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The knowledge of Public Health Midwives on Autism Spectrum Disorder in two selected districts of the Western Province of Sri Lanka

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ABSTRACT

Background: Early interventions are important for improving outcome in autism. However, the diagnosis of autism is often delayed for 3–4 years, which leads to missed opportunities to initiate early intensive behavioural interventions, thus jeopardizing its prognosis. The lack of knowledge among healthcare workers about the features of autism is postulated to be the main reason for this delay.

Methodology: A descriptive cross-sectional study was carried out among the PHMs in the Colombo and Kalutara districts of the Western Province, Sri Lanka. A specifically designed self-administered questionnaire was used to obtain information about the socio-demographic details. The knowledge about the signs and symptoms and common comorbidities of ASD were assessed using the "Knowledge about Childhood Autism among Health Workers (KCAHW) Questionnaire".

Results: Out of 406 participants, 56.9 % (n = 231) were from the Colombo District. The mean knowledge of the participants on the “Knowledge about Childhood Autism among Health Workers (KCAHW) Questionnaire” was 13.23/19 (SD = 2.647). The knowledge was significantly higher in those who had participated in training programmes on autism ($p < 0.01$) and in those who have had contact with a child with autism ($p < 0.05$). Of the participants, 17.2 % (n = 70) believed that autism could be completely cured. 43.6 % and 42.2 % believed that poor attention from parents and parental conflicts during pregnancy and early childhood caused autism in children respectively.

Conclusion: The knowledge of PHMs on autism is inadequate, with regard to the comorbidities, aetiology and treatment options. In service programmes are useful in improving the knowledge of PHMs on autism.

1. Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by impairments in social communication and presence of restricted repetitive interests and behaviours. Epidemiological surveys have shown that the prevalence of ASD is rising worldwide. A study done in a Sri Lankan suburb has found that 1 in 93 children to be affected by ASD (Perera et al., 2009).

Early identification of ASD provides an important opportunity for early interventions, which lead to improvements in cognitive skills, language, adaptive and challenging behaviours (Warren et al., 2011). There is also evidence that the gains from these early interventions are seen even after 2 years (Estes et al., 2015). Research also suggests that the individuals with positive outcomes are more likely to have been identified and treated before 3 years of age (Anderson et al., 2014).

Delays in diagnosis of ASD can cause delays in initiating interventions, which in turn jeopardizes the prognosis (Heidgerken et al., 2005). Previous studies have found that although the symptoms have been noticed as early as 6 months of age, the diagnosis of ASD was not made until the child was 3–4 years old (Planche et al., 2004). An average delay of 4 years has been demonstrated in studies (Howlin and Asgharian, 1999; Howlin and Moore, 1997) between a parent first seeking help and the time of diagnosis.

There may be several reasons for this delay but the lack of knowledge of the medical staff on using autism screening tools and failure to make timely referrals have been suggested (Rhoades et al., 2007).

Studies carried out in several developing countries have revealed that Health Care Workers' (HCW) knowledge about ASD is poor (Al-Farsi et al., 2016; Sampson and Sandra, 2018; Zhang et al., 2018) and that they hold misconceptions about its aetiology and the signs and symptoms. (Imran et al., 2011; Rahbar et al., 2011). A study assessing the knowledge about diagnostic features and comorbidities of

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childhood autism among doctors in a tertiary care hospital in Sri Lanka revealed that 61.9 % doctors considered themselves incompetent in identifying autism. The knowledge on key features such as restricted repetitive interests and behaviours and common comorbidities were the areas most affected (Rohanachandra et al., 2017).

In Sri Lanka, the Public Health Midwife (PHM) is the first contact primary healthcare worker for children under 5 years. Each PHM caters to an established geographic area with a population ranging from 3,000 to 5,000 and is responsible for maintaining a register for all females of reproductive age and families with children less than 5 years (Family Health Bureau and Ministry of Health, 2017). Residing in the community, PHMs make systematic home visits to provide care to pre pregnant couples, pregnant women, post-partum women, newborns, and children under five (Family Health Bureau and Ministry of Health, 2017). The PHM is expected to do home visits once a month during infancy and once in 3 months for preschool children aged 1–3 years. They are expected to monitor growth and development of infants and preschoolers, identify any deviations in development, educate parents and families about psychosocial development and refer to the Medical Officer of Health (MOH) where necessary (Ministry of Health, 2006).

