

## Effectiveness of autism training program introduction at primary health care (PHC) level

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### KEYWORDS

Autism, knowledge, health education program.

### ABSTRACT

Background: Autism spectrum disorder (ASD) has become a public health issue in many countries especially in developing countries. Family members who have a toddler with ASD face significant physical, emotional, and financial challenges. Early detection is crucial to achieve improvement in children with ASD. Objectives: The aim of the current research is to study the implementation of a training program for Autism in 4 health care facilities and to evaluate its initial outcomes. Methodology: An interventional study conducted among 63 health care workers dealing with children 18-30 months in 4 health care facilities (2 urban health care facilities and 2 rural health care facilities) in Giza governorate. A tailored autism health education message as well as training on using the Arabic validated version of the Modified Checklist for Autism in Toddlers (M-CHAT) were provided to the HCWs. Results: 58.7% of participating primary health care workers (HCWs) had a satisfactory level of awareness about childhood autism prior to the intervention, and 71.4% had a satisfactory level of understanding following it. When comparing the study subjects' pre-intervention knowledge scores to their post-intervention knowledge scores, there was a statistically significant improvement in their knowledge about autism ( $p < 0.001$ ). Conclusion: The study's findings validate the value of specialized training programs in raising healthcare workers' awareness of childhood autism. Recommendations: Incorporation of autism spectrum disorder (ASD) within the educational curriculum of medical and nursing schools and ongoing education and training in ASD for health care workers.

## 1. Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder featured by shortfalls in social interactions and communication, restricted interests, and stereotypic behaviors <sup>[1]</sup>. The incidence of ASD has been reported to be elevating over the years. The global prevalence of autism has been reported to be (1–2 %) <sup>[2]</sup>.

Autism spectrum disorder (ASD) is accompanied by lifelong disturbances in functioning, significant family burden, increased death, in addition to high medical costs. The significance of early diagnosis and access to early management of ASD was widely realized. However, the diagnosis of ASD is still not made until around the age of five years old in the US, despite if caregiver concerns should be raised as early as twelve to eighteen months of age. People from poor socioeconomic status or various ethnic backgrounds experience even longer delays in receiving this diagnosis <sup>[3]</sup>.

African children are frequently exposed to established risk factors for mental health issues. In addition, systemic factors including a lack of qualified experts may make child and adolescent mental health problems worse. Compared to the global average of 9.0 mental health workers per 100,000 people, there are only an estimated 1.4 mental health workers per 100,000 people in Africa <sup>[4]</sup>. There are not enough psychiatrists, psychiatric hospital beds, or mental health outpatient coverage in the area, in addition to the lack of mental health specialists. Due to these obstacles, a remarkably small proportion of Africans seek treatment for mental health issues. It is estimated that 98.8% of Africans who require mental health care do not receive them. Alongside systemic issues, it is important to note the part parents play in ensuring their kids and teens receive mental health treatments <sup>[4]</sup>.

There is a growing need to learn more about the prevalence and characteristics of ASD in low- and middle-income countries (LMIC), and research suggests that it is beneficial to work locally with communities to develop awareness, capacity, and clinical abilities for identifying the early signs of ASD. Finding culturally appropriate approaches to address ASD concerns with families is essential. Screening should be done using proven, inexpensive, or free methods that are flexible enough to be trained and used in a variety of contexts. The need to build human capacity, particularly in LMICs has been regarded as a priority concern in the development of interventions for ASDs as well as other developmental disorders <sup>[5]</sup>.

Sufficient awareness and knowledge regarding childhood autism among healthcare workers( HCWs) would guarantee early diagnosis of children having autism and this subsequently would enable evidence-based interventions that enhance prognosis in children having autism. Furthermore, primary HCWs can play an effective role in both evaluation and treatment <sup>[6]</sup>.

After receiving a brief training on the state of knowledge on ASD, healthcare providers are more likely to use trustworthy ASD screening and diagnostic methods to diagnose patients early and to give caregivers more information <sup>[7]</sup>.

Accordingly, the current study aimed to evaluate childhood autism's knowledge among primary HCWs, to provide a tailored autism health education and to train the primary (HCWs) dealing with children 18-30 months on using a validated tool for autism screening for early detection of suspected autistic children 18-30 months who need referral.

