child is not progressing or whatever, then I will think maybe it's a psychological problem or something or (.) then it's not it's like autism. (P6)

The above comments support the fact that when participants are anxious and unable to provide answers for themselves and parents, they use other explanations that could account for the children's developmental delays. This kind of response could be seen as positive in the sense that nurses seem to consider other diagnostic possibilities, which is important in the diagnostic process, especially in relation to sudden changes in behaviour.

Conceptions regarding the nature and the prevalence of autism. In addition to their knowledge and experience of the features of ASDs, and the complexities associated with its detection, only a few participants also exhibited some beliefs about autism that are consistent with current research indicating ASD to be a neurological disorder and a familial incidence and related psychiatric disorders. This is evident from one participant's response:

I think her mother also had some psychiatric problems, you know those that go deep, depression and then stuff like that, you know so I think there could be a connection there because of that history. (P2)

In the 1950s and 60s, parents' emotional reactions to their children and atypical social and emotional functioning of children including poor attachment and lack of reciprocity in social interactions were thought to be the cause of the symptoms of autism (Burkhardt, 2001). However, current research indicates that there is no known cause of the disorder but rather, there is a familial incidence of ASD as well as related psychiatric disorders. In fact, in one South African study, eight percent of children with ASD had a sibling with the disorder and there was a 24.1 % family history of psychiatric illness and learning disabilities (Springer, van Toorn, Laughton & Kidd, 2013). It is however important to note that some nurses also recognized ASD as a neuro-developmental disability resulting from organic and genetic factors which is in line with current

research:

I know autism is neurological; development and behaviour is affected... um... yah that's all of it. (P4)

According to my knowledge it's a neurological problem that the child experiences; growth is affected, learning is affected and speech is affected. (P9)

Although children with autism are challenged with learning difficulties and behaviour problems, movies such as *Rain Man* have contributed to the stereotyping of these children and the resulting stigma and discrimination, by portraying them as loners and gifted in mathematical calculations, music and art. This was evidenced in only a few of the participants' descriptions.

They are interested in the things they want to do; they are all over the room and so on but they are very intelligent in certain ways. (P8)

....and also the children they say are very intelligent apparently. (P5)

The above statements speak to how children with autism are being sensationally and stereotypically portrayed by the popular media, while in reality, the majority of affected children struggle with learning and behaviour problems. While only a few of the participants' comments point to such negative beliefs regarding the disorder, autism has serious implications for the affected child and the family (Altiere & von Kluge, 2009).

In relation to recognition of symptom, although current research findings indicate that autism can be formally diagnosed as early as 18 months of age (Filipek et al., 2000), all of the participants indicated not being able to do so:

But if we could pick it up how could you pick it up? How do you pick it up early? Can you see it? Can you? I only saw the children when they are five or three, but how can you see when it's a baby? Can you pick it up? (P6)

That one I can pick up, but that you can only pick up when the child is like three to four years old, but if it's a baby like two years, you won't pick that up very easily. Even when they are 5 years that is when you can pick up very quickly, but for children twelve

months to a year cause you spend only that amount of time with the child, 10-15min, so for a child under two years it will take a bit (..) say under a year, you won't pick it up, but when they are active and running around then there are certain things that you need to be alert of. (P8)

All of the participants appeared to struggle to understand the age at which autism can be detected as well as how autism may present during infancy or in the early months of a child's life. It appears that they are not familiar with the age at which autism can be recognized and unaware that symptoms of autism can be detected before the ages 3 – 5 years. The above extracts indicate that, among the reasons for this difficulty, is the minimal amount of time participants spend with the very young child, as well as poor manifestations of interpersonally salient features of the disorder and related behaviours such as excessive or lack of motor activity. In addition all of the participants indicated a lack of knowledge about appropriate effective interventions for children with autism:

Because if you detect earlier then I don't know, I don't know much about what is the (...) what will early detection do? (P8)

But what kind of intervention is there for them? (P7)

The above statements indicate that nurses are unaware of the possibilities for ameliorating the negative effects of ASD (Heidgerken et al., 2005), and it is unlikely that they will be able to recommend effective interventions for families of children with autism. This is congruent with an online survey of parents of children with ASD conducted in the US by Rhoades et al., (2007) which found that only a minority of healthcare professionals were able to provide current or relevant information to families of children with autism regarding available evidence-based interventions.

Heidgerken et al. (2005) suggest that the inability of primary health care providers to give further information on intervention options may be explained by their professional training, and all the participants in this study articulated this when asked about their training, in relation to autism:

Umm (.) you know I think we did it in our psychiatric training when we did psychiatric nursing. It was very short according to me, (.) they didn't go in depth, and you had to learn the definition of it most probably, so we were not exposed to it during our training. (P7)

Ah ah, [shaking head] maybe developmental disorders but not so a lot. Like I said what I know is what I read out of books and especially that movie, "Rain Man". (P6)

No, not specifically, those are the kinds of what we do when we are to (.) think specialize in that nursing but nothing pertaining to children especially to autistic children. (P3)

The indication given by participants that autism was not covered during their medical training, or only superficially, echoes findings from other African countries such as Nigeria, where final year undergraduate nursing students reported shared similar experiences (Ingwe et al., 2010).

In light of the above findings relating to conceptions and lack of knowledge about early detection and treatment interventions for autism, it is evident that, although the nursing professionals in this study were knowledgeable around symptom domains of with autism, they were also confused by some aspects of the disorder.

Screening Practices

Developmental screening is intended to identify young children who may need more comprehensive evaluations and the AAP (2001) recommend the standard screening of all infants and children for developmental delays or disabilities. Screening surveillance includes taking a full developmental history, doing accurate and systematic observations of the child, identifying the presence of risk and protective factors as well as documenting the process and findings (Barton, Dumont-Mathieu & Fein, 2012). Some of the participants in this study indicated that they conduct regular screening of young children:

We do developmental screening like I said on newborns, at 9 months, and at 18 month, and then we will see, but normally we generally pick up on developmental (.) umm abnormal development yeah. So if you find that there's a child that doesn't conform to those, we have a tool that we work according to, and if there's anything out of the ordinary we would normally (.) look we will assess. (P3)

Developmental we will only zoom in when it's the 9 months and 18 months. (P7)

It's just a tick sheet you and the mother with a child; it's a tick sheet at the end of the tick sheet you diagnosis. So you just ask a lot of questions. (P10)

These responses clearly reflect awareness of screening for autism as well as a mention of

a tool available to guide this process. Consistent with Robins (2008), participants point out three key child wellness visits when developmental screening should occur: 9, 18, and 24-30 months. Furthermore, it is likely that when nurses make referrals to neuro-developmental clinics based only on a list of developmental milestones, screening may be compromised. This could possibly be attributable to a lack of awareness and scarce resources for specialised screening tools in South Africa which are often readily available in first world countries. The AAP (2001) has suggested a two level approach for the screening and diagnosis of autism which countries such as South Africa could directly apply.

As described in Chapter two, at the first level nurses could conduct a more general developmental screening for atypical development as part of routine well-child care and then follow this with an ASD specific screening (Pinto, Sounders, Guarelli & Levy, 2005). For children showing evidence of abnormalities, a formal diagnostic evaluation by an experienced clinician is warranted after a screening (Filipek et al., 2000). In the case of participants in this study, there is one referral hospital that can be used at the second level for the screening and diagnosis of autism. All of the participants however showed a sense of helplessness and low levels of confidence in conducting initial screening and identifying autism. This speaks to participants' belief in their lack of ability and willingness to taking on screening as part of their job, and they suggested that there are other specialists who can do that kind of work:

I don't feel that I can make an assessment; you pick up something yes, but you know you say this is what I think or whatever, because I know it takes years this, to actually come up with your final conclusion. (P2)

There's nothing that we can do here at the clinics, so we normally refer to the secondary hospital. We don't see the child enough to make a proper diagnosis [possible confusing with "screening"] and we are not trained to diagnose children with autism. (P7)

There's no use in me to decide here; there's other people that can resolve the problem. (P8)

Participants often commented that they felt they cannot make a diagnosis and that there are other health professionals more suited to drawing such conclusions. Although this perception cannot be dismissed, it should however be noted that, in most cases, participants referred to the term 'diagnosis' as both screening and diagnosing. Nurses may have been confused about the distinction between the two terms, or processes, or it is possible that

participants do not know the differences between the process of screening and diagnosis, and as a result, may find it difficult to ascertain their role in screening for autism spectrum disorders. Participants' lack of acknowledgement of their involvement in the screening process potentially compromises both the possibilities of early identification and subsequent early intervention options which have been shown to have significant outcomes (Pinto-Martin, Dunkle, Earls, Fliedner & Landes, 2005).