At present, basic training of PHMs consists of two parts. The first part of training is of 1 year duration and is conducted at the Nurses training schools. The first part focuses on theory component and includes details lectures on primary health care, health promotion, family heath, maternal care (which includes pre pregnant, antenatal, natal and postnatal care), infant and child care and development, expanded programme on immunization, nutrition and school health. This is followed by the second part of six months training, where they have to engage in field training under the supervision of a field PHM (National Institute of Health Sciences, 2013). Those who satisfactorily complete Public Health Midwife Training Program register with the Sri Lanka Medical Council and are certified to practice as PHMs in the community.

As the PHM plays a pivotal role in early identification and appropriate early referral of disordered development, she ought to be conversant with at least the key features of autism. In addition, as she is expected to provide appropriate health education to the family, she should also be equipped with the basic knowledge about its aetiology and treatment options available at present.

The PHMs' knowledge on ASD has not been previously assessed in Sri Lanka. Assessing the knowledge of PHMs' on ASD would be the initial step in identifying any existing gaps in their knowledge that would help in designing future in-service training programmes for the PHMs. In the long term, this would aid in early detection, appropriate referral and interventions for children with ASD, which would improve their prognosis.

2. Methodology

A descriptive cross-sectional study was carried out among the PHMs in the Colombo and Kalutara districts of the Western Province, Sri Lanka. Each district is divided in to several Medical Officer of Health (MOH) areas (Colombo district 18; Kalutara district 12). Data was collected during the monthly meetings of the Medical Officer of Health (MOH). All PHMs of a MOH area are expected to participate in these monthly meetings. All consenting PHMs who were present at the monthly meeting on the day of data collection were included in the study.

A specifically designed self-administered questionnaire was used to obtain information about the socio-demographic details, work experience and knowledge about aetiology and treatment options for ASD.

The knowledge about the signs and symptoms and common comorbidities of ASD was assessed by using the "Knowledge about Childhood Autism among Health Workers (KCAHW) Questionnaire", which was developed in Nigeria, and currently recommended for use in developing countries (Bakare et al., 2008). This has been used in many countries to assess the knowledge of autism among HCW (Al-Farsi et al., 2016; Hayat et al., 2019; Igwe et al., 2011; Imran et al., 2011; Sampson and Sandra, 2018). The questionnaire utilizes widely accepted symptoms of autism and has nineteen questions grouped under four domains; namely, impairments in social interactions, impairment of communication and language development, restricted, repetitive and stereotyped behaviour and common associations of childhood autism. Each of the questions has three options (yes, no, don't know) to choose from with only one of these options being correct. The correct option for each question carries a score of one, while the other two options that are incorrect carry a score of zero each. A maximum and minimum total score of nineteen and zero respectively are possible. The questionnaire is in English language. The English questionnaire has previously been used in Sri Lanka to assess the knowledge of symptoms and comorbidities of ASD among doctors (Rohanachandra et al., 2017). This questionnaire was translated to Sinhala for the use among PHMs. It was initially pretested among 10 PHMs to check the feasibility. All questionnaires were self-administered.

Ethical clearance was obtained from the Ethical Clearance Committee of the University of Sri Jayewardenepura.

Chi square test was used to analyze categorical data. *t*-Test and ANOVA were used to identify difference in means between groups. SPSS version 22 will be used in the analysis.

3. Results

3.1. Sociodemographic details

Out of the 406 participants, 56.9 % (n = 231) were from the Colombo District. 54.2 % (n = 220) had more than 10 years of work experience (Table 1).

Only 28.6 % (n = 116) were happy about their knowledge on autism. However, 75.1 % (n = 305) believed that they were competent in identifying a child with autism. Forty-two point nine (42.9 %) (n = 174) have worked with children diagnosed as having autism and 47.3 % (n = 192) have had contact with a child with autism. Fifty-eight-point nine percent (58.9 %) (n = 239) had participated in at least one training programme on Autism.

3.2. Knowledge on the aetiology of autism

The participants' knowledge about the aetiology of autism is displayed in the table below (Table 2).

3.3. Knowledge on the symptoms and comorbidities of autism

The mean knowledge of the participants on the "Knowledge about Childhood Autism among Health Workers (KCAHW) Questionnaire" was 13.23/19 (SD = 2.647). The knowledge was highest with regard to

Table 1
Socio-demographic details.

