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**Autism Spectrum Disorder: Assessing the level of knowledge  
and perceived challenges to early diagnosis and intervention  
among general practitioners in the city of Tripoli, Libya**

Soad Jubr (JBRSOA001)

Supervisor/s: Reneva Peterson

Jawaya Shea

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of Philosophy in Maternal and Child Health (M.Phil. MCH) Degree

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## **DEDICATIONS**

I dedicate this work to my beloved family, my parents, my sisters and brothers for their prayers, support and love to see me graduate.

I would give a specific dedication to my little "autistic" child who was the source of inspiration to do this dissertation on autism.

I am proud.

# **ABSTRACT**

## **Introduction**

Autism spectrum disorder (ASD) is an important global health problem. It has been shown that early diagnosis and intervention can improve the outcomes in affected children. Lack of knowledge about ASD among health care practitioners can delay the identification of children with ASD as well as early intervention. Currently, a dearth of epidemiological information exists regarding ASD in Africa. The aim of this study was to assess the knowledge of general practitioners (GPs) in Libya regarding ASD and to identify perceived challenges by GPs to early diagnosis and intervention of children with ASD in Libya. The study included the working GPs in the city of Tripoli.

## **Methodology**

This cross-sectional descriptive study was conducted between 1st June 2017 to 31st August 2017 and utilized an electronic platform, the Research Electronic Data Capture (REDCap) from the University of Cape Town to collect study information. The Knowledge about Childhood Autism among Healthcare Workers (KCAHW) is validated questionnaire that explores health care worker knowledge about ASD across four domains. The KCAHW was used in combination with a more detailed questionnaire which explored challenges to early identification and interventions by GP's in Libya. Descriptive statistics are reported in percentages and the Wilcoxon rank sum test was used to explore relationships between domain knowledge scores with age and gender as well as years of experience as a GP.

## **Results**

The number of surveys returned to the REDCap application survey site was 215 which represent a response rate of 58.1%. However, the number of complete responses which could be included in data analysis was found to be only 62, indicating an overall response rate of 16.7%. The median age of the participants was 30 years old, IQR (29-33) years with a female predominance amongst participants (n= 55, 89%). The total median score from the knowledge questionnaire was 10, IQR (8-12). No statistical differences could be found between domain knowledge scores and

participants' age, gender and work practice. Participants showed good knowledge about stereotypical movements and repetitive behaviours in ASD, but 48% were not aware of comorbidities associated with ASD. The main challenges identified by GPs in the management of ASD were lack of awareness, insufficient experience, and health infrastructure in Libya as well as social stigma associated with developmental disorders.

### **Conclusion and recommendations**

GPs in Libya have limited knowledge about certain aspects of ASD. A number of challenges were identified by GPs which hamper the early identification and management of ASD in Libya. There is a need to improve undergraduate medical training about ASD as well as to offer ongoing medical education to GP's to improve recognition and management of ASD in Libya. Further research is indicated to explore the epidemiology, clinical spectrum and severity of ASD as well as intervention in Libya

***Key words:*** *autism spectrum disorder; general practitioners; knowledge; diagnosis*

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## **LIST OF ACRONYMS AND ABBREVIATIONS**

- AAP – American Academy of Paediatrics
- AACAP – American Academy of Child and Adolescent Psychiatry
- AKGH – Al-Khadra General Hospital
- AMA – American Medical Association
- ASD – Autism Spectrum Disorder
- APA – American Psychiatric Association
- CDC – Centres for Disease Control and Prevention
- CHAT– Checklist for Autism in Toddlers
- DSM-IV – Diagnostic and Statistical Manual of Mental Disorders (Fourth edition)
- DSM-V – Diagnostic and Statistical Manual of Mental Disorders (Fifth edition)
- GPs – General practitioners
- HCPs – Health care providers
- HERC – Health Sciences Ethics Research Committee
- ICD – International Classification of Diseases
- IQR– Interquartile Range
- KCAHW – Knowledge about Childhood Autism among Healthcare Worker
- Km – kilometer
- M-CHAT– Modified Checklist for Autism in Toddlers
- REDCap – Research Electronic Data Capture
- UCT – University of Cape Town
- WHO – World Health Organization
- WMA – World Medical Association

## **DEFINITION OF CONCEPTS**

### **1.1. Autism Spectrum Disorder**

For the purpose of this study, the DSM-V definition will be applied (American Psychiatric Association [APA], 2013). ASD can be described as a lifelong disorder that is characterized by deficits in social, communication and behavioural skills, which is associated with stereotypical and repetitive patterns of behaviours and interests (APA, 2013).

### **1.2. Early identification**

Referred to as the earliest age that an ASD child can be detected/identified which is recognized by researchers to be between the ages of 18-36 months (Baron-Cohen *et al.*, 2000).

### **1.3. General practitioners**

A general practitioner (GP) is a physician who is not specialized in any field and practices general medicine (Royal College of General Practitioners, 2010). For the purpose of this study, this term will be used to refer to all medical doctors and physicians who do not have a high degree in the field of the study for example specialist paediatricians, psychiatrists.

### **1.4. Knowledge**

This concept used in this study will refer to the participant's information, education and skills they have regarding the study topic (Hunt, 2003).

### **1.5. Assessment**

In this study, assessment refers to the evaluation process to identify the knowledge and information participants have gained regarding the research topic (Edwards *et al.*, 1998).

## **1.6. Overload**

Refers to the difficulty that parents experiencing in their daily care of their ASD children, as well as the feeling of exhaustion experienced in caring for a child with ASD (Gomes *et al.*, 2015).

## **Dissertation layout**

**Chapter One:** This chapter will give an introductory description and include a relevant background on the topic of the dissertation.

**Chapter Two:** This chapter will present and discuss the different literature available on the study topic.

**Chapter Three (Methodology):** Chapter three will elaborate and give a broad description on the study design and methods utilized for the purpose to complete this study.

**Chapter Four (Results):** This chapter will present the results found from the study.

**Chapter Five (Discussion, conclusion and recommendations):** The last chapter will give a critical discussion of the results in collaboration with previous literature, as well as highlighting a conclusion and recommendations for future research.

# CHAPTER 1: BACKGROUND AND INTRODUCTION

## 1.1. BACKGROUND AND INTRODUCTION

Described as a lifelong disorder, Autism Spectrum Disorder (ASD) can be characterized by varied neuro-developmental deficits that affect the social, communication and behavioural skills of children (American Psychiatric Association [APA], 2013; Boyed *et al.*, 2010). This includes restricted interests as well as repetitive and/or stereotypical patterns of behaviour in children (APA, 2013). These manifestations can be seen in the manner in which the child behaves or interacts with individuals or objects such as toys (Centres for Disease Control and Prevention [CDC], 2015; Woolfenden *et al.*, 2012; Bryson *et al.*, 2007). For instance, a child affected with ASD can manifest with hand flapping, rocking, arranging and rearranging objects, and repeating sounds, words, or phrases in an abnormal way (Bryson *et al.*, 2007). The manifestations range from mild to severe; however, most researchers recognize ASD as a complex disorder that continues throughout the person's life (Boyed *et al.*, 2010). Although ASD manifestations can often be detected early during infancy, diagnosis only typically occurs during the first two years of life (Jo *et al.*, 2015). It has also been shown that boys are affected at a rate of four times more than girls (CDC, 2015; Woolfenden *et al.*, 2012).

ASD has emerged as a global health concern in children. The prevalence of the disorder appears to have increased in many countries, with the latest prevalence ratio estimated to be 1:68 of all children, compared to previous estimations in 2007 (1:150 children) (CDC, 2015). There is a lack of data pertaining to the prevalence of ASD in Africa; hence the need for comprehensive epidemiological studies to determine the magnitude and severity of this problem and whether it complements the global trend (Bello-Mojeed, *et al.*, 2014; Ruparelia *et al.*, 2016). There are limited studies that have attempted to identify the prevalence rate of ASD in African countries. For instance, Esegbe *et al.*, (2015) identified a prevalence rate of 0.7 – 33.6% in some neurological and psychiatric clinics in Nigeria. In a study conducted in Tunisia and Egypt the prevalence rates were estimated to be 11.5% and 33.6% respectively in children with developmental disabilities (Seif-Elden, *et al.*, 2008; Bello-Mojeed, *et al.*, 2014; Ruparelia *et al.*, 2016).

The prevalence rate of ASD in Libya is currently not known (Zeglam & Al-Bloushi, 2012). However, an apparent increase in the prevalence of ASD was reported in study conducted in a tertiary hospital clinic in Tripoli between 2009-2011. The study results showed a prevalence rate ranging from 7:1000 children in 2009 to 10:1000 children in 2011 (Zeglam & Al-Bloushi, 2012; Zeglam & Maouna, 2012). Some research has suggested that the true prevalence of ASD in Libya may, in fact, be higher (Zeglam & Maouna, 2012; Zeglam & Al-Bloushi, 2012). Furthermore, a recent study showed a higher prevalence of ASD in Tripoli with 54% out of 814 children who attended the neurodevelopmental clinic at Al- Khadra General Hospital with speech and language delays between 2011 – 2015 (Zeglam & Al-Ogab, 2015). The trend towards increased ASD prevalence in Libya may continue with as awareness of the disorder is raised in the community and with improved early detection by health care practitioners.

Early identification of ASD is of paramount importance as it allows for early intervention with improved outcomes for affected children (Boyed *et al.*, 2010). For instance, Filipek *et al.*, (2000) reported considerable speech development and intellectual ability improvements in approximately 75% of children who had received earlier intensive intervention for two years or more. Improvements were noted in the children's speech, developmental progress as well as cognitive abilities (Filipek *et al.*, 2000). The authors also reported improvements in caregiver coping and care for their affected children (Filipek *et al.*, 2000). Early identification and diagnosis of ASD requires awareness of ASD and recognition of the early signs and deficits of ASD by the family as well as health workers.

General practitioners (GPs) are frequently the first health care providers (HCPs) to encounter children with suspected autism as they provide health care to children such as immunisations and growth monitoring, and parents often consult GPs first regarding concerns about their children. Thus, the knowledge of GPs concerning ASD plays an important role in early diagnosis (Eseigbe *et al.*, 2015). Unfortunately, knowledge about ASD among GPs is generally poor in Africa (Bello-Mojeed, *et al.*, 2014), and presents a considerable challenge to the early identification and management of the disorder (Zeglam & Maouna, 2012). Limited knowledge about ASD among GPs can lead to a delayed referral for a specialist assessment, and in turn a delay in appropriate therapies (Bello-Mojeed, *et al.*, 2014). Ultimately, these delays can result in a poor outcome for the children affected.

The American Academy of Paediatrics (AAP) recommends that families who are concerned about the disorder should be educated and provided with adequate information, as well as early referral, for intervention and support. Health care providers such as GPs and paediatricians should be adequately trained in the field of mental health, with a particular focus on ASD specifically (Abiodun, 1991). Despite the increasing level of awareness of ASD, considerable gaps remain in the training of HCPs working with children affected with ASD which could account for the lack of knowledge, skills and expert management of children with ASD (Shah, 2001; Casella & Colella, 2004). Appropriate levels of knowledge results in staff confidence when providing educational information and can increasing the level of trust of the families in their health care provider (Kennedy *et al.*, 2004).

It is, therefore, important to explore the knowledge of ASD among GPs in Tripoli, Libya to identify the challenges that may be encountered in their ability to diagnose the disorder. This may assist in identifying deficits in current training, as well as the continuous professional development which if addressed could potentially improve the early diagnosis and referral for treatment of children with ASD. These improvements could ultimately advance the quality of care and outcomes in affected children in Libya.

## **1.2. Problem statement**

There seems to be an increasing prevalence of ASD, which is a serious public health concern among families in Libya (Zeglam & Mauona, 2012). In Libya, the ASD prevalence rate has not yet been accurately estimated. This is due to the lack of reliable epidemiologic data on the disorder as well as the dearth in research infrastructure and available research training programs (Zeglam & Mauona, 2012). Current research conducted in Libya indicates the need for more research on the problem in the country. The public health sector is typically where families obtain their regular health care. Therefore, GPs in these facilities often frequently encounter children who are at risk of ASD development. It is, therefore, important that GPs have enhanced knowledge and information about ASD in order to identify the problem and

appropriately refer families for early specialist service and intervention (Rhoades *et al.*, 2007; Esegbe *et al.*, 2015).