## **2. Methodology**

Study design:

The current study is an interventional study. The study included Physicians and nurses dealing with children 18-30 months in the 4 participating Egyptian health care facilities: (2 urban health care facilities and 2 rural health care facilities) in Giza governorate which were El Talbia ,Kafr Tohormos, El Motamadia and Kerdasa primary health care centers. A convenient sampling technique was applied in which all physicians and nurses dealing with children 18-30 months were included with a total number of 63 participants.

Data collection techniques and tools:

The study was conducted in three phases:

Phase I: Pre-intervention phase

A list of all physicians and nurses dealing with children 18-30 months in the 4 participating health care facilities was prepared together with preparation of the setting where the health education (HE) sessions took place to ensure adequacy, privacy and comfort of the attendees then all those who settled to contribute to targeted study subjects took the modified version of knowledge associated childhood autism among health workers (KCAHW) questionnaire translated into Arabic and the results were assed and interpreted and according to the results the researchers started to plan for the HE sessions. A health education message was prepared by a specialist in community medicine and public health to cover areas of defect of targeted population knowledge , then the health education message was reviewed via a team of four staff members: three consultants of public health and community medicine at faculty of medicine, Cairo University and one consultant of psychiatry at faculty of medicine, Cairo University to ensure the scientific validity and comprehensiveness of the health education message.

After preparation of the HE material required a schedule was set for the health education sessions with the managers of the health care facilities according to the work flow and to ensure that it would not interrupt the work flow including separate sessions for physicians and others for nurses then the seclude was announced and all the targeted physicians and nurses were informed about it.

Phase II: Intervention phase

The intervention phase was guided by the CDC <sup>[8]</sup>. guidelines for effective health education and with Van Diggele et al <sup>[9]</sup>. review on planning, organizing and constructing a small group teaching session.

At the beginning of each session the researcher introduced herself and presented her great appreciation to the attendees for their time. The aim of the educational session was elaborated as a preparatory step for group brain storming concerning the points mentioned in the pretest which revealed their need for acquiring more knowledge about autism spectrum disorder (ASD).

Session plan:

The researcher started the session covering the definition of the disease, time of onset, symptoms, comorbidities, diagnosis, treatment and last but not least correction of some misconceptions about autism. At each of these domains the researcher raised a case scenario and asked the participants for their opinions and suggestions and displayed the ideal responses for each case scenario.

At the end of each session the researcher summarized the most important key messages:

- Definition;
- Clinical manifestations ;
- Early diagnosis and treatment ;
- Management of autism .

Take home messages:

The researcher distributed handouts covering the previous points discussed during the health education session.

Modified Checklist for Autism in Toddlers (M-CHAT) workshop:

The training on the use of M-CHAT was provided by the educator through demonstration and learning by doing with one of the attendees or with one of the available female workers having a child 18-30 months where the questions were asked by the researcher while being observed by the attendees and the researcher interpreted the findings, then the researcher asked one of the attendees to volunteer to use the M-CHAT with a mother of a child 18-30 months and to interpret the results too.

Phase III: Post-intervention phase

Where all physicians and nurses who received the health education responded to the modified version of KCAHW questionnaire translated into Arabic to validate the change in knowledge of autism among them after an interval of 3-4 months and the dropout rate was less than 10 %. All responses of the pretest with dropouts in the posttest were excluded.

Data collection tools used in Phase I and III:

Modified version of KCAHW questionnaire translated into Arabic:

This self-administered questionnaire has twelve questions. There is only one right answer for each question, with a range of possibilities. Every question has a score of 1 for the correct answer and 0 for the erroneous answer <sup>[10]</sup>.

Modification done according to cultural and clinical data by senior child psychiatrist in Ain shams institute of psychiatry. Modification done due to KCAHW questionnaire used psychiatric terminology that is difficult to be understood.

- Modification included 12 questions in 4 domains about symptoms, signs, etiology, onset and treatment of autism <sup>[11]</sup>.

**Table (A): The Modified KCAHW questionnaire <sup>[11]</sup>:**

Modified KCAHW domain	Knowledge validated	Number of items	Total score
Domain1	Communication and language development.	2	2
Domain2	Social interaction.	4	4
Domain3	Restricted, repetitive and stereotyped pattern of behavior.	2	2
Domain4	Co-morbidity of MR, age of onset, etiology and treatment.	4	4
Total		12	12

It was translated into Arabic language. The Arabic version was reviewed by three consultants from the psychiatric department in Ain shams university to assess its validity and used by Samar et al [11], in Ain shams university.