	Number (n)	Percentage (%)
District		
Colombo	231	56.9
Kalutara	175	43.1
Age		
20 – 29 years	80	19.7
30 – 39 years	140	34.5
40 – 49 years	95	23.4
> 50 years	91	22.4
Work experience		
< 1 year	27	6.7
1 – 5 years	68	16.7
5 – 10 years	91	22.4
> 10 years	220	54.2

Table 2
PHM's knowledge on aetiology of autism.

	Number (n)	Percentage (%)
Genetic factors	359	88.4
Medications taken during pregnancy	142	35.0
Birth complications	174	42.9
Parental conflicts during pregnancy and early childhood	172	42.4
Environmental pollutants	131	32.3
Poor attention from parents	177	43.6
Astrological influences	03	0.7

the impairment in communication (89 %) and lowest on the associated comorbidities (52.4 %). For example, only 33 % (n = 134) were aware that autism could be associated with epilepsy and 53.9 % (n = 219) knew that autism could be comorbid with mental retardation. In addition, only 13.1 %(n = 53) were aware that autism was a neurodevelopmental disorder (Table 3).

The knowledge about the symptoms and comorbidities of autism (measured by the KCAHW questionnaire) was significantly higher in those who believed that they were competent in identifying a child with autism ($p < 0.05$), those who have participated in at least one training programme on autism ($p < 0.01$) and in those who have had contact with a child with autism ($p < 0.05$). The knowledge was not significantly associated with the district of work, the age of the participant or their work experience.

3.4. Knowledge about treatment options for autism

Of the participants, 17.2 % (n = 70) believed that autism could be completely cured. Only 62.8 % were aware that speech therapy was used as a part of treatment and 78.1 % (n = 317) were aware of the benefit of occupational therapy. Thirty six point five percent (n = 148) believed that Western medicine was useful in treatment and only 5.2 % (n = 21) believed that Ayurvedic treatment was useful.

4. Discussion

The knowledge of PHMs' on the symptoms and comorbidities of autism was similar to the knowledge of doctors in a tertiary care hospital (mean score 13.23/19, 69.1 %), in a study done in Sri Lanka in 2017 (Rohanachandra et al., 2017). The knowledge of PHMs' was found to be higher than that of doctors in the domains of impairment in social interactions (PHM 86.6 %, doctors 75.8 %), impairment in communication (PHM 89 %, doctors 64.7 %) and presence of restrictive repetitive interests (PHM 69.7 %, doctors 60.7 %). However, doctors had a higher knowledge on the comorbidities and associations of autism (PHM 43.6 %, doctors 67.6 %) (Rohanachandra et al., 2017). This is surprising as one would expect the doctors to have a better knowledge about autism than the PHMs with years of undergraduate medical training. There may be several reasons for this paradox. Firstly, the previous study involving the doctors was done in 2017, and the awareness and common knowledge about autism may have increased since in the community in the ensuing years, accounting for the better knowledge about autism among the PHMs in the current study.

Secondly, Sri Lanka saw the appointment of first board certified Child and Adolescent Psychiatrist in 2014 with the gradual expansion of cadres since. Structured training in child psychiatry soon began in most teaching centres with medical undergraduate receiving some exposure to common child psychiatric problems. Prior to that, the Child and Adolescent Mental Health Services in Sri Lanka were spars and confined to one or two tertiary care centres where the medical undergraduates didn't have any exposure to disorders such as autism, which would probably account for this deficiency. In addition, doctors who have worked predominantly in surgical or adult medical facilities following their undergraduate training may not have had any exposure to children with autism, whereas 42.9 % of PHM's in the current study had worked with children diagnosed as having autism.

Thirdly, the PHMs have regular in-service training programmes organized by the Ministry of Health and 58.9 % of the PHMs in our study have participated in in-service training programmes on autism. On the contrary, an ordinary doctor in Sri Lanka lacks such exposure, which would partly account for this paradox.

In addition, the mean score on the KCAHW, was higher in the PHMs in Sri Lanka than their counterparts in Ghana (Sampson and Sandra, 2018) and Nigeria (Igwe et al., 2011); non-physicians (psychologists, speech therapists, occupational therapists) in Pakistan (Imran et al., 2011) and Saudi Arabia (Hayat et al., 2019); undergraduate medical and nursing students in Nigeria (Igwe et al., 2011) and India (Ellias and Shah, 2019) and general practitioners in Oman (Al-Farsi et al., 2016).