The core aim of this study was to gain a clearer understanding of the level of knowledge of Libyan GPs regarding ASD. The study also hoped to identify the challenges that cause delays in the diagnosis of affected children in Libya.

## CHAPTER 2: SUMMARY OF LITERATURE REVIEW

Despite the current increase in the number of ASD cases diagnosed in Libya, little is known about GPs understanding and knowledge about the disorder (Zeglam & Maouna, 2012). This section presents the available literature on ASD in Libya as well as in other countries. It is necessary for GPs to have adequate knowledge about ASD in order to ensure appropriate and accurate diagnosis of children affected by the disorder. Therefore, this literature review will include a description of ASD, its prevalence rate, the importance of early diagnosis, and the importance of GPs knowledge in improving early ASD diagnosis. In addition, some other challenges that may delay ASD diagnosis and/or intervention will be discussed in the review.

The search strategy for obtaining literature included using the PubMed library (<https://www.ncbi.nlm.nih.gov/pubmed/>), and Google Scholar (<http://www.scholar.google.com>). A number of key words such as "autism spectrum disorder", "diagnosis/early diagnosis", "general practitioners/physician", "knowledge/information", "assessment", and "challenges/barriers" was used to obtain relevant articles. Due to the limited amount of literature on the knowledge, assessment and challenges to autism diagnosis, no time period was defined for this review.

### 2.1. Definition of Autism Spectrum Disorder

ASD is a neuro-developmental disorder that appears during early childhood (APA, 2013; Boyed *et al.*, 2010; Heidgerken *et al.*, 2005). It has become a concerning health problem which affects children worldwide (Centres for Disease Control and Prevention [CDC], 2015). ASD is characterized by persistent social, communication and behavioural impairments accompanied by some restricted, repetitive or stereotyped behaviours and interests (CDC, 2015; APA, 2013; Gomes *et al.*, 2015). These manifestations can differ in severity and range from mild to severe which indicate that every autistic child might have distinct features which requires individualized care (Boyed *et al.*, 2010). It is also recognized that some individuals with the condition are able to live independent and fulfilling lives, whereas others

might be severely impacted by the condition that interferes significantly with their quality of life (Elsabbagh *et al.*, 2012).

The age of appearance of ASD manifestations, and at which diagnosis can be established, is also still varied (Volkmar *et al.*, 2014). Studies have shown that ASD features typically occur in the preschool age; however, some deficits like delayed speech and communication can be detected during early infancy (Jo *et al.*, 2015; Volkmar *et al.*, 2014), such that children can be diagnosed as early as 6 to 18 months of age. In ASD, some children exhibit developmental deficits from the beginning, while in other children normal development might be reported before the loss of skills (Volkmar *et al.*, 2014). Regression in autism is found to be present in about 15-20% of diagnosed ASD cases (Baird *et al.*, 2001). However, delayed diagnosis and late therapy are still challenges because of the role of different critical factors. For instance, many children have a delay in their diagnosis because their parents had the impression that their child would recover in the future (Zeglam & Maouna, 2012). Other factors that contribute to this delay in diagnosis include lack of access to appropriate specialist services to make the diagnosis, and inadequate knowledge and training on the part of the health professionals involved with ASD.

The diagnosis of ASD mainly depends on the presence of deficits in the child's developmental characteristics, and at present, there is no imaging, genetic or other testing that is able to confirm the diagnosis (Volkmar *et al.*, 2014). There are two main diagnostic classification systems for ASD diagnosis which are currently in use, namely, the International Classification of Diseases (ICD) developed by the World Health Organization (WHO) (WHO, 2016), and the Diagnostic and Statistical Manual of Mental Disorders (DSM). Both have similar symptom criteria for diagnosis which are based on the three areas of impairments mentioned above with relative differences in the terminologies (Volkmar *et al.*, 2012). For instance, according to the Diagnostic and Statistical Manual of Mental Disorders Fourth edition (DSM-IV), ASD consists of different categories including autism, Asperger's syndrome, pervasive developmental disorder, not otherwise specified, disintegrative disorders and Rett disorder (Boyed *et al.*, 2010; APA, 2013; CDC, 2015). These disorders all share the diagnostic criteria of ASD used for diagnosis with variability in the impairment features and severity.

The DSM-IV criteria were amended in 2013 to DSM-V, which revised the definition of ASD to include all four previously identified disorders into a single condition with different levels of symptom severity (APA, 2013). ASD is therefore diagnosed when there are deficits social communications and/or interaction as well as restricted or repetitive behaviour patterns or interests or activities (APA, 2013). These diagnostic criteria are still developing as more research is done and further understanding is gained regarding the disorder. As new evidence emerges, and the case definition is adjusted, using the identified criteria will increase the reliability of the diagnosis process of ASD which in turn, will facilitate a greater level of ASD diagnosis, even by inexperienced health professionals (Volkmar *et al.*, 2012).

When a child manifests some of the indicative features of ASD, further developmental assessment is necessary for ASD diagnosis. Furthermore, the recent guideline by the American Academy of Child and Adolescent Psychiatry (AACAP) recommends that developmental assessment and ASD screening of all children should be a mandatory part of routine visits to health facilities (Volkmar *et al.*, 2014). According to these guidelines ASD screening should include inquiries about core ASD symptoms including social and communication deficits as well as the repetitive and stereotyped behaviours (Volkmar *et al.*, 2014). There are two screening instruments that are of potential use and which can assist health professionals in early identification of ASD during the child's health assessment (Baird *et al.*, 2001).

The first screening instrument is the Checklist for Autism in Toddlers (CHAT), which is used as an initial autism-screening tool for children who are younger than 18 months of age and who are at risk of developing ASD (Baird *et al.*, 2001). It contains parent reports and practitioner's observations through direct testing (Charman & Gotham, 2013). However, when the tool was tested in a population setting it was found to have low sensitivity (Baird *et al.*, 2001).

The second screening instrument is a modification of the CHAT, the Modified Checklist for Autism (MCHAT), and contains a questionnaire checklist for parental reporting with no direct testing by the health practitioner (Robins, 2008; Charman & Gotham, 2013). This instrument has been shown to improve the screening method for

ASD children aged between 18-24 months (Baird *et al.*, 2001) and to have higher sensitivity and specificity compared to the CHAT (Robins, 2008).

It is imperative that GPs are aware of these screening tools so that a child who manifests certain deficits will be referred for further screening, assessment and evaluation by an appropriate specialist service (Baird *et al.*, 2001). Furthermore, research has suggested that the recent increase in the prevalence of the disorder might be the result of increased awareness of the disorder or improved availability of the screening and diagnostic instruments. This has important implications for early detection and intervention of the disorder in the affected children (Filipek *et al.*, 2000).

## **2.2. Prevalence of ASD**

There is a clear global ASD distribution with an increase in the prevalence rates over recent years (Boyed *et al.*, 2010). The disorder has affected millions of individuals worldwide and, according to data from the CDC, the global prevalence of ASD has significantly increased from 10% to 17% in recent years, and from 1: 150 children in 2007 to 1:68 children in 2015 (CDC, 2015). It has also been shown that boys are four times more likely to be affected by ASD compared to girls (CDC, 2015; Woolfenden *et al.*, 2012). The increase in ASD prevalence has led to intensified concerns about the disorder as well as ongoing research dedicated to finding effective and accurate diagnosis and intervention, which can improve the quality of life of affected children.

In Africa, there is limited data available on the disorder. The diagnosis of autism was first made in Africa three decades after it was first described by psychiatrist Dr. Leo Kanner (Bello-Mojeed, Bakare, & Munir, 2014). There is a lack of information available to families, and health professionals are often not adequately skilled to engage with affected children (Oshodi *et al.*, 2016). A review conducted by Bello-Mojeed, Bakare and Munir (2014), on autism in Africa, found a clear deficit in available epidemiological data. More specifically, there was a deficit in validated screening measures, diagnostic tools, and strategies to provide clinical care in most resource-limited settings in Africa. Consequently, the diagnosis and prevalence of

ASD is under-estimated for the continent (Bello-Mojeed *et al.*, 2014; Ruparelia *et al.*, 2016).

In Libya, there is dearth of ASD-related research (Zeglam & Al-Bloushi, 2012). Existing publications from Libya have all been produced by a single unit which investigated ASD prevalence among children who were attending a neuro-developmental clinic at Al-Khadra General Hospital (AKGH) in Tripoli (Zeglam & Al-Bloushi, 2012). These studies indicated an increase in the ASD prevalence among the population served by AKGH. However, it remains unclear whether this increased prevalence is due to improved awareness and referral services or if it is a true increase in the ASD prevalence. The latest study identified that about 440 (54%) out of 814 of children who attended the neuro-developmental clinic at AKGH during the study period were diagnosed with ASD (Zeglam & Al-Ogab, 2015). Overall for Libya, there is a lack of data on the disorder and accurate prevalence estimation is not possible. There is an urgent need for more epidemiological studies and more research to improve ASD understanding among health professionals.

### **2.3. Causes of ASD**

The specific causes of ASD are largely unknown. There are many phenomena related to ASD causation and development in children (Boyed *et al.*, 2010). Recent publications have shown links with environmental factors as well as some biological or genetic interactions (Volkmar *et al.*, 2014). These factors are thought to contribute to the development of ASD in children by their effect on early brain development (Boyed *et al.*, 2010). ASD may be regarded as a neurodevelopmental disorder with a strong genetic link. This was based on the high recurrence risk for ASD in siblings and increased recurrence in identical twins, which has strongly supported the presence of an underlying genetic factor (Volkmar *et al.*, 2014).

One of the common genetic disorders associated with 15-25% of individuals diagnosed with ASD is fragile X syndrome (Bailey *et al.*, 1998; McDuffie *et al.*, 2010). Other genetic disorders associated with ASD-like characteristics include: Tuberous Sclerosis Complex (60%), Down syndrome (5%), Angelman syndrome (50%), Cornelia de Lange syndrome (55%), and Rett's syndrome (25%) (Moss &

Oliver, 2012). Researchers suggest that gene effects in those syndromes have an effect on the biological and neurological development of affected individuals, which causes the appearance of ASD like characteristics (Moss & Oliver, 2012). The research also suggested that although multiple genes could be responsible for ASD causation, exposure to specific environmental factors might also be necessary to trigger ASD development in individuals at risk (Moss & Oliver, 2012).

There are different environmental risk factors that have been attributed to development of ASD in children (Grabrucker, 2013); these include exposure to infections or toxins during foetal life which can have an effect on early foetal brain development (Grabrucker, 2013). Previously there was a concern about the relationship between the measles, mumps and rubella (MMR) vaccination and the development of ASD in children as a possible postnatal environmental cause (Volkmar *et al.*, 2014). This concern was raised after an apparent increase in ASD prevalence among children who received the vaccine (Volkmar *et al.*, 2014; Michelle *et al.*, 2017). The research underling this hypothesis has been shown to be flawed, and as yet there is no evidence to support the hypothesis that the MMR vaccine causes ASD (Michelle *et al.*, 2017). The theory remains popular with the lay public and has affected immunization uptake, with outbreaks of measles and morbidity as well as mortality in children. Despite current opinions, debates and existing research, approximately 90-95% of ASD diagnose are considered to be of unknown cause (Boyed *et al.*, 2010; Rahbar *et al.*, 2011). Further research on the subject is therefore urgent and necessary to reach an understanding of the specific causes or risk factors behind the development of ASD in children (Sidjaja, 2015).