The importance of mothers' reports. Regarding diagnosis of autism, participants highlighted the key role that parents play in initiating this process, as they often rely on them to provide information about the child's development, and concerns they may have in this regard. Respondents reported that they only query autism and perform routine screening once parents explicitly indicate abnormalities in the child's development. Most of the participants intimated however that they did not elicit such information on their part:

Sometimes you just concentrate on the main aspect why the mum was here today and if it's a fever you treat the fever. And sometimes if they come up with problems such as behavioural, or when they have been referred to us, then we will ask. (P4)

It's only when the mother comes in with the child you know, we can only take the history by the mother and she says okay my child presents with this and that. (P9)

Maybe the others slip through the cracks because we didn't pick it up; it's only because if the mother comes and the mother actually tells you, otherwise maybe children could just slip through. That's why I told you from the beginning that if the mother doesn't tell me, really, I won't pick it up. The mother must tell me and yes if she does tell me then I will. (P6)

The above statements contradict the literature, which suggests that, while the majority of families correctly identify that their child has a developmental delay, some parents will not express these concerns unless specifically asked by the healthcare professional (Pinto-Martin et al., 2005; Osbourne & Reed, 2007). Additionally, respondents' reported avoidance of directly asking parents about their child's development raises a significant issue regarding the silence and stigma surrounding developmental and intellectual disorders.

A possible explanation for this tendency of professionals to wait for parents to initiate any discussion of developmental concerns may be because of the reported studies of parents

who often notice early abnormalities in their child's development and sometimes well before health professionals (Filipek et al., 2000; Adhern, 2000; Glascoe, 1998). Studies report that parents' early concerns often include speech, language, pointing and awareness, rituals, eye contact and behaviour problems, a finding which is similar to that of this study in terms of the early markers of autism that participants in this study mentioned (Gray, 2002). However, there were some concerns regarding the time parents sometimes take to report such abnormalities. Most of the participants indicated that parents with school going children should be more vocal about their child's developmental concerns and bring these to the practitioner's attention:

The problems that we do have is that the parents actually wait very long before they bring the children to the clinic and make us aware of [developmental problems], especially speech problems. They bring the kids to the clinic a couple of months before they're to start school and then that's a problem for us because speech problem is not something that's sorted out in a few months; it takes a lot of therapy and lots of time so we are encouraging mothers to bring their children to the clinic if there's anything.
(P3)

In most cases we pick them up when they are in school already, or when they start attending crèche. When the teachers will tell the mum (.) there is something wrong with the child. The child is not communicating properly or the child is not behaving properly when compared to other children. And the mummy would say that she thought that it is normal for the child to be like that. And we usually we get them when they are a little bit older. (P10)

A few of the participants discussed the fact that children are often brought to the clinic when they are of school going age and had been referred by teachers and school nurses. Concerns regarding speech and language development became obvious to the educators as there was a marked distinction between the developmental progress of the child and their peers (Osbourne & Reed, 2008). The above responses directly reflect a felt frustration on the part of these participants in terms of the impact of speech problems on a child's education, a somewhat contradictory response as one would expect that if nurses do experience such feelings they would be proactive in their inquiries into a child's development. These comments also point to the fact that in the South African context, when difficulties with speech and relating with peers become more pronounced; parents and teachers are more alarmed as what really concerns them may be the fact that the child does not fit in with others and there may be

stigma associated with such developmental delays (Grinker et al., 2012; Deweerdt, 2012). Additionally, relying on parental reports regarding developmental progress raised concerns to some participants:

But maybe parents also didn't pick that up or they think it is normal for my child to be like this (P9) and

Sometimes they don't know themselves what the child should be doing at a certain age. (P4)

Some of the participants displayed conflicts around accepting parental feedback as a source of information and other ways in which inquiry may be made. Some nurses mentioned that their personal experiences with autism influenced their interest in the disorder and thus, when screening, they were more alert to developmental delays that suggest autism. Their screening practices involved using past experiences of interacting with children with autism in their practice:

So what I do now (.) is just to go according to my prior knowledge because I have been a midwife, that was a very long time ago, but you pick up on skills and you can ask so and so. (P2)

As I say (.) the thing is it's very interesting, and for me I (.) like find it very interesting and once I said I would like to work with children like that. So the thing is this (.) as I say with the child that my brother's wife looks after, I could pick it up because I find it interesting maybe that's why I could pick it up (.) because I have an interest in it. (P6)

(..) because this is very interesting, but you know it's just a pity the lack of knowledge on our side, it's just a pity. Because of my experience that I had (.) you know, because that child was different and it was quite a few years ago, and it's still fresh in my mind. (P9)

The above participants reported their personal experiences of working with children with autism outside and within the clinic setting as having initiated an interest in the disorder and which assisted them in being alert to behaviours which suggested atypical development amongst children they see on a daily basis.

It is evident that the implementation of formal screening procedures was uncommon

amongst participants regardless of the diagnostic value they present. Despite practitioner awareness regarding the prevalence and severity of ASD, as well as their acknowledgement of their role in detection of ASDs, participants' screening efforts remain poor. Instead, in line with the research, participants were resorting to informal screening methods which largely relied on the mother volunteering information about their child's development as well as the practitioner's use of past experiences. As has been discussed, this presents challenges in terms of parents' help-seeking behaviours, scarce resources and the impact of a lack of education prevalent in the context in which the participants in this study work.

Identified challenges in screening for ASD

In addition to the above mentioned difficulties, nurses' experiences in the screening for ASD, multiple systemic problems also contribute to poor compliance and detection of ASD. The referral procedure was reported to be challenging. Four major barriers were identified which affect participants' willingness to screen children with autism during their wellness visits: 1) only one hospital for referral, 2) lack of communication between primary and secondary level systems, 3) time constraints and other priority areas, and 4) lack of training and in-service training opportunities for primary healthcare practitioners.

Inadequate service provision. All of the participants provided some insight into their dissatisfaction with the supply of appropriate services available for children with autism with particular reference to referral hospitals. It has been mentioned that there is only one hospital available in the Western Cape which can take their referrals:

At the moment, we can only refer to [name of hospital], and there's only one [name of hospital] so how many people see children you know. Just make the time, the waiting time for the patient a bit shorter. (P3)

So umm referral it's a bit difficult because you don't always know where you must refer to. Mostly we refer to [name of hospital] but like I once asked the sister (.) the psychology sister here if we can send the children to them and then she said no rather send the child to [name of hospital] but then it's going to take months because they have such a lot of children to see. So it's very difficult especially for mothers. (P6)

All participants reported this as a major area of concern as they have found that children have to wait for long periods to get a diagnosis from the hospital. Because of the demand and high

numbers of children that utilise the services of this hospital, there is an enormous backlog of waiting lists of children in need of help. They find themselves having to endure long waits for their referrals to be attended to.

Lack of communication between primary and secondary systems. Most of the participants indicated that identified at risk children are referred to tertiary systems such as the local main children's hospital they consult with. As recommended by research, professionals should refer children to practitioners experienced in the diagnosis of ASD such as a neuro developmental paediatrician, child neurologist, developmental/behavioural paediatrician or other ASD specialists when further evaluation is needed (Nadel & Poss, 2007). Although participants report utilizing such referral systems, they expressed dissatisfaction with the lack of communication between the two systems. They mention that little feedback is received from the referral hospital regarding the children that they have identified as requiring further assessment. All of the participants describe this process as confusing and lacking coherence and state that this is often frustrating for both themselves and parents:

Like I said we would refer those children to [name of hospital] but we don't have a very good system where we can get report backs from those children so if they are found to have autism or some degree of autism or autistic, then those people would be with [name of hospital]; the clinic is kind of not in the picture anymore. (P3)

The thing is our problem that we cannot get any feedback. And now that we don't get feedback and I just think okay then maybe the child has a psychological problem or what. I will think maybe it's a psychological problem or something or then it's not autism. You see because we don't get feedback so we don't know if our suspicion is right or whatever, so it's very difficult. (P6)

That is the problem because when we refer them there we won't see them again, mostly we don't see them again, so we are not sure whether the child was diagnosed, was it helpful or anything like that. (P7)

A view articulated by the majority of respondents was that communication between the two systems could be made easier if referral hospitals provided feedback. Participants mention that feedback would be helpful in confirming whether their suspicions or preliminary diagnoses were accurate or not. They believed that feedback would be beneficial for their clinical work as

such information could inform future encounters with autistic children:

....Because that is also a learning curve for us then, you know. We refer this child, they tell us what exactly they found also what treatment they recommend and things like that, or they have commenced a certain treatment. So that we know (.) and for future we know what to expect from the next child, or what to do with the next child. Umm (.) most definitely we would benefit from feedback. (P10)

....Even if they just send us a letter with the mother to say this child was screened for this and this, and this and this is fine. So we see that we don't send unnecessary referrals also for future reference and for them also because otherwise we are going to send everybody there with more or less the same symptoms. (P7)

Participants also shared their sentiments regarding the length of time it takes to obtain a diagnosis. The duration of the diagnostic process was a major concern, with many participants expressing concern that this was slow and involved long waiting periods:

The problem I have here is the time spend that we get from the time that we actually make the appointment to the time that the person actually goes, it's a couple of months. It's a long time if the mother is really anxious wanting to know what's wrong with the child; it's very a very long time for them to just sit and wait for two to three months before they get an appointment and with the first few appointments nothing will definitely sort of come out and the mother will still be hanging. (P3)

Mostly we refer to [name of hospital] but then it's going to take months because they have such a lot of children to see. So it's very difficult, especially for mothers with problem children. (P6)

We try to make appointments at [name of hospital] for example at [referral hospital] but you wait so long for an appointment and you have to motivate; if you don't motivate you make your life difficult, so the more you motivate or even lie to get a sooner appointment which I think is grossly unfair. (P1)

All of the participants shared their concerns with regard to the waiting period between their referral to the hospital and the actual diagnosis. They reported that children are often

placed on long waiting lists and shared their insights on how this may negatively affect the intervention outcomes and affect their families as they remain in limbo not knowing how to meet the child's needs. The situation is not unusual as the steps following referral are known to be challenging for both professionals and parents because specialized diagnostic services can be difficult to access and often involves long waits (Barton et al., 2012).