In the present study the cutoff point used for autism knowledge score for physicians, nurses, urban residents, rural residents as well as the knowledge score per domain in each of the previously mentioned divisions, was set at the median score since the data was not normally distributed. Knowledge that was deemed satisfactory was defined as having a score that was equal to or higher than the median; knowledge that was lower than the median was classified as having inadequate knowledge.

Utilizing a modified version of Bloom's cut-off point, each participant's knowledge was categorized as follows: good (i.e., satisfactory, positive, and favorable) if the score fell between 80 and 100%, moderate (i.e., between 50 and 79%), and poor (i.e., unsatisfactory, negative, and unfavorable) if the score fell below 50%. Consequently, categorical transformation was used to display the frequency distribution <sup>[12]</sup>.

**Table (B): Modified Bloom's cut-off point:**

Level of knowledge	Percentage of study subjects having satisfactory knowledge*
Good (i.e. satisfactory, positive, favorable)	≥80%
Moderate	50%-79%
Poor (i.e. unsatisfactory, negative, unfavorable)	<50%

\* Having a knowledge score equal to or above the median score.

Data collection tools used in Phase 2:

Arabic validated version of the M-CHAT:

M-CHAT is a 23-item yes/no questionnaire on child behavior and development noted via parents for children between 18 and 30 months of age. A positive/failed M-CHAT is termed as failing any three items (if the parents gave incorrect/failed response to any 3 items), or any two of six critical items (if the parents gave incorrect/failed response to any 2 items of 2, 7, 9, 13, 14, 15) <sup>[13]</sup>.

**Table (C): Failed responses of M-CHAT \*<sup>[14]</sup>:**

1. No	6. No	11. Yes	16. No	21. No
2.NO	7. NO	12. No	17. No	22. Yes
3. No	8. No	13. NO	18. Yes	23. No
4. No	9.NO	14. NO	19. No	
5. No	10. No	15. NO	20. Yes	

\*Critical items are shaded.

To accurately comprehend the findings, one must be trained. Toddlers who answered "positive" or "failed" on the M-CHAT are suspected of having ASD and require additional assessment by qualified professionals. The American Academy of Pediatrics recommends the M-CHAT, a commonly used tool for early autism screening. According to research, clinicians can use the M-CHAT as a screening tool for ASD <sup>[15]</sup>.

The ethical committee of faculty of medicine, Cairo university revised the study protocol and approved it(code:MD-72-2021). Informed consent was obtained after proper orientation for study subjects regarding the objectives of the study. Participation was voluntary, only those who agreed were included and that the participant may discontinue participation at any time. As stated in the Helsinki Declaration, strict privacy and confidentiality were upheld during the entire data entry, collection, and analysis process.

Statistical analysis:

The statistical software for the social sciences (SPSS) version 28 (IBM Corp., Armonk, NY, USA) was used to code and enter the data. The Kolmogorov-Smirnov and Shapiro-Wilk tests were employed to check the normality of numerical variables, and the results showed that they did not follow a normal distribution. For quantitative data, the median and interquartile range were used; for categorical data, frequency (count) and relative frequency (%) were used to summarize the data. The non-parametric Mann-Whitney test was employed to compare numerical variables. The Wilcoxon signed rank test was utilized as a non-parametric method to compare serial measurements within the same group <sup>[16]</sup>. Utilizing the Chi square (x2) test, categorical data was compared. When the anticipated frequency is less than five, an exact test was utilized instead [17]. P-values less than 0.05 were considered as statistically significant.

Study period:

The study field work was conducted in the period from June 2022 to January 2023.

### 3. Results

**Table (1): Socio-demographic features of the study participants:**

		Residence		Total (N=63) Number (%)
		Urban (N=35) Number (%)	Rural (N=28) Number (%)	
Gender	Male	0(0)	3(10.7)	3(4.8)
	Female	35(100)	25(89.3)	60(95.2)
Occupation	Physicians	13(37.1)	14(50)	27(42.9)
	Nurses	22(62.9)	14(50)	36(57.1)

Qualifications	Bachelor	10(28.5)	16(57.1)	26(41.3)
	Diploma	1(2.9)	0(0)	1(1.6)
	Master	2(5.7)	0(0)	2(3.2)
	Fellowship	1(2.9)	0(0)	1(1.6)
	Nursing diploma	21(60)	12(42.9)	33(52.3)

The median age and median years of practice for the urban residents were 40 (20) and 20 (21) respectively compared to 31.5(11.5) and 9(18) among rural residents respectively.