#### **2.4. Early warning signs indicating risk of ASD in children**

The risk for ASD development can be indicated by a number of signs that appear during early childhood (Boyed *et al.*, 2010). These signs include a group of developmental and behavioural delays that usually occur early during a child's growth and development phase (Boyed *et al.*, 2010). These include the lack of or limitation in the adaptive behaviours such as co-ordinated eye contact, social smiling and responses to name call (Boyed *et al.*, 2010; Wetherby, 2004; Baranek, *et al.*, 2005; Landa, 2007; Sullivan, 2007). Furthermore, the lack of early verbal communication behaviours such as producing vocalizations and babbling can be indicative of ASD in

the young infant (Wetherby, 2004). Repetitive or limited use of objects and toys can also be one of the warning signs that indicate an early ASD appearance in children (Baranek, *et al.*, 2005; Bryson *et al.*, 2007).

Identification and recognition of such signs by GPs who engage with children is imperative. This will assist in facilitating early identification and diagnosis and could help to differentiate ASD from other developmental abnormalities (Rahbar *et al.*, 2011).

## **2.5. ASD co-morbidity**

The diagnosis of ASD can be complicated by the presence of other co-morbidities (Volkmar *et al.*, 2014). Social, cognitive, and adaptive skill deficits are the main issues that have been shown to co-occur with ASD in about 15-55% of children (Volkmar *et al.*, 2014; Elsabbagh *et al.*, 2012). There are also other behavioural difficulties observed in ASD; these include hyperactivity disorders such as attention deficit hyperactivity disorder (ADHD) (28.1%), anxiety disorder (29.2%), obsessive-compulsive disorder (OCD) (8.2%), depression (0.9%), sleep and feeding disturbances (23%) (Volkmar *et al.*, 2014; Belardinelli *et al.*, 2016). In addition, it has been shown that some ASD cases are accompanied by other neurological problems such as epilepsy and seizures (APA, 2013; Volkmar *et al.*, 2014). It is important that HCPs such as GPs are aware of such co-morbidities so that they can differentiate ASD from other developmental and neurological disorders and refer children early for further specialist assessment and diagnosis. Overall, it is important that GPs identify and recognise the early warning signs of ASD. This will ultimately assist in improving the early identification and diagnosis of ASD.

## **2.6. The impact of early identification and intervention of ASD**

The early identification of ASD is important as it facilitates the early referral of children to specialist services (Garg *et al.*, 2014). Early intervention has been shown to be associated with enhanced levels of improvement and positive developmental outcomes in affected children (Bryson *et al.*, 2007). More specifically, it has been found that early identification and intervention services can improve long-term outcomes in language development, social skills and reduce the stereotypical and

ritualistic behaviours presented with the disorder (Bryson *et al.*, 2007). For improved outcomes to be observed, a child should receive at least two or more intensive early interventions in the early preschool years (Filipek *et al.*, 2000; Camarata, 2014). On the other hand, delays in diagnosis could potentially have a long-term negative effect on the child's behavioural and educational development (Heidgerken *et al.*, 2005).

Additional benefits of early intervention include ensuring earlier educational planning for the affected children, reducing the stress on family members and improving the manner in which they deal with their children's disorder (Mandell & Novak, 2005; Filipek *et al.*, 2000).

### **2.7. The role of the GP knowledge in the diagnosis of ASD**

At the primary care level, GPs have an important role in screening for developmental delays and identification of a child at risk of an ASD diagnosis. This facilitates the early diagnosis and access to early intervention services of affected children (Rahbar *et al.*, 2011). Awareness of early childhood development and symptoms of ASD as well as diagnostic criteria for ASD are important components of essential GP knowledge. Rhoades, Scarpa, & Salley (2007) explored the importance of GPs knowledge surrounding ASD and found that the level of GPs knowledge of ASD greatly influenced the age at which a child is diagnosed with the disorder (Rhoades *et al.*, 2007). Results of the survey showed that the average age of ASD diagnosis was 4 years and 10 months, which is considered later than the optimal age of diagnosis at which children can benefit from an early intervention (Rahbar *et al.*, 2011). In this survey, the researchers also found that only approximately 40% of GPs gave additional information to concerned families; 15-34% gave advice on educational programmes, while only 6% referring suspected ASD cases to further specialist assessment. This emphasises the need for GPs to have adequate knowledge in order to enhance their referral of ASD cases.

Continuous professional development for GPs training and improvements in diagnostic skill and knowledge can help in the integration of mental health into primary care (Pillay & Lockhat, 2001). Training is therefore an important tool for improving the knowledge and ability of health professionals including GPs to

diagnose any behavioural or developmental disorders. The training and education of GPs can therefore help in integrating ASD health services and make them available and accessible to the Libyan population.

Although knowledge, awareness, and research about ASD has increased globally, this is much more apparent in resource rich settings (Rahbar *et al.*, 2011; Sidjaja, 2015), and not much is known regarding the disorder in resource limited settings where services for children with special needs are poorly established (Samadi & McConkey, 2011; Bakare *et al.*, 2015). Wide variations are reported in the literature regarding ASD diagnosis, clinical characteristics and interventions offered (Imran *et al.*, 2011; Sidjaja, 2015). For example, Esegbe *et al.*, (2015) conducted a study to evaluate medical doctors in Nigeria in terms of their knowledge about ASD. The authors found good knowledge among the specialists particularly paediatricians and psychiatrists, and in those who had observed a case of ASD in the past (54.5%), whereas knowledge was clearly limited among general practitioners (40.8%). The researchers found that improved knowledge correlated with previous training received, practice in tertiary hospitals and their familiarity with ASD cases in the past (Esegbe *et al.*, 2015). This indicates the salience of educational training of GPs, which can enhance early diagnosis and intervention in ASD, and assist in improving outcomes in affected children (Esegbe *et al.*, 2015).

In a cross-sectional survey conducted in Karachi, Pakistan, the knowledge and attitude of 348 GPs regarding ASD was assessed (Rahbar *et al.*, 2011). The researchers found that GPs under 30 years of age and those who obtained their medical degree in the last 5 years reported an adequate knowledge about ASD (OR = 3.0; 95% CI: 1.71, 5.31, and OR = 2.56; 95% CI: 1.48, 4.42, respectively) (Rahbar *et al.*, 2011). Although these GPs had good knowledge of ASD, some misconceptions were also reported with regard to the signs, symptoms and aetiology of ASD. The survey also found that more than half of GPs in Karachi (55.4%) reported that they had never heard of the disorder. While about 42% of those who reported knowledge about ASD (less than 20% of the total number of GPs surveyed) indicated having a working knowledge of ASD in their work practice (Rahbar *et al.*, 2011). This indicates the great need to improve GPs knowledge through undergraduate, postgraduate, and continuous professional development.

In Libya the available studies about ASD are limited to those that have estimated the prevalence of the disorder (Zeglam & Al-Bloushi, 2012). Similar to reports in other countries, families in Libya usually have their first contact with GPs during their child's routine health visits. The situation in Libya is similar to other developing countries, where there are a limited number of expert professionals who can effectively deal with ASD and assist in the intervention process. In addition, there are inadequate educational and training programmes available, with only little attention given to ASD and other developmental disorders in the Libyan medical school curricula (Zeglam & Al-Bloushi, 2012). This means that early identification and diagnosis of ASD is not available in Libya. The lack of resources in available training resources and clinical expertise present an obstacle to health care providers who are not able to manage cases appropriately as well as concerned families who are not able to get access to appropriate treatment.

## **2.8. Challenges to early identification and intervention of ASD in children**

Additional challenges can also arise if there is a delay with the diagnosis of ASD. It is recognized that ASD and other developmental disorders have a strong effect on the family's daily life routine and can cause an overload, especially on the parents. A systematic review conducted by Gomes *et al.*, (2015) showed that the emotional pressure of having a child with ASD symptoms often caused parents to delay seeking care, which resulted in delayed ASD diagnosis. Inadequate access to health care services as well as social support has also been identified in the review as contributing factors to increased levels of stress and decrease in the parents' quality of life (Gomes *et al.*, 2015).

Siller *et al.*, (2013) indicated that public awareness of the disorder plays a role in identification of the prevalence of ASD in children. This is because raised awareness increases the levels of early identification and diagnosis, which will thereby lead to early intervention and improved outcomes. Another recognized challenge includes the lack of funding for intervention services (Boyed *et al.*, 2010). The social stigma and the feeling of being ashamed or afraid of hearing the ASD diagnosis was also noticed as a barrier (Zeglam & Al-Bloushi, 2012; Zeglam & Mauona, 2012). The wide

variability in the manifestation of the disorder, which differs from mild to severe, together with the different classification of ASD in children, can confuse health professionals in diagnosing the disorder (Koegel *et al.*, 2014).

## **2.9. Rationale**

ASD has emerged as a significant public health concern as the growth in prevalence indicates. Moreover, with the revision of the DSM-V classification it is possible that the number of children diagnosed with ASD might increase substantively (Mandell & Novak, 2005). In many contexts children tend to receive health care from GPs; hence their role in the early identification and diagnosis of ASD in children is critically important (Rhoades *et al.*, 2007). It has been reported that primary health workers including GPs, who have little or no training in psychiatric and mental health in general, often hold on to traditional views of the aetiology of such disorders which affects the accurate diagnosis and cause delay in intervention (Abiodun, 1991). Limited knowledge about childhood autism among GP's could be an important barrier to identifying, diagnosing, and improving the health and well-being of children affected by ASD. Inadequate knowledge of ASD among GPs and failure to give further information to parents may be a reflection of lack of training in the wide range of behaviours that occur across ASD in children (Igwe *et al.*, 2011). This further may also cause a delay in diagnosis and subsequently limits access to care, and early interventions that are known to improve quality of life and prognosis in children with childhood autism (Igwe *et al.*, 2011).

This is the case in Libya where there is a limited number of expert professionals who can adequately make an ASD diagnosis, as well as manage diagnosed children appropriately. The majority of GPs in Libya practice in public hospitals and clinics, where they can be reached by the wider population in the country. It is therefore critical that GPs have sufficient knowledge and skills of ASD and other developmental disorders. To the best of our knowledge, there appears to be no studies that have described or assessed the level of knowledge of ASD among GPs in the country. Current research conducted in Libya focused on estimating the prevalence of the disorder. This study will explore ASD knowledge among Libyan GPs, to identify

any challenges in their ability to recognise, diagnose, and refer children for specialist care.

## **2.10. Study objectives**

The objectives of the study were as follows:

### ***Primary objective:***

To identify the knowledge of GPs in Tripoli, Libya regarding ASD by using a validated questionnaire.

### ***Secondary objective/s:***

To identify the experiences of GPs, specifically the challenges in identifying, diagnosing and making a referral of ASD suspected cases in their clinics.

## **CHAPTER 3: METHODOLOGY**

This chapter presents the study setting and participants recruited in this research study, followed by a description of the sampling strategy, data collection procedure, and the method of data analysis used. Lastly, the potential bias, reliability of the study and the ethical considerations that the researcher adhered to in this research are discussed.

### **3.1. Study setting and participants**

A cross-sectional survey was conducted among GPs in Tripoli, Libya over a four-month period between 1<sup>st</sup> May to 31<sup>st</sup> August 2017. Libya is a developing country located in North-Africa and lies along the Mediterranean coast over 1770 km in length with a population of approximately 6,278 million people according to the year 2015 estimations (World Bank, 2016). Approximately 77.7% of its inhabitants live in urban areas and the remainders reside in rural and desert areas. It is bounded by Tunisia and Algeria from the West; Niger, Chad and Sudan from the South, and Egypt from the East (Figure 3.1). The chaos that followed the revolution in Libya in 2011 has led to instability of the country with no authority in full control as yet (World Report, 2017). Many other issues as a result of the huge damage affected different public institutions and sectors such as the communication services including internet and phone use (World Report, 2017).



Figure 3.1: Map of Tripoli, Libya in the African continent (Google maps, 2016)

Tripoli is the capital city where there is about 1,120 million of the inhabitant population. The Al-Khadra General Hospital (AKGH) is the regional referral hospital where all children with ASD are referred to for further evaluation and diagnosis. It is located in the capital of Tripoli and provides services to the entire population of Tripoli, its suburbs as well as patients from other Libyan cities. The neuro-developmental clinic in the hospital provides services to the referred children who have any developmental and/or language disorders including ASD (Zeglam & Al-Ogab, 2015). It serves about 30-35 patients per session a day from different age groups (0-16 years). In order to practice medicine in Libya, physicians must be certified and licensed by the Health Professions Council (HPC). A total of 7150 working physicians were registered in Tripoli during the study period.