In addition, participants experienced the referral process as confusing and frustrating as there is no defined process for feedback from the referral hospital. The need for a less complicated and more straightforward service system was stressed by some of the participants:

What would be helpful is if there is a tract [tracking system] put in place; if I encounter a child where I suspect that the child may be autistic, you know I refer the child to this place and the child would be sorted right there. (P3)

We would refer those children to [name of hospital], but we don't have a very good system where we can get 'report backs' from those children so if they are found to have autism or some degree of autism or, then those people would be with Red Cross the clinic is kind of not in the picture anymore. (P3)

Similar to Osbourne and Reeds' (2008) study on parents' experiences of communication, participants felt that little communication occurred between helping professionals involved in the diagnostic process. Osbourne and Reed (2008) suggest that improving communication between health care professionals results in the development of stronger professional links that can facilitate the help and support that children with autism and their families could access. For example, ideally the specific diagnosis of ASD is primarily made by child neurologists but other specialists, such as speech therapists, occupational therapists and psychologists are often involved in the provision of care and management of affected children (Moh & Magiati, 2012). As such, a more integrated system could enhance the communication between the different professionals and the needs of children with autism, as well as those of their primary caregivers, can be adequately and timeously met.

Time restraints. The barriers related to screening for autism that the participants reported are consistent with other research findings (e.g. Hix-Small et al., 2007). Nursing professionals indicate that time pressures as well as multiple priority issues are barriers to their efforts for early detection of autism. As with other studies, participants frequently cited insufficient time to conduct developmental screening as a major problem (Hix-Small et al., 2007). Time constraints are associated with other illnesses taking precedence over a screening

of autism as well as with a lack of time to take a proper developmental history of the child. This was explained by participants in terms of the daily caseloads that they are expected to handle. In addition, all of the participants experienced time pressures as a result of the fact that often mothers bringing in their children have pre-established the purpose of the consultation:

You know like with all of the developmental things you pick up so now you just basically got to focus on this one thing that she came with, a sore throat or she's been coughing or she's got a fever because that then is almost like the other things will be less important because you've got a cover, you've got to rush now because the children must be seen you know because there is a huge target that you've got to reach, do you understand? (P2)

We are short staffed also, sometimes you just concentrate on the main aspect why the mum was here today and if it's a fever you treat the fever. (P4)

When we see the child, they come for the problem they come for, so we don't have time to check for all those other stuff; we don't even ask the mothers most of the times; even if the mother is not complaining it can go past us because our main priority is we go directly to the problem they are coming for. (P7)

All of the participants indicated that illnesses such as coughs, pneumonia or physical deformities take precedence over developmental screening as their main concern is curative work. Nurses are required to work according to a tight schedule given the number of children they are required to see on a normal day. As a result often they are under a great deal of pressure. Anything over and above the routine physical examination they are required to perform is seen as a burden:

We supposed to spend ... um... about eleven and a half minutes with child if they want, if they want us to do it like that because that means we've got to see the whole child, the condition the reason why they came and then you still need to look at other things too, because you can't just do it without noticing perhaps that maybe the child is, is three years old and still with a dummy... you know what I mean. (P2)

It's really hectic, that's why the thing is we cannot pick things up because it's like this child comes in, one two three, we must how many minutes with this child out, in comes the next child. You cannot really observe like as I say because it's just in and out very quickly, cause they want us to...the clinic is really about how many children do you see, you see per

day. So you really can't be very observant; like I said its in and out quickly, that's why I say how many children don't slip through our fingers, stuff that we don't pick up because it's so busy, because I say okay I need to see this child. Because the stack of folders, look at these folders of all these children that I have to see; so it's just in and out quickly. So you really can't make are, good observation really good observation. (P6)

Yes that is the problem also with the clinic because we see a lot of children at one time. We are only allowed, not allowed but we don't have the child long enough to make a proper even a diagnosis. Or to see because for the longest we must have the child is 15 minutes because when we see the child, they come for the problem they come for so we don't have time to check for all those other stuff we don't even ask the mothers most of the times; even if the mother is not complaining it can go past us because our main priority is we go directly to the problem they are coming for, but it is not supposed to be like that. You are supposed to see the child holistically every time but time is a big problem at the clinics. We don't have time. (P7)

All of the participants spoke of priority areas when they pointed out when and where their caring responsibility as primary healthcare providers at a public healthcare clinic ended, and expressed a desire for clarity on where the responsibility lies amongst and in relation to mental health care professionals:

If I am not sure I will refer because I am a sister you see, and I do specialise in certain things; there's other people that specialise specifically in that. So there's no use in me to decide here; there's other people that can resolve the problem. (P8)

This could be understood as participants considering that it is not their responsibility to work with autism beyond a certain point. Participants thus sought to shift this responsibility to those whom they believed had the time and the necessary qualifications. In terms of qualifications and speciality, participants believed tertiary level institutions have a number of professionals that are more capable of identifying autism spectrum disorders. Given that mental health is outside their scope of practice, healthcare practitioners may experience a sense of inadequacy and consequently pass responsibility onto those they believe to be more competent. However, one could argue that this feeling of inadequacy is likely to fall away with more specialised mental health training since participants felt that currently they did not have

sufficient knowledge regarding diagnosis and management of the disorder. This situation potentially has implications for South African medical training and program restructuring given ASD's prevalence in society.

Lack of training; medical training and continuing training. Although nurses play a vital role in the assessment and screening of the characteristic features used in the diagnosis of ASD (i.e. social deficits, communication deficits, and the use of stereotypic, repetitive behaviours), the participants in this study indicated that their tertiary training did not prepare them to address the needs of children with ASD. Participants' reports are consistent with the findings of Self, Coufal and Parham (2010) where more than half of the health professionals had received inadequate training regarding the characteristics of autism and autism-specific screening procedures during their undergraduate training, with some stating that autism was never covered in their pre-professional training. The responses indicating training with minimal exposure to autism were divided into two. Some participants described having received a basic and short introduction to autism during their training as professional nurses, and they found content of this difficult to remember:

It wasn't like, how can I explain it; we didn't go much in depth, it was just a short introduction. (P4)

Umm ... you know I think we did it in our psychiatric training when we did psychiatric nursing. Very short, you had to learn. According to me they didn't go in depth, you had to learn the definition of it most probably, so we were not exposed much during our training. (P7)

We have basic training in psychiatry; we don't have that advanced training to do assessments on children; we just do our basic thing. (P10)

These participants considered that they had received insufficient training with regards to autism, and thus they did not consider themselves knowledgeable in the area. It appeared that participants' pre-professional training did not include a detailed section on autism and thus the nurses expressed some anxieties in conducting screening for autism. Without adequate training, or no training at all, participants felt that they were unable to meet the particular needs of children with autism and indicated a lack of knowledge and skills to work with these children.

Secondly, information was obtained by some of the participants themselves, usually

from libraries, documentaries or the Internet:

It's basically what books are saying and what I've heard. It's basically what I've heard; it's not what I've dealt with, it's what I've heard and what I've seen on television and newspapers. (P1)

I don't know much about autism but the things that you read okay in magazines you see okay...and like what's the movies name...you know that movie...Rain Man, it was very interesting. (P6)

Given the substantial literature and media surge on the positive effects of early identification of children with ASD, it is encouraging that participants indicated that they are busy gaining knowledge regarding ASD from multiple sources. This is important as it ascertains in what other capacity, or via which channels, practitioners are acquiring this knowledge so these efforts can be strengthened and sustained. However, overall, respondents indicated that those of their current knowledge and skills that are relevant to autism spectrum disorders limit their ability to play an effective or central role in recognition and screening. As a result of this they felt helplessness, a situation echoed in the study of Osbourne and Reed (2008), and all of the participants requested more extensive and in-depth professional training in screening for, and treatment of, ASD, in particular, in terms of what signs and symptoms to look out for:

Maybe if they can give us more signs and symptoms that we must look out for, yah that would be nice. (P5)

So I mean we are here to help but we are not helping really because we don't know what to do; we don't know what to look out for. (P6)

On the developmental screening we do six weeks, fourteen weeks all that; there should be tools like this stating out the signs and symptoms of autism. (P9)

The length of the participating nurses' field experience varied between 3 and 15 years, during which time they had all been working within the primary healthcare system. Interestingly, there were inconsistencies in terms of participants' pre-professional training and the levels of knowledge of ASD. Respondents with more working experience indicated that they considered themselves to have lower levels of knowledge regarding the disorder than did those nurses with shorter periods of working experience. One could argue that this is not surprising given the relatively recent emphasis on the awareness and prevalence of autism, and therefore there may

not have been any opportunities available for training in ASD specific screening procedures during their tertiary education (Bakare et al., 2009). However, for respondents with shorter periods of working experience, this is somewhat worrisome as it would be expected that this would be an advantage and there would have been more emphasis on ASD in more training programs. This contradicts the findings of Self et al. (2010) whose study showed that those professionals with a relatively greater number of years in the field were likely to have received training on ASDs.