Regarding the pre-intervention knowledge among study subjects 82.5% knew that indications of autism involve impairment of social interaction, 73% knew that symptoms of autism include verbal communication's impairment while 68.3% knew that both impairment of play pattern and repetitive movement are symptoms of autism. yet only 9.5% and 14.3% knew the etiology and treatment of autism respectively.

While post-intervention, all study subjects (100%) knew that symptoms of autism include impairment of verbal communication, impairment of social interaction and impairment of play pattern also 100% knew that children with autism show detachment from their parents. Meanwhile 88.9% knew etiology of Autism and 76.2 % knew treatment of autism.

There was statistically significant higher pre-intervention knowledge score among physicians compared to nurses (P=0.001).

There was statistically significant enhancement in the post intervention knowledge scores as compared to the pre intervention knowledge scores among urban residents, rural residents, physicians and nurses ( P< 0.001).

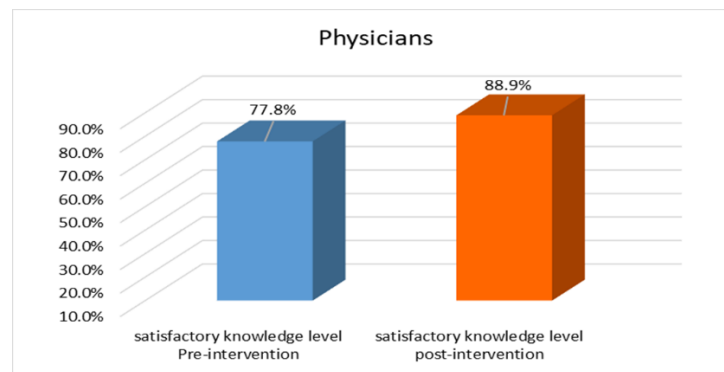


Figure (1): Satisfactory level of knowledge of childhood autism pre-intervention and post-intervention among physicians.

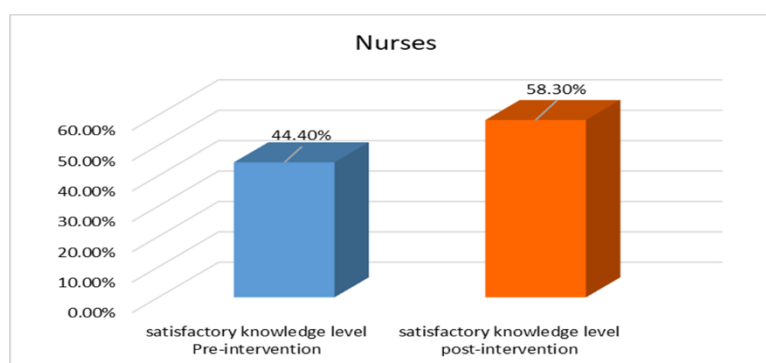


Figure (2): Satisfactory level of knowledge of childhood autism pre-intervention and post-intervention among nurses.

**Table (2): Overall knowledge score of childhood autism among study participants:**

	Knowledge score		p-value*
	Pre-intervention	Post-intervention	
Median (IQR)	6 (4)	11 (2)	<0.001

\* Wilcoxon signed rank test

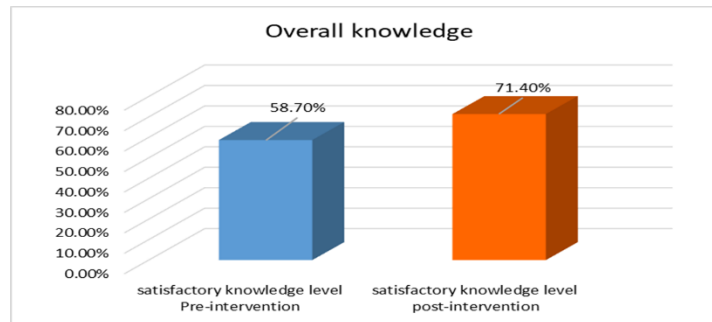


Figure (3): Satisfactory level of overall knowledge of childhood autism pre- intervention and post-intervention among study participant.