### **3.2. Study design**

A cross-sectional, descriptive study design was applied in this study among GPs in Tripoli, Libya using an online survey containing a questionnaire.

### **3.3. Recruitment**

The participants were recruited through the use of purposive sampling because of their work nature of being in contact with people on whom the research problem was focused on (Mathers, Fox, & Hunn, 2009). This sampling strategy is based on the assumption that in order to gain insight into an experience, the researcher should

select participants from whom information which is most relevant to the study can be obtained (Palys, 2008; Burns, *et al.*, 2008). As the study explores the knowledge of Libyan GPs about ASD as well as the challenges of ASD diagnosis, GPs were considered the suitable target group to gain enriched information on the research problem.

All participants were selected according to their eligibility to be part in the study (This will be discussed later). The participants included GPs who have qualified as physicians in Tripoli area. GPs were identified as being the most appropriate because they are the first contact with patients and can explore and describe their working experiences with ASD at the primary healthcare setting. Access to participants was gained through an application sent to the HPC in Tripoli to provide a list of practicing GPs in the area with their contact details. An application submitted to the HPC in Libya and a request of the list of registered and practising GPs in Tripoli was applied for. As the Libyan HPC was not able to release contact details of GPs on the register, participants were recruited through social media. In addition, written posts included invitation and recruitment letters was submitted to different medical groups (Appendix 3). The potential participants in this study included GPs in the private and public health sectors in Tripoli and working at different hospitals and clinics in and around the area of Tripoli and included participants from AKGH as well.

### **3.4. Inclusion & exclusion criteria of sample**

#### ***Inclusion criteria***

1. The study included all GPs from the Tripoli area who routinely manage children between the ages of 1 and 16 years of age and who make referrals to AKGH for further assessment and diagnosis.

#### ***Exclusion criteria***

1. All specialists who are responsible for ASD assessment and diagnosis
2. Other GPs who are not working with children were excluded.

### 3.5. Sample size calculation

The participants involved in this study were medical doctors who are working as GPs in Tripoli, Libya. In 2017 a total of 7153 medical doctors qualified as GPs were registered with the Libyan HPC in Tripoli. The sample size was calculated using an online survey calculator to generate a representative sample with a precision of 5%, and 95% confidence interval (Survey Monkey, 2017; Figure 3.2). This equates to a required sample size of 365. To allow for a 30% response rate, 500 questionnaires were aimed to be distributed in order to reach the desired sample size (Garg *et al.*, 2014). However, this desired number could not be reached, and only 370 GPs were obtained (See results chapter)

$$\text{Sample Size} = \frac{\frac{z^2 \times p(1-p)}{e^2}}{1 + \left(\frac{z^2 \times p(1-p)}{e^2 N}\right)}$$

Figure 3.2: Survey calculator formula used to calculate the sample size (Survey Monkey, 2017)

### 3.6. Data collection

An online survey was developed based on a questionnaire consisting of the following three main sections, namely demographic information, the Knowledge about Childhood Autism among Healthcare Workers (KCAHW) and the self-administered questionnaire. This questionnaire was tested and validated for its use in this study (see piloting section). Questions included the demographics details of the participating GPs, including gender, age, the highest qualification obtained, the place where they have qualified as GP, the years of practice and average number of ASD cases they seen before (Appendix 1A).

The second section assessed the GPs knowledge about ASD using the structured KCAHW which contained 19 questions divided into four domains that describe ASD in children (Appendix 1B). These domains include social interaction, impairment in communication, obsessive and repetitive behaviours, characteristics of autism as a disorder and its co-morbidities (Eseigbe *et al.*, 2015). Each domain contains a number of items and scores (Table 3.1; Appendix 1D). The median KCAHW score in this study was used as measure of the knowledge level among respondents. A total score

of 19 (i.e. 25 questions are correctly answered) will indicate a sufficient knowledge. In this study, the median score was used as benchmark to determine adequate knowledge among GPs participated. This is because there were assumptions that the finding's values would be not normally distributed in this study.

Table 3.1: KCAHW questionnaire's domain items and scores (Bakare *et al.*, 2008).

<b>KCAHW domain</b>	<b>Knowledge assessed</b>	<b>Number of items</b>	<b>Total score</b>
1	Impairments in social interactions	8	8
2	Impairments in communication	1	1
3	Obsessive and repetitive pattern of behaviours	4	4
4	Characteristics of autism as disorder and its co-morbidities	6	6

The third section was the self-administered questionnaire, which contained questions pertaining to assess knowledge, training, as well as experiences regarding challenges GPs consider playing a role in the delay of ASD diagnostic process (Appendix 1C). As medical education in Libya is provided in English, the questionnaire and all health information in this study was provided in the English language with clear defined questions.

### *3.6.1. Data collection tool*

Data was collected and managed through the Research Electronic Data Capture (REDCap), electronic data capture tools hosted at the University of Cape Town (UCT). REDCap is noted as being a secure web-based application designed to support data capture for research studies and was made available to researchers and students at UCT. The interface has been found to be useful and user-friendly and is beneficial because it provides an audit trail for tracking data manipulation and export procedures. An additional advantage is that REDCap makes provision for automated export procedures to common statistical packages (Harris *et al.*, 2009).

To ensure confidentiality of the data, electronically stored data was kept password protected and only the investigator had access to the computer. All data were stored on a password-protected computer and will be destroyed five years after completion of the study in accordance with the university's HREC requirements. No identification by names or email addresses was required and the automatic IP collection key on the online survey was switched off to prevent automatic collection of IP addresses.

### **3.7. Pilot testing**

Pilot testing is important to ensure that the survey would be feasible in the experimental study (Teijlingen Van *et al.*, 2001). Challenges that need to be addressed before the study are also identified through pilot testing. Pilot testing is beneficial in assessing whether questions are easily understood, and whether questions need to be revised (Teijlingen Van *et al.*, 2001). The questionnaires including KCAHW were piloted and tested on 10 physicians in Tripoli to identify the ease in accessing the online survey, and whether there may be any challenges related to completing the survey online. In addition, for questionnaire clarification, validation, and any emendations required before this study conducted (Appendix 4).

### **3.8. Data analysis**

The current study conducted data analyses of the results from the 62 completed surveys. Data were imported from the REDCap website to a Microsoft Excel spreadsheet and then to a STATA data file, using version STATA 12 for Windows. Due to the small sample size, the mean score could not be reported as data was not normally distributed. The median and interquartile ranges in each domain and for the total score were therefore calculated instead for all participants.

The GPs participated in this survey were characterized using descriptive statistical analysis. A non-parametric test (Wilcoxon rank sum test) of distributed knowledge scores in each domain analysis was applied to determine whether there was a significant difference between participants' characteristics and their KCAHW scores.

The qualitative data in the open-ended responses in the self-administered questionnaire were analysed by generating meaning from participants' perspectives through a process of induction, followed by empirical generalisations derived from the literature and theorising about the meaning perceived by the researcher. The analysis involved deriving insight and meaning, reviewing the data several times to verify emergent ideas and theories. There are four general stages involved in analysing qualitative information: the first stage involves identifying broad themes; the second stage involves making comparisons and expanding emerging frameworks; the third stage involves refining categories and looking for relationships within the data. The final stage involves theorising the insights and understanding gained from the data (Heath & Cowley, 2003).

### **3.9. Potential bias**

#### *3.9.1. Selection bias*

Selection bias refers to the process of participant's recruitment and inclusion criteria in the study (Smith & Noble, 2014). Recruitment bias could occur as the participants of the study were recruited through social media and were invited to participate in the survey through a post on the internet, which might exclude individuals without internet access. However, the researcher included the snowballing sampling strategy and increased the sample size so that the bias could be minimized.

#### *3.9.2. Gender bias*

Gender bias can appear with recruiting and retaining study participants, and when gender differences are not considered between males and females during recruitment stage (Holdcroft, 2007; Moss-Racusin *et al.*, 2012). Efforts were made in this study in order to recruit a compatible number of participated GPs from both genders. However, this was difficult to obtain which might have led to a potential bias.

### **3.10. Reliability and Validity**

The reliability in quantitative research refers to the extent of the consistency and representation of an assessment tool when it is used over time (Golafshani, 2003), while the validity can be determined by whether the tool accurately measures the objectives that the researcher hoped to reach (Golafshani, 2003). The KCAHW

questionnaire, which was designed by Bakare et al., (2008), is a basic tool that assesses the knowledge of autism. It has been used in previous studies (Eseigbe *et al.*, 2015; Shaukat *et al.*, 2014) which emphasizes its reliability and internal consistency (Igwe *et al.*, 2011). The data collection tool was piloted on 10 participants to ensure that the questions were understood and elicited relevant information, and was therefore deemed appropriate for use in the study. There were no concerned problems identified with the tool and all piloted participants indicated that the questions were easy to read, took maximum 10 minutes to complete and it covered relevant aspects of ASD knowledge.

### **3.11. Ethical considerations**

All GPs involved in this study were informed about the study and informed consent was obtained from each of the participants (see Appendix). Confidentiality and privacy of participants were kept safe and neither the questionnaires contained any information that may have identified the individuals who participated. The study was approved by the University of Cape Town (UCT) Health Sciences Faculty Human Research and Ethics Committee (HREC) (Appendix 5), and the Ministry of Health in Tripoli, Libya (Appendix 6). It is necessary to ensure that this research study follows correct clinical practice and ethical principles for research involving human subjects as stipulated in the Helsinki Declaration (last revised in 2013). The declaration includes several principles in terms of ensuring participant autonomy, non-maleficence, beneficence, and justice (World Medical Association (WMA), 2013). All previous points were adhered to in this study, and detailed description was included in the participant's consent form to ensure their understanding to the purpose of this study (Appendix 2).

#### *3.11.1. Informed consent*

Voluntary participation was sought from every participant and consent was taken thereafter (Appendix 3).

#### *3.11.2. Participant's autonomy and confidentiality respect*

All participants were informed that all information they provided in the questionnaire would be protected (WMA, 2013), and only the researcher was knowledgeable of

participants' identity in the study. Data and results were only used from the online survey questionnaire and these were kept private. All questionnaires included numbers instead of the participant's name.

#### *3.11.3. Non-maleficence*

Medical research should be conducted in a manner that minimises any possible harm to the participants (WMA, 2013; Singh, Kagee & Swartz, 2014). There was no harm to the participants after their participation in this study.

#### *3.11.4. Justice*

According to the declaration regarding principles, all participants in the study should be treated equally (WMA, 2013). An agreement was undertaken from all participants to allow them to voluntarily participate and indicate their consent before the commencement of the study.

### **3.12. Risks and benefits of this study**

The participation in this survey study was anonymous; hence there was no inherent risk in completing the online survey. Although participants received no direct benefits for their participation in this research study, the survey related to important aspects of the diagnosis of ASD which could potentially improve participant's knowledge, understanding and experiences of diagnosing and managing children with ASD in Libya.

## **CHAPTER 4: RESULTS**

### **4.1. Introduction**

The purpose of the study was to investigate how ASD is diagnosed in Libya by determining the level of education about the disorder, and through assessing the relevant sample in the concerned population. An electronic survey link was emailed to 370 certified medical doctors in Tripoli and 62 completed surveys were returned from the total (n = 215).

This chapter presents the results of the collected and analysed data including descriptive statistics, inferential statistics and some qualitative findings related to the identified challenges in diagnosis and management of ASD.

### **4.2. Demographic Data**

The total number of electronic surveys emailed to GPs totalled 370. The number of surveys returned to the REDCap application survey site was 215 representing a response rate of 58.1%. However, the number of complete responses was found to be only 62 which were included for data analysis, indicating an overall response rate of 16.7%.