Some responses of participants highlighted this need for more comprehensive training in ASD, participants frequently asking whether there would be any training offered as an outcome of the current study, and indicated a preference of one day workshops and seminars in conjunction with clinical exposure, to be held outside the clinic setting. One participant expressed this desire:

If they could give us maybe one day, come for two hours or whatever, three hours or so, just to give us the basics that you should know. (P5)

The above findings have shown that, although barriers to developmental screening in primary care are many and significant, the participants in this study showed themselves to be willing to engage in training efforts if made available. Thus, it appears that the nurses who participated in this study would be willing to receiving in service training on ASD and screening practices.

In summary, it is clearly evident from the findings of this and other studies that there are multiple perspectives regarding screening for ASD. The most common barriers included limited time and work pressure, the lack of training, and limited professional responsibility. Work pressure as a result of the limited time and short appointment duration negatively militated against the likelihood of screening occurring in the public health clinical setting. These perspectives, and the screening barriers that ensue, result in a complex interplay of factors impacting on the early and accurate detection of ASD, often resulting in missed opportunities to screen, and thus to treat, ASD (Self et al., 2010).

Chapter five follows with a detailed discussion of the results and conclusion to the thesis.

CHAPTER FIVE

Discussion and Conclusion

The following discussion reinstates the main findings of the study and how they relate to the broader autism spectrum disorder literature. A more detailed discussion commenting on the findings and their implications and the limitations of the study ensue. The researcher concludes by presenting recommendations for improving the early detection of ASD and directions for future research.

The level of knowledge of early symptoms of autism spectrum disorders shown by the participants in this study contradicted the findings of studies on health professionals in this area. It is therefore commendable and heartening that, in comparison with the respondents of these studies, the respondents in the current study showed considerable familiarity with the earliest manifestation features of ASD, specifically around communication, language, speech and social behaviours. As suggested by Johnson and Meyers (2007), these are areas that should be carefully monitored by health professionals through assessing the developmental milestones appropriate for specific ages during regular check-ups for children.

The participants' descriptions of other disorders that they have often seen to co-exist with autism have been well documented by studies that focused on co-morbidity of the disorder (Daley & Sigman, 2002; Bryson et al., 2003). One possible explanation for the saliency of these characteristics is that they manifest explicitly in interpersonal spaces such as the clinic, and therefore it is likely that in those contexts participants comment on the more peculiar characteristics associated with the disorder but not necessarily the established key markers of the disorder itself. However, although displays of the disorder through such behaviours may occur in some children, these may not be exclusively used to identify children with disorders (Daley & Sigman, 2002). It is also important to note that such anecdotal descriptions were provided by each participant when presenting recollections of what stood out for them the most when examining these children; thus this could be said to explain the impact that such behaviours had on the participants in a social setting context.

Given the high rates of abuse in the general socio-economic context in which the participants work, this is encouraging as it indicates that nurses show some psychological knowledge and sensitivity about such issues, as shown in their thinking. However, such statements are also indicative of the potential of nurses for misleading parents about their child's disorder when they are presented with questions regarding a child's prognosis (Ahern,

2000). Primary healthcare providers' tendency to provide incorrect information and to dismiss the early indicators of autism has been corroborated in other studies (e.g. Boushey, 2001; Carbone et al., 2009; Keenan et al., 2010; Roth, 2001). Concern has been expressed in terms of cautioning health professionals against this kind of response, as misinforming parents who may hold unreasonable expectations regarding the true abilities of their child, which in turn may cause delays in accessing early intervention options, which greatly compromises the significant gains that can be achieved for ASD children diagnosed at a young age due to the plasticity of the brain (Van Tongerloo et al., 2012).

Similar to the findings of the study done by Shah (2000) on medical students' levels of knowledge in this area, participants in this study were unable to correctly identify the treatment options most likely to be effective for children with autism. It could be argued that providers may not see any real or immediate benefit to performing routine developmental screenings if they are unaware of the benefits of early detection and subsequent prompt intervention. This situation is problematic, and should be of serious concern as a lack of knowledge around symptoms and appropriate, timely treatment options, as presented by the participants, may affect what information is given to parents about intervention options and appropriate referrals.

Early recognition and diagnosis of ASD can be challenging during primary care visits as symptoms during infancy may be difficult to identify, or may present differently from the ways in which the disorder manifests at a later developmental stage (Wetherby et al., 2004). If nurses are unaware of such complexities, they may defer the detection of autism to a later stage and encourage parents *"to wait until two years"*, as one participant stated, and advise them that *"when a child is a year old you won't be able to pick it up here and there, because the child doesn't talk, he's active, yes you can maybe then say okay let's give him some time maybe"* (P8).

Thus, based on the responses from participants and mentioned studies, it could be argued that nurses may be unable to respond to questions from parents relating to intervention options because of an existing knowledge gap in their training. In addition, and for the same reason, participants in this and other studies are not aware of the benefits of early detection and how this subsequently informs early intervention options available for children with autism. However, as pointed out by Hyman and Johnson (2012), understanding the early presentation of the disorder and the interventions available is important in order to effectively and timeously provide the necessary care of these children and their families. Autism South Africa (2000) advocates that the practical information on autism and related topics should be made available to families of children with autism. Parents need to be empowered with information

regarding the nature and typical features of autism spectrum disorders, practical guidelines on how to assist their children across a spectrum of problematic behaviours, and information regarding educational resources and training programmes for children with autism that will enable them to initiate practical assistance for their children (Autism South Africa, 2000; Nissenbaum, Tollefson, & Reese, 2002).

This can only be possible if nursing professionals are adequately trained. However, it is important to note that, besides their evident inadequate training in the area, participants' experience of working with children with autism is also still minimal and sole reliance on varying levels of prior knowledge and personal experience, as mentioned by participants, is problematic in terms of accurate and early diagnosis of ASD. A strong possibility exists of there being a mismatch between their own personal and/or randomly acquired knowledge and experience, and evidence-based information about ASD, thus leading to a missed chance in early detection and the obtaining of appropriate therapy (Ho, Yi, Griffiths, Chan & Murray, 2013).

The findings of this study also indicate that participants rely on a list of developmental milestones to identify children with developmental delays. This is not uncommon as practitioners often make use of a list of developmental milestones during routine visits to screen children for autism spectrum disorders (Sices et al., 2003). While other studies suggest several ASD-specific instruments for screening (Robins et al., 2001), participants in this study indicated that they rely on a general developmental delay checklist to signal any form of atypical developmental. However, it has been pointed out that autism-specific screening is vital in the early identification of autism because global developmental screening alone does not adequately identify children at risk for ASD (Mandell et al., 2005) and participants' use of a general developmental check list suggests that nurses may not correctly identify children with ASD.

Although it can be argued that nurses should trust their initial impressions, reliance on standard developmental milestone reviews alone leads to significantly fewer children receiving developmental services (Hix-Small et al., 2007). The use of such screening practices evidenced by the participants, where they rely on their experience and developmental to detect potential developmental problems, has been found to be ineffective and shown to identify fewer children with developmental delays (Sices et al., 2004). Thus, a developmental checklist by itself may be insufficient for detecting concerns in a large number of children. An approach that explores for more intricate impairments than the basic behavioural markers observed during general clinical observations may be more reliable in the detection of autism. Thus a combination of developmental screening and the use of

screening tests yields better outcomes (Robins, 2008; Hix-Small et al., 2007; Sices et al., 2004).

In addition to this, it has been found that nursing professionals fail to elicit developmental concerns from parents. In this context, as pointed out earlier, it is essential for health care professionals to screen children in areas of speech, social, and communication development during check-ups and this should occur regardless of whether parents voice concerns about their child's development (Johnson & Meyers, 2007; Sand et al., 2007). Although parents are often the first to notice developmental concerns with the child, as previously discussed, the literature encourages health professionals to probe into a child's development during check-ups. Participants P4, 9 and 6 stated that they wait for mothers to volunteer information and do not necessarily initially elicit developmental concerns from parents.

This is a major area of concern for public healthcare, not to mention parents of children with ASD, as this suggests the possibilities of missed opportunities for early detection of autism within clinical settings. This concern has been echoed by previous research, where helping professionals were found to fail to elicit concerns about developmental issues from parents who are supposed to be the key source of information regarding a child's developmental stages and needs (Gray, 2006). The process of eliciting parental concerns about developmental problems identifies as many possible developmental problems as using a valid assessment instrument, and, similar to the findings of the current study, in most cases, the former is not made sufficient use of in screening processes to identify children with ASD (Halfon et al., 2001).

Given that nurses are most likely to be the initial point of professional contact for children with autism and their families, the importance of inquiries about the child's development cannot be over emphasised. Some parents, especially first time parents, may be unaware of appropriate developmental milestones, may not readily identify atypical developmental patterns, or may simply fail to recognize the extent to which they facilitate their child's functioning (Barton et al., 2012). In the South African context, this may be further complicated by the fear and stigma that may be great enough to discourage any form of disclosure of a child's early difficulties (Grinker et al., 2012).