However, knowledge of the PHMs appeared to be inadequate in certain areas, especially on the common associations of autism. For example, only 13.1 % were aware that autism was a

Table 3
PHM's knowledge on the KCAHW questionnaire.

	Yes	No	Don't know
Domain 1 – Reciprocal social interactions			
• Marked impairment in the use of multiple non-verbal behaviours during social interaction	90.4 %	4.9 %	4.7 %
• Failure to develop peer relationship appropriate for developmental age	91.4 %	4.9 %	3.7 %
• Lack of spontaneous will to share enjoyment, interest or activities with others	93.1 %	3.4 %	3.4 %
• Lack of social or emotional reciprocity	95.1 %	2.2 %	2.7 %
• Staring into open space and not focusing on anything specific	71.2 %	22.2 %	6.7 %
• The child can appear as if deaf or dumb	78.6 %	10.8 %	10.6 %
• Loss of interest in the environment and surroundings	90.9 %	4.7 %	4.4 %
• Social smile is usually absent in a child with autism	88.4 %	7.9 %	3.7 %
Domain 2 – Impairment in communication			
• Delay or total lack of development of spoken language	88.2 %	5.9 %	5.9 %
Domain 3 – Restricted repetitive interests and behaviours			
• Stereotyped and repetitive movement (e.g. Hand or finger flapping)	83.3 %	5.2 %	11.6 %
• May be associated with abnormal eating habits	59.1 %	16.0 %	24.9 %
• Persistent preoccupation with parts of objects	75.9 %	9.4 %	14.8 %
• Love for regimented routine activities	59.6 %	19.2 %	21.2 %
Domain 4 – Common associations			
• Autism is childhood schizophrenia	19.7 %	53.7 %	26.6 %
• Autism is an auto-immune condition	47.3 %	33.0 %	19.7 %
• Autism is a neuro-developmental disorder	13.1 %	56.7 %	30.3 %
• Autism could be associated with mental retardation	53.9 %	35.2 %	10.8 %
• Autism could be associated with epilepsy	33.0 %	34.7 %	32.3 %

neurodevelopmental disorder and 33 % knew that autism could be associated with epilepsy. In addition, 40.1 % were not aware that children with autism preferred regimented routine activities and that they may have abnormal eating habits.

The present study found that the mean knowledge was significantly higher in PHMs who believed that they were competent in identifying a child with autism, those who have participated in training programmes on autism and in those who have had contact with a child with autism. Numerous other studies have also demonstrated that HCW who have had contact with children with autism had a significantly higher knowledge (Bakare et al., 2008; Igwe et al., 2011; Sampson and Sandra, 2018). This shows the importance of clinical exposure on improving the knowledge in autism.

PHMs also had many misconceptions with regard to the aetiology of autism, with 43.6 % and 42.2 % believing that poor attention from parents and parental conflicts during pregnancy and early childhood caused autism in children respectively. Similar beliefs were witnessed among HCW from other countries such as Pakistan and Oman. A study by Imran et al. demonstrated that 35.6 % of the HCW believed that cold and rejecting parenting styles were responsible for the poor social interactions seen in autism (Imran et al., 2011). Likewise, 22 % of the general practitioners in Oman believed that autism occurred as a result of negligence by parents (Al-Farsi et al., 2016). These beliefs may lead to parental guilt and worsening of mental health in the parents of children with autism.

In our study, 17.2 % of the PHMs believed that autism could be completely cured. Similar opinions about treatment was seen in Oman where 12 % of the general practitioners believed that autism could be completely cured (Al-Farsi et al., 2016) and in Pakistan where 44 % of the non-physician HCW believed that children will outgrow autism with age. Advising that autism can be completely “cured” may instil false hope in the parents.

Only 62.8 % of PHMs were aware of the role in speech therapy in the treatment of a child with autism, whereas 78.1 % knew about the need for occupational therapy. Poor knowledge about the treatment options may delay the initiation of such evidence based early intervention activities for these children. In addition, when the HCW are unable to provide accurate information, parents may turn to other questionable sources of information such as the internet or other parents (Rhoades et al., 2007), which may be overwhelming and confusing for the parents.

Furthermore, one study has shown that 33 % of the physicians discussed non-evidence based methods of treatment with parents (Skellern et al., 2005). However, the findings of our study showed that only 5.2 % believed in non-evidence based treatment options such as Ayurvedic medicine.