The median age of respondents was 30 years of age, IQR (29-33) years; with only five GP's older than 40 years in the selected sample (figure 4.1). The majority (n=55) of participants were females (89%) and only 7 (11%) were males amongst the GPs that participated (Figure 4.1). Ninety three percent (93.4%) of the participating GPs received their undergraduate medical training in Libya. The majority of respondents (58.3%) had only been in clinical practice between 1-5 years, and only 30% had more than 5 years experience in clinical practice.

Amongst the 62 respondents, 11(17.74 %) had trained in Primary Health Care (PHC) units, while 47 (75.8%) trained in general hospitals, and only four (6.4%) had trained in private sector units. GP's in the sample had limited exposure to children with autism: only eight (12.9%) had seen > 10 cases, 31(50%) had seen between 1 to 5 cases and 14 (22%) had never seen a case with autism (Table 4.1).

Table 4.1: Demographic information of medical GPs that participated in this study

	<b>Demographic</b>	<b>Frequency (%)</b>
<b>Age</b>	>30 years	26 (41.9%)
	<30 years	36 (58.0%)
<b>Gender</b>	Females	55 (89%)
	Males	7 (11%)
<b>Degree</b>	Bachelor	43 (71.6%)
	Masters	3 (5.0%)
	Other*	14 (23.3%)
<b>Qualifications</b>	Libya	57 (93.4%)
	Africa	2 (3.2%)
	Other#	2 (3.2%)
<b>Work experience</b>	< 1yr	7 (11.6%)
	1-5yr	35 (58.3%)
	>5yr	18 (30%)
<b>Place of practice</b>	Primary Health Care	11 (17.7%)
	General	47 (75.8%)
	Private	4 (6.4%)
<b>Type of patients in practice</b>	Children	46 (74.1%)
	Adults	4 (6.4%)
	Both	12 (19.3%)
<b>Case of ASD**</b>	no cases	14 (22.5%)
	1-5 cases	31 (50.0%)
	6-10 cases	9 (14.5%)
	>10 cases	8 (12.9%)

\* Diploma in Child Health, Subspecialist, Paediatrician, Medical board exam

#UK, USA

\*\* Autism Spectrum disease

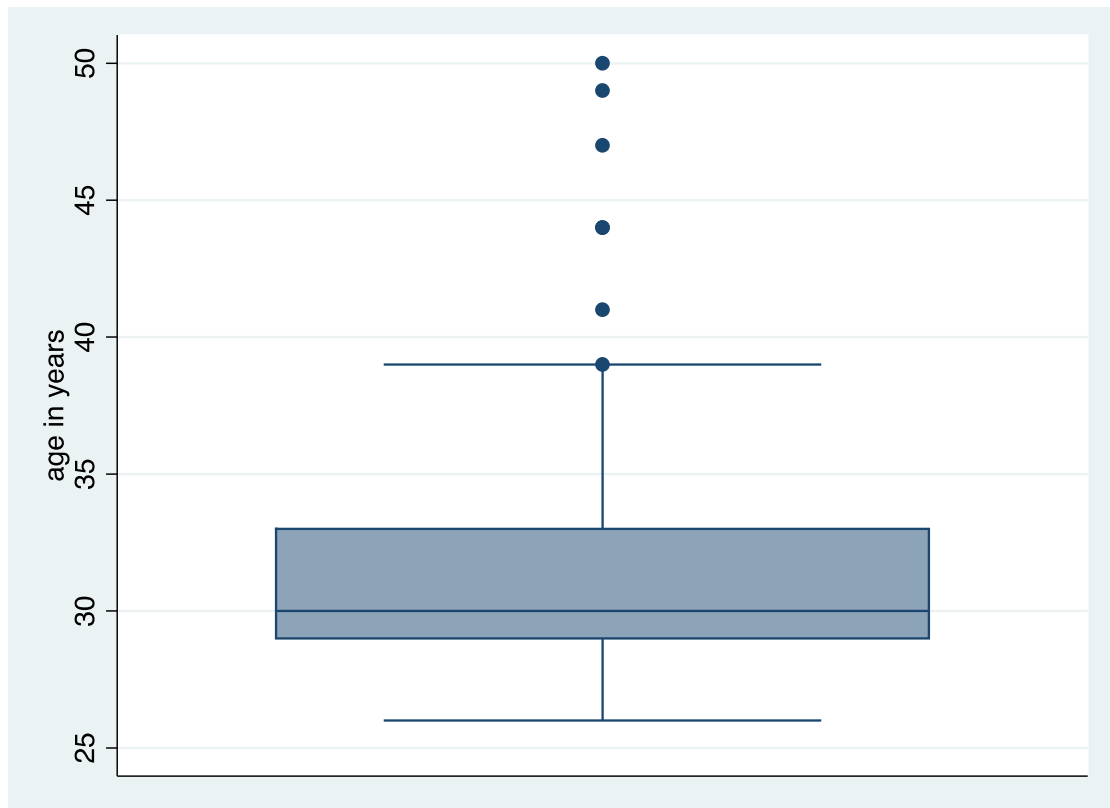


Figure 4.1: Box and Whiskers plot of the distribution of age of 62 study participants

### 4.3. Analysis of domain questions on KCAHW questionnaire

Questions in Domains 1–3 of the KCAHW questionnaire contained information that focused on the recognition of ASD manifests among GPs involved in this study. The questions in Domain 4 contained information that could explore the participated GPs knowledge about some of ASD aspects. The scoring of the knowledge questionnaire was based on the original Bakare *et al.*, (2008) structured scoring system (Appendix 1D), in which a score of one indicated a correct answer only. The total median score was therefore used as a benchmark to determine the level of knowledge of the GPs. A score equal to or above the median score was identified as good knowledge, while the scores below the median were identified as insufficient knowledge. The median score in each domain was also calculated to indicate the knowledge and knowledge deficit among participants. The total median score on the KCAHW questionnaire among the GPs that participated in this study was found to be 10 out of a total of a possible score of 19 (Table 4.2).

Table 4.2. Median KCAHW scores among participated GPs per each domain

<b>KCAHW Domain</b>	<b>Median score</b>	<b>IQR</b>
Domain 1	6	5 to 7
Domain 2	0	0 to 1
Domain 3	2	1 to 3
Domain 4	2	1 to 3
<b>Total</b>	<b>10</b>	<b>8 to 12</b>

KCAHW= Knowledge about Childhood Autism among Health Workers

Most GPs (89%) understood fairly well the different stereotypical and repetitive behaviours of ASD such as hand or finger flapping, abnormal eating habit, persistent pre-occupation with parts of objects, and love for regimented routine activities. On the other hand, GPs were less knowledgeable about the manifestations associated with ASD and showed large deficits about co-morbidities (48%), social interaction (25%), and communication impairments (24%) (Figure 4.2).

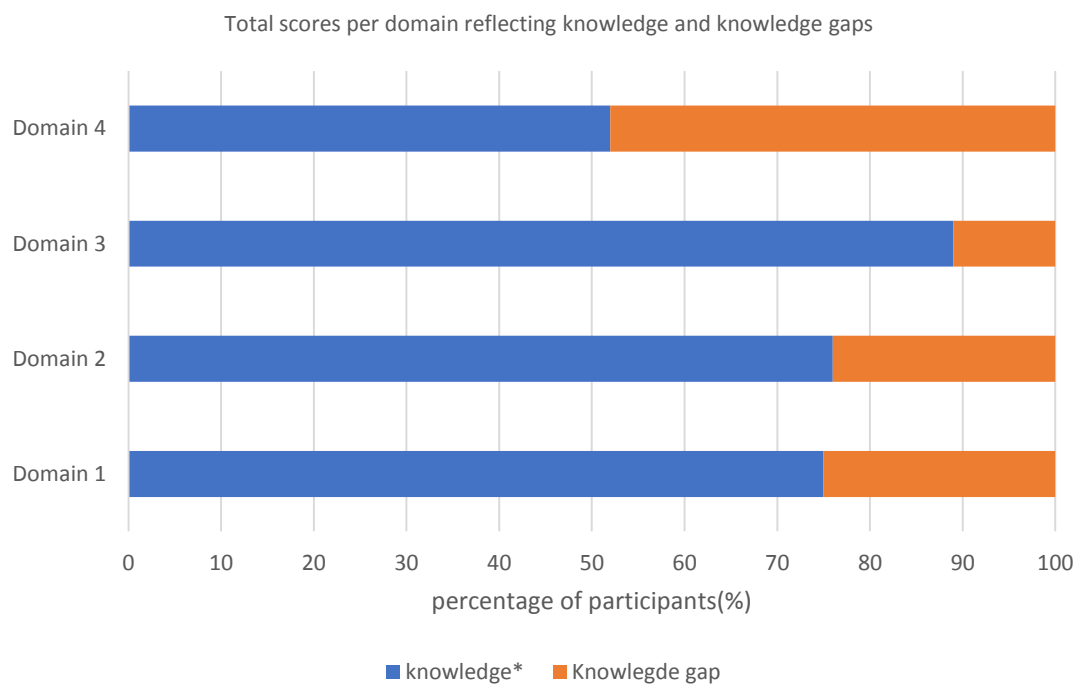


Figure 4.2: Total scores per domain reflecting knowledge and knowledge gaps

#### 4.3.1. The distribution of KCAHW scores in each domain among participated GPs

A descriptive analysis with some inferential statistics was applied to report the distribution of knowledge questionnaire scores among the participated medical GPs in Tripoli. A complex analysis was limited by the small sample size, the total sample

size settled at 62 after the incomplete forms were excluded. A non-parametric test (Wilcoxon rank sum test) was applied to identify differences of distributed knowledge scores in each domain with age and gender. There was no significant difference in domain scores when age and sex of participants were considered. The distribution of domains scores by gender, age and work experience are shown in Table 4.4. There were no clear differences between age groups (p=0.94), gender (p=0.81), and work experience (p=0.61) with knowledge scores.

Table 4.3. Distribution of knowledge scores by gender, age and work experience

		Domain 1: score			Domain 3** score			Domain 4*** score		
		≤50% (≤4/8)	>50% (>4/8)	p value#	≤50% (≤2/4)	>50% (>2/4)	p value	≤50% (≤3/6)	>50% (>3/6)	p value
		n(%)	n(%)		n(%)	n(%)		n(%)	n(%)	
<b>Gender</b>	Female	7(12.7)	48(87.2)	0.91	38(71.7)	15(28.3)	0.13	44(84.6)	8(15.3)	0.94
	Male	1(14.2)	6(85.7)		6(100)	0(0)		6(85.7)	1(14.2)	
<b>Age*</b>	≤30yrs	3(9.6)	28(90.3)	0.36	24(77.4)	7(22.5)	0.64	24(82.7)	5(17.2)	0.81
	>30yrs	5(17.8)	23(82.1)		18(7)	7(28)		23(85.1)	4(14.8)	
<b>Work experience##</b>	≤5 years	4(9.5)	38(90.4)	0.19	32(78.0)	9(21.9)	0.47	35(87.5)	5(12.5)	0.61
	>5 years	4(22.2)	14(77.7)		11(68.7)	5(31.2)		14(82.3)	3(17.6)	

#p-value from Wilcoxon rank-sum test

\*missing data 3/62 for age

\*\* missing data 3/62 for domain 3 score

#### 4.4. Analysis of Self – administered questionnaire responses

An additional questionnaire was also included which contained questions that explored the challenges identified by GPs regarding their identification, diagnosis and management of ASD in children. GPs rated their own knowledge of ASD within the moderate to high range (62.9%), with only 3.2% reporting a low self-knowledge about autism. GPs regarded general knowledge and training on ASD in Libya as adequate (86% moderate to high knowledge of ASD). Thirty eight percent of GPs were however unaware of the specific diagnostic criteria for ASD. More than 90% of GPs were aware of referral pathways for children with suspected ASD and 77% of GPs had knowledge of special schools for learner with ASD. Seventy percent of GPs were unaware of the existence of support groups for families and children affected by

ASD in their practice. The average waiting time for further assessment and intervention by a specialist was indicated as more than six months in a suspected child (Table 4.4). There was a significant number of GP's who did not know the waiting period for specialist review (44%) or intervention for children with ASD (40%) in their practice. A surprisingly high percentage of GP's expressed uncertainty about whether they would be likely to refer families to support groups (70%) and uncertainty that families would utilize the support group (48%).