A watch and wait approach as described by participants can therefore compromise the current efforts being proposed for identifying young children with ASD and it has been suggested that professionals need to play a proactive role in eliciting important information about a child's development from parents (Hix- Small et al., 2007). An open ended form of

questioning may be a way of collecting initial parental concerns, and clinicians have to listen carefully and scrutinize such concerns, as some parents may have difficulties in expressing or describing their child's atypical development (Sices et al., 2004). Nurses' silence regarding a child's development compromises an opportunity to facilitate honest communication between parents and professionals on developmental issues of concern (Pinto-Martin et al., 2005). Open and honest communication at this stage is especially important as it initiates and directs the processes to follow. Therefore, contact and communication experiences of parents with professionals leading up to and during the diagnostic process is important, and if contact with professionals is viewed by parents in a negative light, subsequent intervention programs may be less successful (Osborne & Reed, 2008).

Developing a trusting relationship between primary healthcare practitioners and parents of children with autism may also facilitate a more accepting attitude on the part of parents. This suggests that the participants' watch and wait approach reported above, is not helpful as most parents prefer a sincere, proactive and honest involvement by the primary healthcare in issues relating to their child's development (Pinto-Martin et al., 2005; Osborne & Reed, 2008). Several authors suggest that parental satisfaction and positive attitude is directly related not only to the receipt of an early diagnosis but to accurate information about their child's projected developmental trajectory and prognosis (Samms-Vaughan & Frank, 2008; Carbone et al., 2009; Keenan et al., 2010).

Moreover, when nurses do not ask questions around a child's development, this may suggest an unconscious collusion with the parents' denial of their child's developmental disability. In addition, parents with some knowledge of ASD may be in fear of, and resistant to, the possible diagnosis of their child because they are aware of the implications of the disorder, whereas parents who are less knowledgeable about the disorder may experience higher levels of confusion (Gray, 2006). It has also been suggested that educated parents with more economic resources are reportedly more alert in noticing their children's atypical development earlier and may proactively seek help (Moh & Magiati, 2012).

The potential challenges that the educational backgrounds of parents living in socio-economically disadvantaged contexts may pose in the screening and diagnosis process in a South African context are important to consider in any research concerning practitioner-parent interaction in the diagnosis of autism spectrum disorders (Hix-Small et al., 2007). Such a lack of knowledge and resources makes it difficult for these parents to seek professional assistance and some may see the developmental lags as a reflection of their poor parenting skills (Lasser & Corley, 2008). Either way, parents may be unable to discuss their anxieties

with their child's primary healthcare provider. In light of the context in which the participants work, one would expect that they would be aware that parents from low socio-economic and deprived backgrounds may not be sufficiently articulate or literate to explain and describe non-typical behaviour or development at an earlier stage.

Although it has been well established that screening for autism is possible in primary healthcare clinics, priority is given to disabilities and illnesses with high frequencies (Robins, 2008). Nursing professionals were thus primarily concerned with the physical illnesses a child presents with at the clinic, which indicates that they were strictly screening for physical conditions specifically within their professional scope of practice, while no reference was made to screening for mental health or developmental issues. Against the backdrop of high mortality rates of children, poverty and HIV/AIDS, nurses in the South African context may therefore be less focused on early screening and diagnosis of autism spectrum disorder as it coincides with a period in children's lives when issues determining short-term survival compete with developmental disabilities. Furthermore, participants' comments highlight the deficiencies in the current system of primary health care in South Africa, which allows limited time to implement routine screening at each well-child visit (Pinto-Martin et al., 2005). The connotations associated with screening for atypical development influence practitioners' perceptions of screening. The fact that screening for ASD is considered by the public healthcare establishment as a mental health problem implies that screening would not be considered to be a priority.

Nurses continually struggle to meet competing demands on their time, as well as meeting patient targets, and search for methods that are rapid and easy to administer (Pinto-Martin et al., 2005). Thus participants cited workload and time pressures as barriers to screening. If one looks at the extent of healthcare issues which need addressing in the South African context, it can be argued that these two factors are unfortunately unlikely to change in the near future. With well-child checks typically scheduled for 15 to 30 minutes, there is insufficient time for assessment of all domains of development in addition to the administration of vaccines and discussions of other areas of concern with other professionals and with parents (Hix-Small et al., 2007). Nurses are expected to work more in less time, and their schedule is continuously compounded and burdened with more tasks.

Contrary to research, participants in this study did not cite reimbursement as a major barrier to a lack of screening for autism in the clinic. However, it is argued in some studies that health professionals, already feeling pressured by short well child visits, are unlikely to integrate screenings as part of consultation without adequate reimbursement (Pinto-Martin et al., 2005).

Participants stated that, with a lower case load and more time available for child wellness visits, their efforts for screening for autism spectrum disorders would significantly improve.

Although time constraints have been cited as one of the major barriers to screening for autism in this study, there have been plausible suggestions for ways in which nurses can integrate developmental screening into child wellness visits. Several studies have suggested that nurses can quickly learn to conduct routine developmental screening and autism-specific screening while performing other necessary duties during the wellness visit (Robins, 2008; Pinto-Martin et al., 2005). Collaborative efforts such as the use of parent based surveys and the use of clinical observations are said to take less time away from the nurse during the limited time of well-child check-ups than the time spent by the nurse attempting on her or his own to identify the developmental disorder (Pinto-Martin et al., 2005; Hix-Small et al., 2007). It is important to take note of this suggestion since all the participants in the current study indicated that, if time and work pressure were less of an issue, they would be more likely to engage in screening for autism.

In conclusion, nursing professionals held some misconceptions, and demonstrated inaccurate knowledge, concerning some facts about autism spectrum disorder, as well as lacking knowledge specific to screening, early identification and intervention. While it is unreasonable to expect nursing professionals to become experts in the field of ASD, it is necessary that they have a sound knowledge of the basic characteristics and symptoms of the disorder. This study has highlighted the crucial importance of comprehensive courses in introductory knowledge of ASDs during medical school training, and continuing education in terms of updating this knowledge, as nursing professionals are most likely to encounter these children, particularly in the public health care system. This may require immediate and ongoing changes in the curriculum for students during their medical training. Although it is unrealistic to expect programs to focus entirely on autism, it may be reasonable to suggest that all programs address autism in some focused manner in terms of characteristics, course, treatment and management.

It has been shown that asking parents about their child's development can help with timely and appropriate referral, diagnosis and early intervention care (Hix- Small et al., 2007) as it encourages parents to focus on the developmental milestones of their child and facilitate communication between healthcare providers and parents, and the result of this can be that parents will also bring more relevant and valuable information to their clinicians (Pinto et al., 2005). The healthcare professional, in avoiding screening by not openly discussing a child's development with the parents, deprives that child of an opportunity to benefit from early intervention programs that work best at a younger age and which improve the child's

developmental outcome later in adulthood.

It is concerning that, in the screening practices of the participants, the majority had not implemented any formal autism screening measures, given that the literature indicates that the use of such measures can improve the detection rate. The screening practices of some of the participants appeared to be mostly based on their – often limited - experience. Despite the popularity of the screening methods amongst the participants, they may only detect severe cases of ASD, as it is possible that they see children on the high end of the spectrum, as opposed to children presenting with more subtle forms of autism. The results from this study are concerning in many regards if they indicate that a large majority of nursing professionals are not familiar with the recommended guidelines of routine screening at wellness visits, as it is highly likely that early identification of children who utilise public facilities is not taking place. Considering the increasing number of children presenting with ASD in primary health care settings, the response to the early identification and screening of the disorder has been slow.

Interestingly, nursing professionals' admission to not using any screening tools for autism during regular check-ups, and their reasons for not doing so, assisted the researcher in understanding their reliance on clinical observations and past experiences to identify children with ASD. Additionally, this response reveals something about nursing professionals' confidence in their competency when it comes to developmental screening. In fact, the majority of the respondents reported that their lack confidence in their ability to recognise developmental red flags would indicate a need for further evaluation during regular child wellness check-ups. However, as has been discussed in the context of the increasing prevalence of children diagnosed with ASD, it is important for nursing professionals to understand that clinical observations and personal experiences alone is not enough to identify ASD as this creates many missed opportunities to recognize significant numbers of children at risk for autism.

An important finding from this study is that a model of collaboration between primary and secondary healthcare systems, one in which nursing professionals feel supported in their efforts of early identification of children at risk for autism, is essential in this context. Adequate and consistent communication in the form of clinical feedback offered to nursing professionals would be valuable in many respects. Firstly, given the limited availability of resources in the form of autism developmental clinics, referral units, affordable specialists and specialist schools in South Africa and other developing countries, this kind of communication could ensure that referrals are made speedily and directly to appropriate professionals.

This opening up of the channels of communication between primary and secondary health care systems could in several aspects significantly lessen the burden on already over

stretched systems attempting to meet the needs of increasing numbers of children with ASD. The feedback resulting from this communication can provide learning opportunities for nursing professionals. For example, when a nursing professional's referral to a tertiary hospital in fact results in an autism diagnosis and is communicated to the primary health care professional, feedback may help broaden their knowledge in terms of autism features and associated behaviours. A collaborative systems approach to autism screening and referral would also help professionals feel supported in their role as first line developmental screening professionals, and would potentially increase the numbers of children identified at earlier ages.

Participants brought to light another important aspect of the early diagnosis of ASD, and one which could be adopted in the South African context in the interests of reducing the delay between initial referral and diagnosis. International research recommends that simultaneous referrals to early intervention providers, and to diagnosticians and audiologists, should be made with hospital referrals so that intervention can begin as quickly as possible (Barton et al., 2012). Thus, to facilitate early intervention, it is important that primary health care professionals not only timeously refer children to secondary level systems, but also to other professionals whose services may benefit children with autism in their wait for diagnosis.