Again there was statistically significant improvement in the post intervention knowledge score as compared to the pre intervention knowledge score for each of the four domains of the modified KCAHW questionnaire (language and communication development, restricted, social interaction, repetitive and stereotyped pattern of behavior and co-morbidity of MR, age of onset, etiology and treatment) ( $P < 0.001$ ).

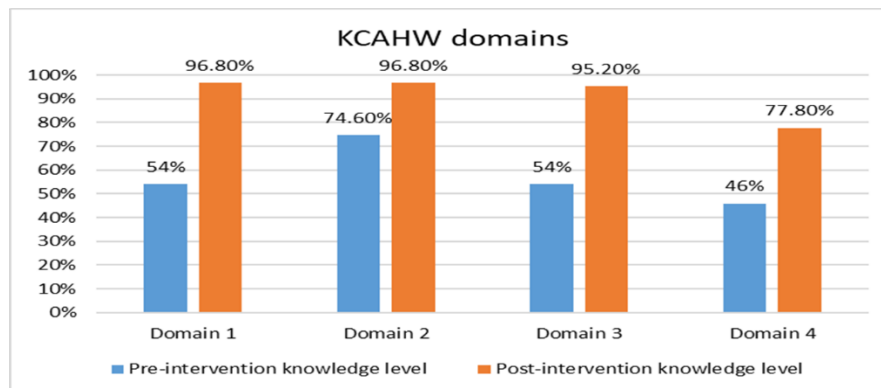


Figure (4): Satisfactory level of knowledge of childhood autism per domain of the modified KCAHW questionnaire pre- intervention and post-intervention among study participant.

#### 4. Discussion

The current study aimed to validate childhood autism's knowledge among primary HCWs, to provide a tailored autism health education and to train the primary (HCWs) dealing with children 18-30 months on using a validated tool for autism screening for early detection of suspected autistic children 18-30 months who need referral.

Considering the sociodemographic characteristics of the studied group the median age of the urban residents 40(20) was higher than the median age of the rural residents 31.5(11.5). Likewise, the median years of practice of the urban residents 20(21) was much higher than the rural residents 9(18). This might be explained by the high turnover among physicians in the primary health care facilities in rural areas owed to lack of motivation and poor rural resources.

There was a female predominance as females represented almost all of the study participants. This is similar to another Egyptian study conducted by Samar et al <sup>[11]</sup>, who aimed to validate the HCWs' awareness about autism at family medicine centers enrolling 110 primary health care workers of which 91.8% were females. The dominance of female gender in primary care facilities might be that they allow more personal time free for family, which females consider as an important factor while choosing a work place <sup>[18]</sup>.

Compared to nurses, doctors had a statistically substantially higher pre-intervention knowledge score regarding childhood autism. A study by Igwe et al <sup>[19]</sup>, which included 300 final-year undergraduate medical and nursing students at the University of Nigeria in Enugu State, Nigeria, and evaluated the factors influencing knowledge about childhood autism, supports this conclusion. The medical students had a higher level of knowledge than the nursing students. This difference could be owed to the academic curricula in medical schools compared to that in nursing institutes.



Considering the pre-intervention knowledge level of childhood autism among study participants, moderate level of knowledge among physicians and poor level of knowledge among nurses were detected. This may be the result of not receiving sufficient training on ASD in medical and nursing faculties and during their training. Secondly, they may not have had sufficient time and opportunity to attend in-service training or meetings to obtain information about childhood autism. Inadequate understanding of autism among medical professionals can lead to incorrect diagnoses, delayed diagnosis, and delayed intervention. Furthermore, research has demonstrated that health care providers, without sufficient understanding, do not provide caregivers with information; as a result, caregivers turn to other sources of support, including the media and other parents. This might result in caregivers receiving inadequate information, which would increase their financial burden, increase caregiver challenges, and raise the parents' risk of developing mental health issues.

Considering the overall knowledge of childhood autism, a moderate level of pre-intervention knowledge was detected since almost half of the study subjects had satisfactory level of knowledge pre-intervention. This is less than what was noted via Bakare et al <sup>[20]</sup>, in their study performed in Nigeria to evaluate knowledge about childhood autism among 134 HCWs where almost two thirds of their study subjects had satisfactory level of knowledge. The disparity in knowledge level may be attributed to the different type of study participants in both studies, Bakare et al <sup>[20]</sup>, study included pediatricians and psychiatrists who are more likely to be knowledgeable of childhood autism than the current study participants who included GPs and nurses. This ignorance could result from the undergraduate curriculum's lack of coverage of autism, the low number of postgraduate degrees awarded to current study subjects, and Egypt's comparatively newfound awareness of the illness.