Table 4.4: Responses of medical GPs to self-administered questionnaire

Variable	Frequencies		
	High	Moderate	Low
Own knowledge on Autism	21(33.8%*)	39(62.9%)	2(3.2%)
GP* level of knowledge and training on ASD	26(44.0%)	25(42.3%)	8(13.5%)
Level of awareness in Libya of ASD	30(48.3%)	24(38.7%)	8(12.9%)
	<b>Don't</b>	<b>Yes</b>	<b>No</b>
Knowledge on diagnostic criteria for ASD	30(48.3%)	24(38.7%)	8(12.9%)
Knowledge of where to refer child with ASD	1(1.6%)	57(93.4%)	3(4.9%)
Knowledge of special schools in Tripoli	5(8.2%)	46(75.4%)	10(16.3%)
Knowledge of support groups for ASD in Tripoli	7(12.0%)	10(17.2%)	41(70.6%)
Adequacy of health services for ASD*	37(60.6%)	5(8.2%)	19(31.1%)
Ethnic and social disparities in diagnosis of ASD*	20(32.75)	10(16.3%)	31(50.8%)
Social factors affect diagnosis of ASD*	9(14.7%)	10(60.6%)	15(24.5%)
	<b>Always</b>	<b>Sometimes</b>	<b>Rarely</b>
Consideration of ASD as a diagnosis	17(28.3%)	28(46.6%)	15(25.0%)
Difficult to identifying ASD in children	10(16.9%)	37(62.7%)	12(20.3%)
Delay in diagnosing children with ASD	3(4.8%)	40(64.5%)	19(30.6%)
	<b>Don't</b>	<b>&lt;3months</b>	<b>&gt; 6months</b>
Average waiting time for specialist care	27(44.2%)	10(16.3%)	24(39.3%)
Average waiting time for intervention	25(40.3%)	17(27.7%)	20(32.2%)
	<b>Uncertain</b>	<b>Likely</b>	<b>Unlikely</b>
Likelihood to refer to ASD support groups	41(70.6%)	10(17.2%)	7(12.0%)
Likelihood to use ASD support groups	28(48.2%)	17(29.3%)	13(22.4%)

\*ASD= Autism Spectrum Disorder

#### 4.5. Qualitative analysis

The open-ended questions on the online questionnaire were designed to obtain more detailed explanations about the different challenges that might have influenced the process of ASD diagnosis and management in Libyan children. Perspectives of GPs regarding challenges encountered in the delay of ASD diagnosis and management

were explored using inductive analysis and theorizing of the GPs' experiences in the qualitative responses. The themes that emerged from the open-ended questions include: lack of awareness, insufficient experience, health infrastructure, and stigma.

#### *Lack of awareness*

The majority of participated GPs (46; 74.1%) indicated that the reason for the delay in diagnosing ASD related to the lack of awareness of the condition amongst families and the community. This contributed to delays in seeking medical care. GPs also indicated that a low level of the parents' awareness and education of the condition affected their acceptance and understanding of ASD, as well as their refusal to refer their children for proper assessment and diagnosis. This was emphasized by a 49-year-old GP who had practiced in a primary health care facility for more than five years and other GPs:

*Lack of knowledge and awareness has caused parents [to]<sup>1</sup> refuse to accept, refuse to seek medical help, and refuse to use medical help - IP 51*

*Yes, family education and awareness could play [a] very important role to accept[ing] their child, understanding his condition, and find[ing] the way to help him, no matter what other people [are] saying, instead of denying his condition and keep hiding him from people in [their] surrounding[s] – IP 139, IP 85*

#### *Insufficient experience*

Lack of awareness of doctors to refer children with ASD for further assessment was identified as an important challenge in about 18 (29%) of the participated GPs. This was associated with ignorance of the suspected cases by doctors especially when it was associated with other medical problems as clearly stated by some of the participants:

*Yes, there is a lack of awareness among parents, and lack of awareness of the health professionals to educate the people about how to integrate the patient with the community – IP 78*

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<sup>1</sup> Added phrases for clarity within [ ]

*Besides the refusal of the parents to seek health service[s], doctors' ignorance [was found] if associated with other medical problems – IP 15*

### *Health infrastructure*

All of the participants provided some insight into their dissatisfaction with the supply of appropriate services available for ASD children with a particular reference to referral services. It has found that there is a deficit in the specialized centers for adequate rehabilitation and care as indicated by 12 (19.3%) of the participants:

*No, the level of service provided is not optimal for such children and [they] usually share the same centers with children with special needs and disabilities – IP 93*

*Specialists for children with ASD are not enough and health services are concentrated mainly in the capital not in rural areas – IP 85*

The lack of specialist services to make the diagnosis of ASD was also indicated by 21 of the participated GPs (33.8%). This was followed by difficulties in access to specialist services, such as transport and finances (17, 27.4%). The lack of adequate number of expert specialists for both diagnosis and management of ASD such as speech and behavioral therapists was a main challenge identified by the participated GPs. It has been mentioned by the participants that there is only one specialist who is well known to deal with such cases:

*No, because only one physician is well known and provides services for those patients, so that would delay the appointment and delay the diagnosis and in case that the diagnosis had been concluded what is the next step? I don't know if there is [any] specialized school and centers to help them! – IP 197*

*No, [there is not] enough specialist[s] and expert professionals to deal with the increasing number of diseased children – IP 151*

### *Stigma*

All of the participants consistently emphasized that social stigma is a considered challenge that could cause delay in seeking health services in Libya. Study participants stated that a large number of families found the diagnosis stigmatizing.

They stated that the child is labelled as mentally retarded, and that the child's behaviour will be a source of embarrassment:

*Yes, all Libyan families look to ASD [children] as [a] mentally retarded person and deal with him as [a] closed page from their life that [they] don't try to open – IP 171*

Participants (18, 29.03%) reported that parents refused to accept the idea that their child had ASD. It was associated with the feeling of shame and the fear of being discriminated against by others in the community, highlighted below:

*Parents will be shame[d] to take their autistic child to a doctor, because of the increase in the possibility that other people will know that they have an abnormal child – IP 113*

Participants also stated that parents hoped that the child's behaviour would change as the child grew:

*Parents don't want to believe that their child is abnormal and they have hope that their child's behaviour will improve when s/he [is] growing up – IP 15*

The effect of traditional habits and societal influences was identified by 6 (9.67%) of the GPs. There was a habit in some Libyan families that having an abnormal child or mentally retarded child meant keeping them away from other people.

*Yes, because of our social and cultural thinking, our response to the disease and the reflection of it on the family and negligence in our country..... – IP 70*

*Yes, I think social and cultural factors affect the acceptance of the problem and the idea of having a child with ASD – IP 93*

## **CHAPTER 5: DISCUSSION, CONCLUSION AND RECOMMENDATION**

This chapter entails the discussion of the main findings in the study and how they relate in accordance to literature available on ASD. In addition to the detailed discussion on the findings and their implications, this chapter also includes the limitations of the study. The researcher concludes by presenting a number of recommendations for improving the level of knowledge among GPs, early detection of ASD and provides guidance for future research.

Based on our review of the relevant literature about the disorder in Libya, the current study was the first to examine the knowledge of GPs about ASD and the beliefs and experiences about the delay in the diagnosis of the disorder. The total median score on the KCAHW questionnaire among participated GPs was 10, IQR (8-12) with a marked difference in the obtained score compared to the study that was done by Esiegbe *et al.*, (2015) on medical doctors in Nigeria, which gave a median score of 15. The low scores in our study reflect potentially lower levels of knowledge about ASD in Libya as compared to Nigeria. However, the Nigerian study had 167 participants of whom only 76 (46%) GP participants who were shown to be more likely to have a median score below 15 as compared to specialists in the sample (50, 66%). Both Libyan GPs and Nigerian doctors showed similar knowledge gaps about comorbidities in ASD (Domain 4) as well as similar knowledge levels about ASD when specialists are excluded from the Nigerian sample.

In Karachi, Pakistan, Rahbar *et al.*, (2011), in their study used a different knowledge questionnaire to assess GPs knowledge about ASD, reported that 55.4% of the participants had never heard of autism, while only 44.6% of GPs were aware of the disorder in children. In our study, Libyan GP's (89%) were more aware of the stereotypical movements and repetitive activities as symptoms of ASD but showed knowledge gaps about communication impairments (25%) and social impairments (24%). This could reflect their clinical experience which has limited exposure to cases

with ASD. The clear gap however was in GP's understanding of ASD as a disorder and more specifically the associated co-morbidities (48%). This finding was also reported in the study by Esiegbe *et al.*, (2015). Almost a third of participating medical doctors (31.1%) were not knowledgeable about co-morbidities in ASD as well as the onset period of ASD.

In our study, most of the Domains with higher median scores were obtained by GPs who were aged less than 40 years and who were practicing in a general hospital. This might also be related to their previous exposure to ASD. However, there was no significant association found between knowledge about childhood ASD and age or gender of the participated GPs. Esiegbe *et al.*, (2015) indicated that the above was also identified as participating factors with the doctors who had good knowledge scores in Nigeria. In their study, good knowledge was significantly associated with doctors who was a paediatrician or psychiatrist, and who were practicing in a tertiary hospital, while poor knowledge was significantly found among participating general practitioners.

The widest knowledge gap was identified in Domain 4 of the questionnaire, which is focused on ASD as a disorder and its co-morbidities such as associated seizures and other behavioural difficulties. More than 80 percent of children with ASD present with comorbidities and the recognition and management of these are essential in management of ASD (Volkmar *et al.*, 2014). Although all GPs showed deficits in the knowledge of autism in this study, the majority of GPs (62.9%) reported that they felt confident to recognize ASD. They also rated their training and knowledge of ASD as moderate to high.

Despite the current increase in research efforts, there is no specific diagnostic test for ASD, and assessment and diagnosis mainly depend on the evaluation of a child's behaviour to identify manifests of ASD using behavioural assessment tools (Crowe & Salt, 2015). The AAP/NICE guidelines also recommend the routine developmental assessment of young children and the screening for any significant ASD symptomatology. Diagnostic evaluation should also be performed to determine the presence of ASD and that health professionals should be trained to perform these assessments (Volkmar *et al.*, 2014; Crowe & Salt, 2015). Another recommendation is

that health providers should assist the concerned families to obtain appropriate, evidence-based, and structured educational and behavioural interventions for their children with ASD. This early intervention has been shown to be effective at improving the outcomes in affected children (Volkmar *et al.*, 2014). In the Libyan setting, besides the inadequate awareness level on the disorder, there is also a dearth in special health facilities and a lack of expert professionals for ASD and other neuro-developmental disorders. The majority of present ASD centers however is newly developed and lack experience and quality health care provision. In addition, these centers are almost all within the private sector that might have financial burdens on the families and their children with ASD.

Shortages in the number of ASD specialists and the specialized hospitals are considered to be main challenges encountered in Libya. However, this is less conducive to positive change, since government attention, funding, and support, are still very limited. Social pressure, stigmatisation, and cultural influence, are also considered issues that have to be taken into account for ASD diagnosis in Libya. For example, the social stigma of having a child with ASD was indicated as a reason to delay seeking a health professional for diagnosis (Zeglam & Al-Bloushi, 2012).

The challenges identified by the participants in this study regarding ASD diagnosis and management are similar to challenges encountered in the care of special needs children in other African countries (Esiegbe *et al.*, 2015). In addition, the high financial costs, the presence of transport issues, and difficulty in accessing a specialist service can also have a negative impact on the educational and developmental attitude of ASD children (Bakare & Munir, 2011). The implications of the identified challenges together with the knowledge gap among health professionals are all precipitating factors that can increase the load on families and ultimately lead to a poorer outcome in the affected ASD children (Esiegbe *et al.*, 2015).