While it would be useful that nursing professionals familiarise themselves with the available screening tools, and find a way to incorporate this into their everyday practice, it seems unfair to expect nursing professionals to have a knowledge of such screening tools if these are not made available to them, or to find the space to use them, in their overburdened daily schedules. It appeared that the number of years the respondents had been in the field did not affect whether or not they had received adequate training in ASD characteristics and screening. Additionally, time spent in the profession did not influence whether or not these nurses had received any form of continuing or in-service training. This pattern of results is concerning as it reflects a long standing neglect of ASD training in a context that would make it crucial for nurses to be prepared to address this increasingly high-incidence population. This points to issues of public health care provision, such as the need for appropriate training around ASD.

Given that the findings of this and other studies show non usage of screening tools by nursing professionals, a strong case can be made for targeting these barriers to screening in professional training initiatives. Nurses would also benefit from clear and specific guidance on how to incorporate routine developmental screening into their practice, given that a lack of clear instructions increases the likelihood of delay in identification and appropriate intervention services. However, despite this paucity of training, healthcare professionals are still expected to be an authority on child development in South Africa and in other developing

countries.

A substantial and growing body of evidence points to the key to early detection of autism for nursing professionals to be conducting routine screening of all children at specified well child visits using validated standardized screening instruments. However, currently far too many of those children and their families, who have no choice but to use the public health care system, have to endure long waiting periods in order to receive any form of ASD diagnosis and the subsequent implementation of early intervention services. If the present situation is allowed to continue, the potential and future prospects of a child with autism spectrum disorder in South Africa remains compromised, an issue we cannot continue to ignore.

Limitations

This research project is limited in its ability to generalise its findings to other cases. The sample comprised of nurses residing in Cape Town, where there is a larger network of autism facilities compared to other provinces. To some extent, this may affect the experiences of nurses in this region, and thus this cohort of individuals have their own unique interactions with autism in the clinic setting, which may differ from those of nurses in other provinces. In addition, the sample is limited to nurses in the public health sector. As mentioned earlier, disparities in working conditions and resources are factors which may produce differences in terms of findings between the public and private settings. Qualitative research recognizes that the elements that shape research findings, such as the participants and the researchers, change if and when the study is repeated.

Recommendations

As with most projects, the limited scope of this one prevented many other important questions on this topic from being addressed. Nationwide, comprehensive programs are needed to address the identified barriers currently existing which prevent nursing professionals from identifying and screening young children for autism. Through the undertaking of this study, one major concern identified was that nursing professionals have not been conducting routine ASD screenings. Future studies may further explore the justification and reasons for this practice and look into strategies that would support efforts at conducting routine accurate ASD screening in the public health care system.

In addition to gaining information from quantitative studies, it is important to elicit more qualitative information concerning the needs of students and professionals in the field of child development in general and ASD in particular. Further research should incorporate a needs based assessment of the learning and information gaps nursing professionals feel it is necessary to fill for them to be able to provide competent and quality care when working with children

with autism spectrum disorder and with their families. In addition, based on recommendations from participants in this study, changes need to be made urgently to the existing pre-professional education curriculum; participants expressed the wish for training that would be helpful in preparing them to identify, screen and refer children with ASD. Thus future research could explore opportunities for implementing these pre-professional education changes in higher education in South Africa as well as in-service training. More research is needed to identify the types and modes of in-service training that currently practicing nursing professionals would be most likely to participate in.

Given that the overall competency of healthcare professionals is of great importance, particularly in the public health care system, a collaboration model that is worth considering is that of the screening, diagnosis and care of children with autism being conducted by a multi-disciplinary team, and that collaboration in further investigation for ASD be related to nursing professionals' referral practices. This kind of collaboration between the primary and secondary public health care sectors may yield interesting findings on how nursing professionals perceive and utilise existing referral sites, and how this impacts on the early identification of children at risk for autism spectrum disorder.

This study was designed to build on work done in previous international and sub-Saharan studies in understanding the experiences of nursing professionals working with autism spectrum disorder (ASD) in a South African primary healthcare setting. The findings of this study have increased the researcher's understanding of the current autism screening practices among nurses, as well as helping her to understand the barriers preventing routine autism screening from taking place, and to identify the training needs of nursing professionals in this field. These findings can be added to the growing number of other efforts to identify and diagnose children with autism spectrum disorders at the earliest possible stage.

References

- Ahern, K. (2000). "Something is wrong with my child": A phenomenological account of a search for a diagnosis. *Early Education and Development, 11*(2), 187-201.
- Al-Qabandi, M., Gorter, J. W., & Rosenbaum, P. (2011). Early autism detection: Are we ready for routine screening? *Pediatrics, 128*(1), e211-e217.
- Altieri, M. J., & von Kluge, S. (2009). Family functioning and coping behaviours in parents of children with autism. *Journal of Child and Family Studies, 18*(1), 83-92.
- American Academy of Pediatrics. (2001). Developmental surveillance and screening of infants and young children. *Pediatrics, (108)*, 192-195.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders: DSM-IV-TR®*. Arlington, VA: American Psychiatric Publishing.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders, fifth edition: DSM-5*. Arlington, VA: American Psychiatric Publishing.
- Autism South Africa. (2000). *My child may be affected by autistic spectrum disorder: Information for parents*. Greenside, South Africa: Author.
- Babbie, E.R. & Mouton, J. (2006). *The practice of social research*. Cape Town, South Africa: Oxford University Press.
- Baird, G., Charman, T., Cox, A., Baron-Cohen, S., Swettenham, J., Wheelwright, S., & Drew, A. (2001). Screening and surveillance for autism and pervasive developmental disorders. *Archives of Disease in Childhood, 84*(6), 468-475.
- Bakare, M. O., Ebigbo, P. O., Agomoh, A. O., Eaton, J., Onyeama, G. M., Okonkwo, K. O., & Aguocha, C. M. (2009). Knowledge about childhood autism and opinion among healthcare workers on availability of facilities and law caring for the needs and rights of children with childhood autism and other developmental disorders in Nigeria. *BMC Pediatrics, 9*(1), 12.
- Barton, M. L., Dumont-Mathieu, T., & Fein, D. (2012). Screening young children for autism spectrum disorders in primary practice. *Journal of Autism and Developmental Disorders, 42*(6), 1165-1174.
- Blackwell, J., & Niederhauser, C. (2003). Diagnose and manage autistic children. *The Nurse Practitioner, 28*(6), 36-43.
- Boushey, A. (2001). The grief cycle--one parent's trip around. *Focus on Autism and Other Developmental Disabilities, 16*(1), 27-30.
- Braun, K. V. N., Pettygrove, S., Daniels, J., Miller, L., Nicholas, J., Baio, J., & Brocksen, S.

- (2007). Evaluation of a methodology for a collaborative multiple source surveillance network for autism spectrum disorders—Autism and developmental disabilities monitoring network, 14 sites, united states, 2002. *Morbidity and Mortality Weekly Report*, 56, 29-40.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Bryson, S. E., Rogers, S. J., & Fombonne, E. (2003). In review. *Canadian Journal of Psychiatry*, 48, 506-516.
- Burkhardt, S. (2001). Counseling issues for parents of children with autistic spectrum disorders. *Advances in Special Education*, 14, 211-233.
- Senders, M., Freeman, K. G., DePaul, D., & Levy, S. E. (2002). Caring for children and adolescents with autism who require challenging procedures. *Pediatric Nursing*, 28(6), 555-562.
- Carbone, P. S., Behl, D. D., Azor, V., & Murphy, N. A. (2010). The medical home for children with autism spectrum disorders: Parent and pediatrician perspectives. *Journal of Autism and Developmental Disorders*, 40(3), 317-324.
- Coonrod, E. E., & Stone, W. L. (2004). Early concerns of parents of children with autistic and nonautistic disorders. *Infants & Young Children*, 17(3), 258-268.
- Creswell, J. W. (2012). *Qualitative inquiry and research design: Choosing among five approaches*. Thousand Oaks, CA: SAGE .
- Croen, L. A., Grether, J. K., Hoogstrate, J., & Selvin, S. (2002). The changing prevalence of autism in california. *Journal of Autism and Developmental Disorders*, 32(3), 207-215.
- Crown, N. J. (2009). Parenting a child with disabilities: Personal reflections. *Journal of Infant, Child, and Adolescent Psychotherapy*, 8(1), 70-82.
- Daley, T. C., & Sigman, M. D. (2002). Diagnostic conceptualization of autism among Indian psychiatrists, psychologists, and pediatricians. *Journal of Autism and Developmental Disorders*, 32(1), 13-23.
- Dawson, G. (2008). Early behavioral intervention, brain plasticity, and the prevention of autism spectrum disorder. *Development and Psychopathology*, 20(3), 775.
- De Giacomo, A., & Fombonne, E. (1998). Parental recognition of developmental abnormalities in autism. *European Child & Adolescent Psychiatry*, 7(3), 131-136.
- Denzin, N. K., & Lincoln, Y. S. (2011). *The SAGE handbook of qualitative research*. Thousand Oaks, CA: SAGE.
- De Vos, A. S., Delpont, C., Fouche, C., & Strydom, H. (2011). *Research at grass roots: A*