The present study revealed that in-service programmes on autism help to improve the knowledge of HCWon autism. This is supported by 2 previous studies (Bordini et al., 2015; Silva et al., 2018). However, some studies suggest that instructive training did not improve the developmental surveillance or the confidence to screen children for autism (Bauer et al., 2009; McKay, 2006). The present study suggests that the training programs in Sri Lanka should not only focus on signs and symptoms of autism, but also need to incorporate facts about aetiology and treatment options. In addition, as many studies have shown, having previous contact with children with autism significantly improved the knowledge of HCWs, training programmes should not only include lectures, but should also include a component of clinical training.

Although our study showed that the knowledge of PHMs on signs and symptoms of autism was satisfactory, previous studies on detection of developmental delays by the PHM’s have found conflicting results. A study on patterns of presentation of disabilities to a tertiary care centre in Sri Lanka has found that the community primary health care team (PHC) which also includes the PHM, had a delay in detection of mental retardation with no associated physical disabilities, compared to the detection of children with physical disabilities (Senanayake et al., 2000). This study has also found that none of the parents of children with disabilities have been alerted by the community PHC team (Senanayake et al., 2000). Furthermore, a study on presentations of speech delay in Sri Lanka has found that only 4.3 % of the referrals to speech therapy were from the community PHC team (Walpita and Ginige, 2014). This may reflect that the theory knowledge does not reflect the actual clinical skills of the PHMs. Therefore, we suggest that the basic curriculum of the PHMs should be improved with more emphasis on clinical training. At present, the field training of the PHM involves accompanying the field PHM in domiciliary visits and clinics to gain competence in delivering these services. We suggest than in addition, the PHM curriculum should include a period of clinical training, where she is given opportunity to train in paediatric clinics, disability clinics, specialized autism clinics and child mental health clinics, where they can be exposed to a variety of deviations in development. This would enable them to improve their clinical skills in detecting developmental abnormalities and autism in children. In addition, they would be able to observe the therapeutic interventions, which will assist them in providing information to parents with regard to the treatment options for autism as well as other developmental disorders. Furthermore, during their training, the PHMs are trained to administer tools such as the Edinburgh Postnatal Depression Scale to screen post-partum women with depression and 24 h dietary recall to assess children and women for dietary assessment. Similarly, they could be trained to carry out a culturally validated screening tools for autism such as the Pictorial Autism Assessment Schedule (PAAS) or Modified Checklist for Autism in Toddlers (MCHAT) (Perera et al., 2017, 2009). This would aid in early identification of children with autism. The NIHS, which is responsible for training and curriculum development of the PHMs, needs to take these observations into consideration in their curriculum revision.

In addition, previous studies have demonstrated that a delay in development was only indicated in 6% of the Child Health Developmental Record (CHDR), which is the tool used by the PHMs to monitor child development (Senanayake et al., 2000). This study has revealed that in 89.5 % of the children who presented with some form of disability, the details relating to child development was incompletely filled and did not indicate any abnormality (Senanayake et al., 2000). However, these studies have been done in the past and the practices of the PHMs may have changed over the years. Nevertheless, systems to monitor and review the actual practices of the PHMs need to be developed. This can take the form of in-service assessments or periodic audits and can be done by the relevant Medical Officers of Health (MOH) of the allocated area and can be used to ensure the quality of community child health services.

One limitation of our study is that it was done in two urban areas in Sri Lanka. The knowledge of PHMs in the rest of the country may not be comparable to the findings of this study.

Author declaration

We wish to confirm that there are no known conflicts of interest associated with this publication and there has been no significant financial support for this work that could have influenced its outcome.

Yasodha Maheshi Rohanachandra was responsible for the conception and design of the work, the analysis and interpretation of data, drafting the work, revising it critically for important intellectual content and final approval of the version to be published.

Shamini Prathapan was responsible for the design of the work, interpretation of data, drafting the work, revising it critically for important intellectual content and final approval of the version to be published.

H.G. Irosha Amarabandu were responsible for the acquisition and analysis of data, drafting the work and final approval of the version to be published

We confirm that the manuscript has been read and approved by all named authors and that there are no other persons who satisfied the criteria for authorship but are not listed. We further confirm that the order of authors listed in the manuscript has been approved by all of us. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately, investigated and resolved.

We confirm that we have given due consideration to the protection of intellectual property associated with this work and that there are no impediments to publication, including the timing of publication, with respect to intellectual property. In so doing we confirm that we have followed the regulations of our institutions concerning intellectual property.

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