### **5.3 Study limitations**

Firstly, this study was limited by the small sample size which reflects a low response rate in a questionnaire-based study. In order to improve the response rate, two

reminders were sent to all participants. As the study was online and anonymous, incomplete responders could not be traced directly. The final survey of 62 GPs with completed responses were included in the study analysis, while the uncompleted questionnaires had to exclude.

Feedback from participants indicated that internet connectivity was a major contributing factor in questionnaire completion. Almost all of the participated GPs had indicated that they struggled to access and complete the survey due to the weak network. The socio-political climate in Libya could have played a role on the low response rate in this study, as this was an online survey, which required a good internet access to complete the questionnaire. The conflict and political instability in the country has affected many means of life including communication, electricity and network services (United Nations Development Programme [UNDP], 2016).

The electronic nature of the survey might be a reason that there were limited responses for GPs older than 40 years of age who may have been excluded from participation as a result of this. Access to internet in Libya is newly developed (and as indicated in the other settings), the younger generation (<40 years old) tend to have a higher technological background. They are therefore more interested in connecting to social media and recently available electronic applications and websites than older individuals such as the participated GPs in our study (Al-Subaihi, 2008). In a study conducted in Saudi Arabia, which aimed to compare the response rate of telephonic interviews and surveys utilizing web-based application, it was found that the reason for the majority of Saudi people to choosing not to interact with web surveys was more of a cultural reason with more males responding better than females (Al-Subaihi, 2008). Al-Subaihi (2008) also indicated that the effects of internet coverage, social thoughts towards internet usage, and gender differences in accessing internet should all be considered factors on data quality and response rates of web-based survey research in developing societies.

In this study besides the presence of some technical issues like inadequate internet coverage among participants, the socio-cultural perspectives could also have played a role in the low response rate and this led to significantly more Libyan female doctors participating than male GP doctors. Other reasons might include the unfamiliarity

with and usage of the web-based surveys application, the hesitance of GPs to disclose their email addresses, and possibly ignorance to our invitation due to work constraints (as indicated by some GPs). The other limitation in the current study is that the study involved only GPs who work with children, from specific places and within Tripoli, which might affect generalizability to other settings in the country. The last limitation is that the survey included recruited participants who were using social media, and this could have limited a large population of GPs who could assist in completing the survey but were not active on social media during the study period.

#### **5.4. STUDY CONCLUSION**

GPs in Libya had a median score of 10 IQR (8-12) on the KCAHW, indicating inadequate knowledge compared to previous studies conducted in African countries. The limited knowledge was about certain aspects of ASD like age of onset, diagnostic criteria for ASD as well as comorbidities. Significant challenges were identified by GPs which hamper the early identification and management of ASD in Libya were including lack of awareness of society as well as health workers, insufficient experience of health workers, poor health infrastructure in Libya as well as the social stigma associated with these developmental disorders.

#### **5.5 RECOMMENDATIONS**

The following section presents recommendations that the researcher hopes that will be to be taken up by both the political and health authorities in the country of Libya including the Ministry of Health and the Libyan association of Paediatrics. More focus needs to be directed towards ASD and other neuro-developmental disorders in Libya, starting from increasing the undergraduate curricula content on such disorders. This will therefore help increasing the level of education amongst undergraduate medical students in Libya. Comprehensive programs are also needed to address the identified challenges which prevent GPs from properly identifying and assessing suspected children for ASD. Additional focus is also required on training programmes and continuing medical education of doctors especially those practicing in the public health sectors. Efforts should also be made at conducting routine accurate ASD assessment screening in the public health care system.

Improving the knowledge about ASD among health care professionals is also considered an important component of research infrastructure in developing countries (Rahbar *et al.*, 2011), which can assist in the development of effective surveillance and research programs on ASD (Esiegbe *et al.*, 2015). In addition, more support is required to encourage medical doctors to immerse themselves in such important specialties that are in accordance with the increasing prevalence of ASD in the country. Recommended educational and supportive programmes, conferences on a routine base should be addressed towards the low level of awareness on the condition among Libyan families. This can assist in increasing their understanding of normal and abnormal child development, and in turn lead to seeking earlier medical advice.

Recommendations for future research about ASD which is informed by gaps identified by this study are discussed below. Studies to examine health care professionals' knowledge and attitudes about autism in Libya, and to further explore and justify reasons for inadequate GPs practice. In addition, investigations into strategies that would narrow gaps in care for affected children with autism are required, and to support efforts at conducting routine accurate ASD assessment and screening in the public health facilities. Further to epidemiological studies, it is important that future research consider mixed methods of enrolment in order to generalize the concerns about the GPs needs in the field of the child's development and its abnormalities and more specifically ASD. Research should incorporate and assess the requirements for the basic learning and information gaps that GPs feel are necessary in order to provide competent and adequate care when working with ASD children and their concerned families.

This study was designed to build on existing previous international and sub-Saharan studies; this study was the first to our knowledge to be conducted in North Africa and Arabic countries. The findings of this study have increased the researcher's understanding on the current situation of autism in Libya; also provided an increased understanding on the challenges encountered in ASD identification, diagnosis and accurate earlier intervention, as well as on the educational and training needs of Libyan GPs in this field. Lastly, these findings contribute to the growing number of research studies on identifying and diagnosing suspected children with ASD at the earliest possible stage, aiming to ensure an improved prognosis in the future.

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## **APPENDICES**

### **Appendix 1: Knowledge about childhood autism**

#### **Appendix 1A: Demographic questionnaire of the recruited participants:**

1. Please indicate your gender

(A) Female (B) Male

2. Which age group do you fit into?

(A) 25-34 years old (B) 35-44 years old (C) > 45 years old

3. What is the highest degree you have completed?

(A) Bachelor's degree (B) Master's degree (C) Other

4. Where did you obtain the above qualification?

(A) Inside Libya (B) From an African country (C) Other

5. How many years of work experience do you have?

(A) <1 year (B) 1-5 years (C) >5 years

6. Where do you currently practice as a GP?

(A) Primary healthcare unit (B) General Hospital (C) Private sector

7. Regarding your work as a general practitioner, which patients do you work with?

(A) Adults only (B) Children only (C) Both

8. What is the number of ASD cases you have come into contact with at your clinic?

(A) No cases (B) 2-5 (C) > 10 cases

## **Appendix 1B: Knowledge about Childhood Autism among Healthcare Worker (KCAHW) questionnaire**

N.B. Please do not consult any formal text book to answer these questions.

Please mark the best answer with a circle. Thank you for your time.

The following behaviours best describe a child with childhood autism:

### **Domain 1**

- i. Marked impairment in use of multiple non-verbal behaviours such as eye to eye contact, facial expression, body postures and gestures during social interaction?  
(A) Don't Know, (B) Yes, (C) No
- ii. Failure to develop peer relationship appropriate for developmental age?  
(A) Don't Know, (B) Yes, (C) No
- iii. Lack of spontaneous will to share enjoyment, interest or activities with other people?  
(A) Don't Know, (B) Yes, (C) No
- iv. Lack of social or emotional reciprocity?  
(A) Don't Know, (B) Yes, (C) No
- v. Staring into open space and not focusing on anything specific?  
(A) Don't Know, (B) Yes, (C) No
- vi. The child can appear as if deaf or dumb?  
(A) Don't Know, (B) Yes, (C) No
- vii. Loss of interest in the environment and surroundings?  
(A) Don't Know, (B) Yes, (C) No
- viii. Social smile is usually absent in a child with Autism?  
(A) Don't Know, (B) Yes (C) No

### **Domain 2**

- i. Delay or total lack of development of spoken language?  
(A) Don't Know (B) Yes (C) No

### **Domain 3**

- i. Stereotyped and repetitive movement (e.g. Hand or finger Flapping or twisting)?  
(A) Don't Know (B) Yes, (C) No
- ii. May be associated with abnormal eating habit?  
(A) Don't Know, (B) Yes, (C) No
- iii. Persistent preoccupation with parts of objects?  
(A) Don't Know, (B) Yes, (C) No
- iv. Love for regimented routine activities?  
(A) Don't Know, (B) Yes, (C) No

### **Domain 4**

- i. Autism is Childhood Schizophrenia?  
(A) Don't Know, (B) Yes, (C) No
- ii. Autism is an auto-immune condition?  
(A) Don't Know, (B) Yes, (C) No
- iii. Autism is a neuro-developmental disorder?  
(A) Don't Know, (B) Yes, (C) No
- iv. Autism could be associated with Mental Retardation?  
(A) Don't Know, (B) Yes, (C) No
- v. Autism could be associated with Epilepsy?  
(A) Don't Know, (B) Yes, (C) No
- vi. Onset of Autism is usually in, (A) Neonatal age, (B) Infancy, (C) Childhood

## **Appendix 1C: Self-administered questionnaire to identify challenges to early ASD diagnosis and intervention**

1. How would you grade your knowledge about ASD?  
(A) High (B) moderate (C) low
  
2. In your opinion, what is the level of general practitioners' education and training regarding ASD?  
(A) High (B) Moderate (C) Low
  
3. How often do you consider a diagnosis of ASD when children attend your clinic?  
(A) Often (B) Sometimes (C) Rarely
  
4. How often do you find difficulty in identifying ASD in children?  
(A) Always (B) sometimes (C) rarely
  
5. Are you aware of diagnostic criteria for identifying ASD in children?  
(A) Don't know (B) Yes (C) NO
  
6. How often do you use the identified criteria in diagnosing ASD in children?  
(A) Always (B) Sometimes (C) Rarely
  
7. If you have a suspected case of ASD, do you know where to refer the child for further assessment and diagnosis?  
(A) Don't know (B) Yes (C) No
  
8. Do you think that there is a delay in diagnosing children with ASD in Libya?  
(A) Always (B) sometimes (C) rarely
  
9. In your opinion what do you think could be the reasons for the delay in diagnosing ASD?

- (A) Lack of awareness of doctors to refer for assessment
- (B) Lack of awareness of the condition in families and community
- (C) Lack of specialist services to make the diagnosis
- (D) Difficulties in access to specialist services like transport, finances etc
- (E) Other: Please specify

10. In the case of a child suspected of having ASD, what is the average waiting time for the child to be further assessed by a specialist?

- (A) Don't know (B) 1-3 months (C) > 6 months

11. What is the average waiting time for a child suspected of having ASD in accessing an intervention service?

- (A) Don't know (B) 1-3 months (C) > 6 months

12. How would you describe the level of awareness on ASD among the Libyan society?

- (A) High (B) moderate (C) low

13. Do children in the area of Tripoli have access to a school for children with ASD or any special schooling?

- (A) Don't know (B) Yes (C) No

14. Do children in the area of Tripoli have access to any support groups for children diagnosed with ASD?

- (A) Don't know (B) Yes (C) No

15. If there were a support group service available for children diagnosed with ASD, how likely are you to refer parents in your district to the support group service?

- (A) Very likely (B) Not likely (C) Uncertain

16. If there were a support group service for children with ASD, how likely are parents in your district to use the support group service?

- (A) Very likely (B) Not likely (C) Uncertain

17. In your opinion, are the health services for children diagnosed with ASD in Libya adequate?

(A) Don't Know, (B) Yes, (C) No

If you answered either "yes" or "no", please explain why

.....

18. Are there possibly any kind of ethnic or social disparities regarding the diagnosis of ASD in children in Libya?

(A) Don't Know, (B) Yes, (C) No

If you answered "yes", please explain

.....

19. In your opinion, are there possibly any social factors (such as feeling ashamed) might play a role in the delay in diagnosing children with ASD in Libya?

(A) Don't Know, (B) Yes, (C) No,

If you answered either "yes", please explain

.....

## **Appendix 1D: Scoring of Knowledge about Childhood Autism among Health Workers (KCAHW) questionnaire**

### **Domain 1**

i. Marked impairment in use of multiple non-verbal Behaviours such as eye to eye contact, facial expression, body postures and gestures during social interaction?

(A) 0 (B) 1 (C) 0

ii. Failure to develop peer relationship appropriate for developmental age?