- primer for the social science and human professions*. Pretoria, South Africa: Van Schaik.
- DeWeerd, S. (2012). Culture: Diverse diagnostics. *Nature*, 491(7422), S18-S19.
- Dietz, C., Swinkels, S., van Daalen, E., van Engeland, H., & Buitelaar, J. K. (2006). Screening for autistic spectrum disorder in children aged 14–15 months. II: Population screening with the early screening of autistic traits questionnaire (ESAT). design and general findings. *Journal of Autism and Developmental Disorders*, 36(6), 713-722.
- Dumont-Mathieu, T., & fein, D. (2005). Screening for autism in young children: The modified checklist for autism in toddlers (M-CHAT) and other measures. *Mental Retardation and Developmental Disabilities Research Reviews*, 11 (3), 253-262.
- Filipek, P., Accardo, P., Ashwal, S., Baranek, G., Cook, E., Dawson, G., & Kallen, R. (2000). Practice parameter: Screening and diagnosis of autism report of the quality standards subcommittee of the american academy of neurology and the child neurology society. *Neurology*, 55(4), 468-479.
- Filipek, P. A., Accardo, P. J., Baranek, G. T., Cook Jr, E. H., Dawson, G., Gordon, B., & Levy, S. E. (1999). The screening and diagnosis of autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, 29(6), 439-484.
- Finlay, L. (2002). Negotiating the swamp: The opportunity and challenge of reflexivity in research practice. *Qualitative Research*, 2(2), 209-230.
- Fombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental disorders: An update. *Journal of Autism and Developmental Disorders*, 33(4), 365-382.
- Galinat, K., Barcalow, K., & Krivda, B. (2005). Caring for children with autism in the school setting. *The Journal of School Nursing*, 21(4), 208-217.
- Gill, J., & Liamputtong, P. (2009). Walk a mile in my shoes: Researching the lived experience of mothers of children with autism. *Journal of Family Studies*, 15(3), 309-319.
- Glascoe, F. P. (1998). *Collaborating with parents: Using parents' evaluation of developmental status to detect and address developmental and behavioral problems*. Nashville, TN: Ellsworth & Vandermeer Press.
- Glascoe, F. P. (2005). Screening for developmental and behavioral problems. *Mental Retardation and Developmental Disabilities Research Reviews*, 11(3), 173-179.
- Goin, R. P., & Myers, B. J. (2004). Characteristics of infantile autism moving toward earlier detection. *Focus on Autism and Other Developmental Disabilities*, 19(1), 5-12.
- Gray, D. E. (2006). Coping over time: The parents of children with autism. *Journal of Intellectual Disability Research*, 50(12), 970-976.

- Grinker, R.R., Chambers, N., Njongwe, N., Lagman, A.E., Guthrie, W., Stronach, S., ...
 Wetherby, A.M. (2012). "Communities" in community engagement: Lessons learned from
 autism research in South Korea and South Africa. *Autism Research*, 5(3), 201–210.
- Gupta, V. B., Hyman, S. L., Johnson, C. P., Bryant, J., Byers, B., Kallen, R., & Yeargin-
 Allsopp, M. (2007). Identifying children with autism early? *Pediatrics*, 119(1), 152-153.
- Halfon, N., Hochstein, M., Sareen, H., O'Connor, K., Inkelas, M., & Olson, L. (2001, April
 28- May 1). *Barriers to the provision of developmental assessments during pediatric
 health supervision*. Baltimore, MD: Pediatric Academic Societies Meeting.
- Heflin, L. J., & Alaimo, D. F. (2006). *Students with autism spectrum disorders: Effective
 instructional practices*. Columbus, Ohio: Pearson Prentice Hall.
- Heidgerken, A. D., Geffken, G., Modi, A., & Frakey, L. (2005). A survey of autism
 knowledge in a health care setting. *Journal of Autism and Developmental Disorders*,
 35(3), 323-330.
- Hix-Small, H., Marks, K., Squires, J., & Nickel, R. (2007). Impact of implementing
 developmental screening at 12 and 24 months in a pediatric practice. *Pediatrics*, 120(2),
 381-389.
- Ho, H. S., Yi, H., Griffiths, S., Chan, D. F., & Murray, S. (2013). 'Do it yourself' in the parent-
 professional partnership for the assessment and diagnosis of children with autism spectrum
 conditions in hong kong: A qualitative study. *Autism : The International Journal of
 Research and Practice*, doi:10.1177/1362361313508230
- Howlin, P., & Moorf, A. (1997). Diagnosis in autism: A survey of over 1200 patients in the
 UK. *Autism*, 1(2), 135-162.
- Hyman, S. L., & 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., & Okonkwo, K. O. (2010).
 Research factors influencing knowledge about childhood autism among final year
 undergraduate medical, nursing and psychology students of University of Nigeria, Enugu
 State, Nigeria.
- Imran, N., Chaudry, M. R., Azeem, M. W., Bhatti, M. R., Choudhary, Z. I., & Cheema, M. A.
 (2011). A survey of autism knowledge and attitudes among the healthcare professionals in
 Lahore, Pakistan. *BMC Pediatrics*, 11(1), 107.
- Johnson, C. P., & Myers, S. M. (2007). Identification and evaluation of children with autism
 spectrum disorders. *Pediatrics*, 120(5), 1183-1215.
- Keenan, M., Dillenburger, K., Doherty, A., Byrne, T., & Gallagher, S. (2010). The

experiences of parents during diagnosis and forward planning for children with autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities*, 23(4), 390-397.

Kogan, M. D., Blumberg, S. J., Schieve, L. A., Boyle, C. A., Perrin, J. M., Ghandour, R. M., . . . 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.

Lakić, A. (2012). Screening, identification and evaluation of autism spectrum disorders in primary health care. *Vojnosanitetski Pregled*, 69(5), 437-443.

Landa, R. J., Holman, K. C., & Garrett-Mayer, E. (2007). Social and communication development in toddlers with early and later diagnosis of autism spectrum disorders. *Archives of General Psychiatry*, 64(7), 853.

Lasser, J., & Corley, K. (2008). Constructing normalcy: A qualitative study of parenting children with asperger's disorder. *Educational Psychology in Practice*, 24(4), 335-346.

Lian, W., Ho, S., Yeo, C., & Ho, L. (2003). General practitioners' knowledge on childhood developmental and behavioural disorders. *Singapore Medical Journal*, 44(8), 397-403.

Malcolm-Smith, S., Hoogenhout, M., Ing, N., Thomas, K. G., & de Vries, P. (2013). Autism spectrum disorders—Global challenges and local opportunities. *Journal of Child & Adolescent Mental Health*, 25(1), 1-5.

Mandell, D. S., Listerud, J., Levy, S. E., & Pinto-Martin, J. A. (2002). Race differences in the age at diagnosis among medicaid-eligible children with autism. *Journal of the American Academy of Child & Adolescent Psychiatry*, 41(12), 1447-1453.

Mandell, D. S., Novak, M. M., & Zubritsky, C. D. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics*, 116(6), 1480-1486.

Mitchell, C., & Holdt, N. (2014). The search for a timely diagnosis: Parents' experiences of their child being diagnosed with an Autistic Spectrum Disorder. *Journal of Child & Adolescent Mental Health*, 26(1), 49-62.

Moh, T. A., & 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.

Nadel, S., & Poss, J. E. (2007). Early detection of autism spectrum disorders: Screening between 12 and 24 months of age. *Journal of the American Academy of Nurse Practitioners*, 19(8), 408-417.

Nadon, G., Feldman, D. E., Dunn, W., & Gisell, E. (2011). Mealtime problems in children

with autism spectrum disorder and their typically developing siblings: A comparison study. *Autism*, 15(1), 98-113.

- Nissenbaum, M. S., Tollefson, N., & Reese, R. M. (2002). The interpretative conference: Sharing a diagnosis of autism with families. *Focus on Autism and Other Developmental Disabilities*, 17(1), 30-43.
- Osborne, L. A., & Reed, P. (2008). Parents' perceptions of communication with professionals during the diagnosis of autism. *Autism*, 12(3), 309-324.
- Oser, C., & Shaw, E. (2001). *Early identification of young children with autism spectrum disorders: Improving practices*. (Unpublished manuscript, University of North Carolina, Chapel Hill, NC).
- Ozonoff, S., Goodlin-Jones, B. L., & Solomon, M. (2005). Evidence-based assessment of autism spectrum disorders in children and adolescents. *Journal of Clinical Child and Adolescent Psychology*, 34(3), 523-540.
- Padgett, D. K. (2008). *Qualitative methods in social work research*. Thousand Oaks, CA: SAGE.
- Parker, I. (2005). *Qualitative psychology: Introducing radical research*. London: SAGE.
- Pinto-Martin, J. A., Souders, M. C., Giarelli, E., & Levy, S. E. (2005). The role of nurses in screening for autistic spectrum disorder in pediatric primary care. *Journal of Pediatric Nursing*, 20(3), 163-169.
- Pizur-Barnekow, K., Muusz, M., McKenna, C., O'Connor, E., & Cutler, A. (2012). Service coordinators' perceptions of autism-specific screening and referral practices in early intervention. *Topics in Early Childhood Special Education*, 33, 153.
- Powell, J., Edwards, A., Edwards, M., Pandit, B., Sungum-Paliwal, S., & Whitehouse, W. (2000). Changes in the incidence of childhood autism and other autistic spectrum disorders in preschool children from two areas of the West Midlands, UK. *Developmental Medicine & Child Neurology*, 42(9), 624-628.
- Rhoades, R., Scarpa, A., & Salley, B. (2007). The importance of physician knowledge of autism spectrum disorder: Results of a parent survey. *BMC Pediatrics*, 7(1), 37.
- Rice, C. (2009). *Prevalence of autism spectrum disorders--autism and developmental disabilities monitoring network, united states, 2006*. Department of Health and Human Services, Centers for Disease Control and Prevention.
- Robins, D. L., & Dumont-Mathieu, T. M. (2006). Early screening for autism spectrum disorders: Update on the modified checklist for autism in toddlers and other measures. *Journal of Developmental & Behavioral Pediatrics*, 27(2), S111-S119.