Regarding knowledge of childhood per domain a moderate level of pre-intervention knowledge for the first three domains (language and communication development, restricted, social interaction, repetitive and stereotyped pattern of behavior) and poor level of pre-intervention knowledge for the last domain (co-morbidity of MR, age of onset, etiology and treatment) of the modified (KCAHW) questionnaire was detected among study participants. This could reflect their clinical experience which has restricted exposure to ASD cases since study subjects worked in primary health care facilities providing services based mainly on referral to a higher level of health care for further investigations and treatment once developmental disorders are suspected, together with the poor feedback and follow up of referred cases. The previous finding indicates the need for education and training in ASD and developing a strategy to endorse healthcare providers' knowledge of autism.

Almost half of the study participants had satisfactory level of knowledge of the communication and language development domain and also the restricted, repetitive and stereotyped pattern of behavior domain of the modified KCAHW questionnaire pre-intervention. This is much lower than what was reported by Kılınçel and Fikriye <sup>[21]</sup>, in Turkey who analyzed pediatricians' knowledge about autism where almost four fifths of their study subjects were knowledgeable of the language and communication problems as well as repeating or restricted interest symptoms associated with autism. The disparity in knowledge level may be attributed to the different type of study participants in both studies, the Turkish study included pediatricians who are more likely to be knowledgeable of childhood autism than the current study participants who included general practitioners (GPs) and nurses. Both domains require observation and interaction with autistic patients which are lacking among our study subjects.

Almost three quarters of the study participants had satisfactory level of knowledge of the social interaction domain of the modified KCAHW questionnaire pre-intervention. This is in agreement with Jubr <sup>[22]</sup>, in Libya who aimed at validating the knowledge's level and perceived obstacles to ASD early diagnosis and intervention among general practitioners in the city of Tripoli in Libya, where almost three quarters of their study subjects were knowledgeable of the impairment in social interaction associated with autism spectrum disorder.

Almost half of the study participants had satisfactory level of knowledge of co-morbidity of MR, age of onset, etiology and treatment domain of the modified KCAHW questionnaire pre-intervention. This goes with Jubr <sup>[22]</sup>, in Libya who found that almost half of their study subjects were knowledgeable of co-morbidity of MR, age of onset, etiology and treatment domain.

Regarding the impact of the intervention on knowledge of childhood autism there was statistically significant improvement in the urban residents, rural residents, physicians and nurses knowledge scores of autism following the educational intervention ( $P < 0.001$ ) as compared to the pre-intervention knowledge scores among study participants. The overall success of the training program in improving ASD knowledge could be related to the team engagement and group learning during the educational and training sessions. These results show that

Autism training is useful in strengthening health care provider knowledge of autism.

These findings are in line with the results of many related studies as that of Biel et al <sup>[23]</sup>, who included 14 pediatric primary care providers (PPCPs) who were provided with a training concentrating on improving young Latino children's identification at risk of ASD. Their participants scores on an exam testing ASD knowledge elevated from 50.8% pre-testing to 75.7% post-testing, Eray and Murat<sup>[24]</sup>, in Turkey who conducted a study to assess effectiveness of autism training program using a questionnaire prepared by the researchers found that there was a significant difference between pre-training and post-training scores of the questionnaire and Mazurek et al <sup>[25]</sup>, study carried out in the United States and Canada to assess the extension's effectiveness for community health outcomes model as applied to primary care for autism among 104 HCWs who indicated significant improvement in knowledge ( $P < 0.001$ ). All of these findings support the need for introducing health education and training programs for health care workers regarding autism spectrum disorder (ASD) to enhance knowledge and improve standard practices of HCWs.

A good level of post-intervention knowledge for the first three domains (language and communication development, restricted, social interaction, repetitive and stereotyped pattern of behavior) and a moderate level of post-intervention knowledge for the last domain (co-morbidity of MR, age of onset, etiology and treatment) of the modified KCAHW questionnaire was detected among study participants.

## 5. Conclusion

The study's findings corroborate the usefulness of specialized training programs in raising healthcare professionals' awareness of childhood autism; nonetheless, more effort must be put into creating efficient educational programs that can assist physicians in converting these gains into modifications to their practice, and ultimately to the health outcomes of autistic cases.

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Self-funded.

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