(A) 0 (B) 1 (C) 0

iii. Lack of spontaneous will to share enjoyment, interest or activities with other people?

(A) 0 (B) 1 (C) 0

iv. Lack of social or emotional reciprocity?

(A) 0 (B) 1

(C)

v. Staring into open space and not focusing on anything specific?

(A) 0 (B) 1 (C) 0

vi. The child can appear as if deaf or dumb?

(A) 0 (B) 1 (C) 0

vii. Loss of interest in the environment and surroundings?

(A) 0 (B) 1 (C) 0

viii. Social smile is usually absent in a child with Autism?

(A) 0 (B) 1 (C) 0

### **Domain 2**

i. Delay or total lack of development of spoken language?

(A) 0 (B) 1 (C) 0

**Domain 3**

i. Stereotyped and repetitive movement (e.g. Hand or finger flapping or twisting)?

(A) 0 (B) 1 (C) 0

ii. May be associated with abnormal eating habit?

(A) 0 (B) 1 (C) 0

iii. Persistent preoccupation with parts of objects?

(A) 0 (B) 1 (C) 0

iv. Love for regimented routine activities?

(A) 0 (B) 1(C) 0

**Domain 4**

i. Autism is Childhood Schizophrenia?

(A) 0 (B) 0 (C) 1

ii. Autism is an auto-immune condition?

(A) 0 (B) 0(C) 1

iii. Autism is a neuro-developmental disorder?

(A) 0(B) 1 (C) 0

iv. Autism could be associated with Mental Retardation?

(A) 0 (B) 1 (C) 0

v. Autism could be associated with Epilepsy?

(A) 0 (B) 1 (C) 0

vi. Onset of Autism is usually in, (A) 0 (B) 0 (C) 1

## **Appendix 2: Informed Consent Form**

### **Part 1 - Information sheet**

Dear doctor,

My name is Soad Jubr, a paediatric doctor and a student on the Master's Programme in Maternal and Child Health (M.Phil. [MCH]) at the University of Cape Town, South Africa. This study is conducted for the purpose of the fulfilment of a Master's degree in Maternal and Child Health (MCH) within the Department of Paediatrics and Child Health at the University of Cape Town, South Africa. It will provide increased knowledge and a better understanding on the disorder of ASD and the challenges that families face during the diagnostic and intervention process.

I am sending this letter to invite you to participate in my research study. I am doing a survey to assess the knowledge of GPs regarding ASD and their experiences with the challenges encountered in the delay of diagnosis and intervention among Libyan children affected with ASD. The information and insight gained from this study will increase the understanding of managing ASD in Libya. The research study will only include health care providers who work with children.

With your permission, I would like you to complete the following questionnaires. The questionnaires and all health information will be provided in the English language with clearly defined questions. Your participation in this study is completely voluntary and is not associated with any risk or harm and will not affect you or your rights in any way. You may withdraw from this study at any time by sending me an email saying I am not interested in participating in the study. A questionnaire will be sent to those that are "willing to participate" through an Online survey link on Redcap for completion online.

To protect your confidentiality, your name will not appear on the questionnaire as this will be an online study. I will only use data and results from the questionnaire, without including your name. This study will not be shared with anyone other than myself (the researcher) and my supervisors at the University of Cape Town. If you have any questions or if you would like to receive a final copy of this research study

after completion, please feel free to contact me. This letter will serve as a consent form for your participation and will be kept in my personal locked file until the completion of the study. All data will be stored on a password-protected computer to which only the researcher has access. All data will be destroyed after a period of five (5) years.

**Contact information for any queries:**

If you have any questions about this research, please feel free to contact:

The researcher:

Soad Jubr (M.Phil. MCH student, University of Cape Town, South Africa)

**Email:** [d.jubr@yahoo.co.za](mailto:d.jubr@yahoo.co.za) or [jbrsoa001@gmail.com](mailto:jbrsoa001@gmail.com) ; **Telephone** +27742198996 or +27713227659.

Supervisors contact details:

Jawaya Shea (M.Phil. MCH programme convener)

**Email:** [Jawaya.shea@uct.ac.za](mailto:Jawaya.shea@uct.ac.za) ; **Telephone:** +27216585030, University of Cape Town, South Africa

Dr. Reneva Petersen (Consultant at Paediatric neurodevelopment clinic, Red Cross war memorial Children Hospital, Cape Town)

**Email:** [r.petersen2@uct.ac.za](mailto:r.petersen2@uct.ac.za)

University of Cape Town, South Africa

Or contact:

UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences

Human Research Ethics Committee

**Email:** [sumayah.ariefdien@uct.ac.za](mailto:sumayah.ariefdien@uct.ac.za); Tel: +27214066492

**Part 2 - Consent declaration for participation in a research study**

I acknowledge that the researcher has explained the requirements of this study, privacy and expected potential risks involved in participating in this study. I understand there is no direct benefit of participating in this study and that obtaining data from my participation will assist the researcher to complete a Master's degree in

Maternal and Child Health. I have voluntarily consented to participate and the researcher indicated that I can withdraw from the participation at any time that I will or wish to do so. By signing below and providing my contact information I am indicating that I consent to participate in this study.

Signed

.....Date.....

(Day/month/year)

Name: .....

Phone Number, Email Address, or Postal Address:

.....  
.....  
.....

***Statement by the researcher***

I have accurately described the information sheet to the potential participant, and to the best of my ability made sure that the participant understands what is required to do in this study.

**Researcher Name:** Soad Jubr .....

**Researcher signature:** .....

**Date:** .....

(Day/month/year)

Phone Number, Email Address, or Postal Address:

.....  
.....  
.....

**Supervisor:**

**Dr.:** R Peterson....**Signature:**.....**Contact**

**details:** (Tel).....**(Email address)**

.....  
.....

### Appendix 3: Recruitment and invitation letter



Dear doctors,

I am a paediatric doctor and a master student at University of Cape Town, South Africa. I am writing this letter to invite you to participate in my research study. I am doing an online survey titled "**Autism spectrum disorder: Assessing the level of knowledge and challenges to early diagnosis and intervention among general practitioners in Tripoli, Libya**". I am doing this study to better understand the way in which children with Autism Spectrum Disorder (ASD) are diagnosed in Libya, and to understand the experiences of doctors in diagnosing and managing children diagnosed with ASD.

I hope that you will be able to assist me by agreeing to participate in this online survey. To participate, you should be a doctor or general practitioner who delivers healthcare to children at a "public or private" health facility in Tripoli. The questionnaire will be send to those willing to participate through link of the online survey on Redcap application or through an email.

#### **CONFIDENTIALITY**

Confidentiality will be upheld by not using your name or any identifying information in the questionnaires and the automatic IP address key will be switched off to prevent collection of your IP address if you complete the survey. The collected information will be stored on a password-protected computer to which only the researcher has access. Your responses will be reported anonymously in a dissertation that be submitted for my Masters Dissertation. If the information is helpful to other doctors, I

hope to publish the research in a journal, and it is important that you know about this in advance. Please be aware that no identifying information will be published in any documents.

### **AUTONOMY**

Your participation in this research is voluntary and there will be no consequences for you in situations where you decide to withdraw. You are also free to decline answering the questions with which you are not comfortable, and can withdraw from the study at any point.

### **BENEFITS**

You will receive no direct benefits from participating in this research study. However, your responses may help me to understand the experiences of diagnosing and managing children with ASD.

### **RISKS**

I do not expect that there are likely to be any risks involved in participating in this study.

### **CONFIDENTIALITY**

The information you provide will remain confidential and anonymous. Your survey answers will be stored on a password protected electronic format. It does not collect identifying information such as your name, email address, or any personal information. No one will be able to identify you or your answers, and no one will know whether or not you participated in the study.

### **CONTACT INFORMATION**

If you have any queries, please don't hesitate to contact the investigator:

Dr Soad Jubr

Email address: [d.jubr@yahoo.co.za](mailto:d.jubr@yahoo.co.za)

Or

Dr R. Petersen

Email: [r.petersen2@uct.ac.za](mailto:r.petersen2@uct.ac.za)

UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences

Human Research Ethics Committee

**Email:** [sumayah.ariefdien@uct.ac.za](mailto:sumayah.ariefdien@uct.ac.za); Tel: +27214066492

**ELECTRONIC CONSENT:**

Please select your choice below. You may print a copy of this consent form for your records. Clicking on the “**Agree**” button indicates that

- You have read the above information
- You voluntarily agree to participate
- You are a qualified doctor above 18 years old

Agree

Disagree

Your assistance and participation will be greatly appreciated.

Thank you.

Soad Jubr

## **Appendix 4: Questionnaire on completion of pilot phase**

Thank you for participating in this important research about autism. Please take a few moments to provide us with your valuable feedback.

- i. How long did it take you to complete the questionnaires?
- ii. The questionnaires were easy to read and complete: Agree/  
Disagree
- iii. Were any of the questions unclear / confusing in their meaning?  
If yes: which questions:
- iv. Can you think of additional questions that would be important for the researcher to include in this questionnaire? Please let us know.

## Appendix. 5. Faculty HREC approval letter



UNIVERSITY OF CAPE TOWN  
Faculty of Health Sciences  
Human Research Ethics Committee



Room E52-24 Old Main Building  
Groote Schuur Hospital  
Observatory 7925  
Telephone [021] 404 7682 • Facsimile [021] 406 6411  
Email: [pos.bhams@uct.ac.za](mailto:pos.bhams@uct.ac.za)  
Website: [www.health.uct.ac.za/fhs/research/humanethics/forms](http://www.health.uct.ac.za/fhs/research/humanethics/forms)

03 July 2017

**HREC REF: 196/2017**

**Dr R. Peterson**  
Paediatrics & Child Health  
Room 3.17-3<sup>rd</sup> Floor, ICH Building  
Red Cross Children's Hospital

Dear Dr Peterson

**PROJECT TITLE: AUTISM SPECTRUM DISORDER: ASSESSING THE LEVEL OF KNOWLEDGE AND CHALLENGES TO EARLY DIAGNOSIS AND INTERVENTION AMONG GENERAL PRACTITIONERS IN TRIPOLI LIBYA (MPhil candidate-S Jubr)**

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study. This is subject to capturing all the pilot procedures and the questions to be asked in the protocol.

**Approval is granted for one year until the 30th July 2018.**

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: [www.health.uct.ac.za/fhs/research/humanethics/forms](http://www.health.uct.ac.za/fhs/research/humanethics/forms))


*We acknowledge that the following student will be involved in this study: Soad Jubr*

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval **before** the research may occur.

**Please quote the HREC REF in all your correspondence.**

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Yours sincerely

  
**PROFESSOR M. BLOCKMAN**  
**CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE**  
Federal Wide Assurance Number: FWA00001637.  
Institutional Review Board (IRB) number: IRB00001938

HREC 196/2017

## Appendix. 6. Libyan Ministry of Health approval letter

State of Libya  
Ministry of Health  
Health Information Centre



دولة ليبيا  
حكومة الوفاق الوطني  
وزارة الصحة  
مركز المعلومات والتوثيق

التاريخ 1 / 1  
الموافق 14 / 1 / 2017 م

الاشارة : ..... 17 / 1

Written permission from Ministry of Health

Ministry of Health Libya  
Tel:00218913244195  
Fax:00218217200004  
Email: Mdaganee@gmail.com  
Principle name: Mohamed Ibrahim Saleh

**From: Ministry of Health in Tripoli, Libya**

**To:** Dr. Soad Jubr (Master student at University of Cape Town, South Africa)

**Re:** Survey study in health institutions in Tripoli

I herewith acknowledge receipt of your letter requesting consent to have permission of doing survey study in Tripoli, Libya titled "Autism Spectrum Disorders: Assessing the level of knowledge and challenges to early diagnosis and intervention among general practitioners in Tripoli, Libya".

We will send a permission letter on our behalf to the managers of healthcare units and hospitals in Tripoli, Libya to conduct the study and to allow you questionnaire the general practitioners who are working at these health institutions.

Yours sincerely

Mohamed Ibrahim Saleh  
Director of Health Information Center