- Robins, D. L. (2008). Screening for autism spectrum disorders in primary care settings. *Autism, 12*(5), 537-556.
- Robins, D. L., Fein, D., Barton, M. L., & Green, J. A. (2001). The modified checklist for autism in toddlers: An initial study investigating the early detection of autism and pervasive developmental disorders. *Journal of Autism and Developmental Disorders, 31*(2), 131-144.
- Roth, P. H. (2001). A mother's account. *Focus on Autism and Other Developmental Disabilities, 16*(1), 17-19.
- Samms-Vaugh, M, & Franklyn-Banton, L. (2008). The role of early childhood professionals in the early identification of autistic disorder. *International Journal of Early Years Education, 16*(1), 75-84.
- Sand, N., Silverstein, M., Glascoe, F. P., Gupta, V. B., Tonniges, T. P., & O'Connor, K. G. (2005). Pediatricians' reported practices regarding developmental screening: Do guidelines work? do they help? *Pediatrics, 116*(1), 174-179.
- Schwartz, H., & Drager, K. D. (2008). Training and knowledge in autism among speech-language pathologists: A survey. *Language, Speech, and Hearing Services in Schools, 39*(1), 66.
- Self, T. L., Coufal, K., & Parham, D. F. (2010). Allied healthcare providers' role in screening for autism spectrum disorders. *Journal of Allied Health, 39*(3), 165-174.
- Shah, K. (2001). What do medical students know about autism? *Autism, 5*(2), 127-133.
- Sices, L., Feudtner, C., McLaughlin, J., Drotar, D., & Williams, M. (2004). How do primary care physicians manage children with possible developmental delays? A national survey with an experimental design. *Pediatrics, 113*(2), 274-282.
- Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry, 47*(8), 921-929.
- Springer, P. E., van Toorn, R., Laughton, B., & Kidd, M. (2013). Characteristics of children with pervasive developmental disorders attending a developmental clinic in the Western Cape Province, South Africa. *South African Journal of Child Health, 7*(3), 95-99.
- Stone, W. L. (1987). Cross-disciplinary perspectives on autism. *Journal of Pediatric Psychology, 12*(4), 615-630.
- Strunk, J. A. (2009). School nurses' knowledge of autism spectrum disorders. *The Journal of School Nursing, 25*(6), 445-452.

- Turner, L. M., Stone, W. L., Pozdol, S. L., & Coonrod, E. E. (2006). Follow-up of children with autism spectrum disorders from age 2 to age 9. *Autism, 10*(3), 243-265.
- Van Tongerloo, M. A., Bor, H. H., & Lagro-Janssen, A. L. (2012). Detecting autism spectrum disorders in the general Practitioner's practice. *Journal of Autism and Developmental Disorders, 42*(8) , 1531-1538.
- Vaughan, M. S. (2005). *The Jamaican Pre-School Child: The Status of Early Childhood Development in Jamaica (Results from the Profiles Project)*. Kingston: Planning Institute of Jamaica.
- Wetherby, A. M., Woods, J., Allen, L., Cleary, J., Dickinson, H., & Lord, C. (2004). Early indicators of autism spectrum disorders in the second year of life. *Journal of Autism and Developmental Disorders, 34*(5), 473-493.
- Williams, J., Scott, F., Stott, C., Allison, C., Bolton, P., Baron-Cohen, S., & Brayne, C. (2005). The CAST (childhood asperger syndrome test) test accuracy. *Autism, 9*(1), 45-68.
- Willig, C. (2013). *Introducing qualitative research in psychology*. London, England: McGraw-Hill International.
- Wing, L., & Potter, D. (2002). The epidemiology of autistic spectrum disorders: Is the prevalence rising? *Mental Retardation and Developmental Disabilities Research Reviews, 8*(3), 151-161.

Appendices

Appendix A: Interview Schedule

Appendix B: Information Letter and Consent Form

Appendix C: Key on the transcription system

Appendix A: Interview Schedule

Interview Protocol Project: Nursing professionals' understanding of autism spectrum disorders: A Phenomenological investigation

Time of interview:

Date:

Interviewer:

Interviewee:

Guiding questions

1. Tell me about the common difficulties/problems that you often come across in your Work
 - Probe around intellectual disorders, general developmental disorders and autism
2. What are the problems that parents often report in these children
 - Probe for behavioural problems, communication delays, language difficulties, stereotypical behaviours, poor self-care, poor play skills
3. When you examine the children what are some of the things you have noticed about them that stood out for you
 - Probe for eye contact, lack of responsiveness, rigid adherence to routines, not wanting to be touched, sensitivity to sights, sounds, touch, poor gross and fine motor skills
4. Can you tell me what helps you recognise a child with an autism disorder
 - Probe for features distinguishing it from ID and other PDDs, such as stereotypical behaviours, unusual motor movements
5. What happens when you suspect autism ?
 - Probe for the following:
 - Who do you consult and why in terms of time, qualification and experience
 - Where do you refer and is that helpful (i.e. do you feel it is adequate);
 - Do you get any feedback about the children you have referred and
 - Do you ever get to see them again?
6. Can you tell me about your training as a professional – how helpful has it been in helping you recognise a child with autism -probe basic training and in-service/continuing education courses.

7. What would be most helpful for you that would assist you in recognising and diagnosing autism?
8. What are the challenges to getting these training needs met?
9. How do you understand the impact of late diagnosis of autism on the well being of a child?
10. Do you think it is important for nurses to have knowledge and awareness regarding autism? If yes, why?

Appendix B: Participant Information Letter and Consent Form

UNIVERSITY OF CAPE TOWN



Department of Psychology
University of Cape Town
Rondebosch 7701 South Africa
Telephone (021) 650 9111
Fax No. (021) 650 4104

Dear Nurse

Study purpose and Procedure

I hereby request your participation in a research project that aims to explore the knowledge and awareness of autism amongst nurses. This includes knowledge regarding symptoms and diagnosis as well as experiences of encountering children with autism in a clinical setting. The information provided by you may help form an understanding on what baseline knowledge nurses possess in order to ultimately contribute to the care of children with autism.

Your participation will involve one 60-minute interview conducted at a place of your convenience. In this interview the researcher will ask questions that relate to your knowledge about autism in children.

Potential risks

There are no known risks specific to this kind of study participation.

Possible benefits

It is hoped that this study will increase your knowledge and awareness regarding autism. In doing so, you may highlight areas in which you may require support, in order to provide quality care for children affected by the disorder.

Termination of research study

You are free to choose whether or not you would like to participate in this study. Please also note that you have the right to withdraw from this research project at any time. The researcher will provide you with any significant new findings developed during the course of this study that may relate to or influence your willingness to continue participation.

Confidentiality

Your identity in this study is completely confidential. All identifying information will be kept in separate locked cabinets which are only accessible by the researcher. Once the researcher has transcribed the interviews, she will provide a pseudonym for real names of participants and any tape recordings will be destroyed upon completion of the study. The results of the study, including any other data published, will not include your name or include any identifiable references to you.

Please refer any further questions you have about this study to the following:

Principal researcher: Batetshi Matenge

Phone Number: 0766747315

Supervisor: Dr Nokuthula Shabalala

Phone number: 021 650 3900

I have read and understand this consent form, and I understand that I will receive a copy of this form. I voluntarily choose to participate, but I understand that my consent does not take away any legal rights in the case of negligence or other legal fault of anyone who is involved in this study.

Participant Name:

Participant Signature:

Date:

Principal Investigator Signature:

Date:

I give consent for the audio of this interview to be recorded. I understand that the audio-recording is to accurately record the information that I provide, and will be used for transcription purposes only. If I feel uncomfortable at any time during the interview I may request the researcher to turn off the audio-recorder. Or, if I do not wish to continue, I may ask the researcher to stop the interview at any time.

Participant Name:

Participant Signature:

Date:

Principal Investigator Signature:

Date:

Appendix C: Key on the Transcription System

- Square brackets mark overlap between utterances.
- The symbol (. . .) indicates that some of the transcript has been deliberately omitted.
- Material in round brackets (()) is the transcriber's descriptions.
- A small gap or pause between utterances is indicated by (.)
- The two numbers in brackets at the end of quotes refer to the participant's interview number respectively.
- Non-verbal information, such as laughs and pauses are indicated as (laughs) respectively. No other non-verbal information was recorded.