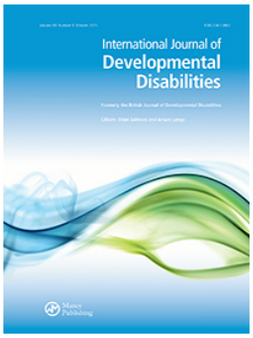

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A *SWOT* analysis of parent-mediated intervention for children with autism spectrum disorder: *Oman as a Regional Model*

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The prevalence of autism in the Arabian Gulf region is on the rise leading to overstretching of the pre-existing intervention services. The World Health Organization Caregiver Skills Training Program is a novel renovation being studied around the globe to overcome the scarcity of resources, improve autistic children's outcome and empower parents with comparable results to therapist-based models. Recently, Oman achieved great success in advocating for autism and initiated the first screening program for autism in the region. This review aims to use a Strength, Weakness, Opportunities and Threats (SWOT) analysis matrix to investigate the potential for using a parent-mediated intervention program as a supplementary approach to the currently used therapist-based intervention model in the country as an example for Gulf region.

Keywords: SWOT analysis, autism spectrum disorder, parent-mediated intervention

Introduction

Strength, Weakness, Opportunities and Threats (SWOT) analysis is a strategic planning technique used by institutions to gain more insight into circumstances around interventions (Yang 2010). It relies on examining external and internal factors that are compatible or incompatible with the proposed intervention to exploit advantages and anticipate and sort out deficiencies in order to maximize chances of success. Although the SWOT approach was first used by competitive company managers, it is nowadays gaining more popularity as a tool of planning for public health programs (van Wijngaarden *et al*. 2012).

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that is characterized by a constellation of two main features; social communication deficits and stereotypic repetitive behaviour that are evident from early childhood (American Psychiatric Association 2013). The prevalence of ASD is increasing worldwide as the World Health Organization (WHO) estimated that ASD is affecting 1 in 160 children (World Health Organization 2017b). However, recent estimates from the United States published in 2020 revealed that prevalence reached up to 1 in 54 which is considered 10% more than country's last reported figure (World Health Organization 2017a, Maenner *et al*. 2020). From an economical perspective, autistic children cost the UK budget around £3.1 billion per year with the cost increasing with age (Buescher *et al*. 2014). The rapid increase in autism prevalence around the globe, limited diagnostic capacity and improper intervention services along with the substantial economic and social cost require an immediate public health action. Interestingly enough, most children with autism live in low to middle-income countries with limited or no access to care (Salomone *et al*. 2019).

Based on the currently available evidence, there is no pharmacological treatment for the core symptoms of ASD. Medications are limited to treat comorbidities e.g. epilepsy and attention deficit hyperactivity disorders (CDC 2020). Although there is no gold standard intervention protocol for ASD, applied behavioural analysis (ABA) is the most extensively studied approach for intervention. ABA aims to encourage positive behaviours and build a child's social skills (Kelly *et al*. 2016,

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CDC 2020). Specifically, ABA is defined as "The science in which tactics derived from the principles of behavior are applied to improve socially significant behavior and experimentaton is used to identify the variables responsible for the improvement in behavior" (Heward 2014). This approach is provided mainly as a strict, well-controlled one-to-one therapist-based model. However, the shortage of qualified personnel urged the need for adopting non-specialist less strict modalities of intervention with the same theoretical and practical strategies underpinning ABA (Afzaal *et al*. 2019). This lead to the emergence of non-specialist based intervention exemplified in this review by Parent-Mediated Intervention (PMI) approach (Salomone *et al*. 2019). One of the applications of ABA model that was designed for pre-schools aged children is the Early Start Denver Model (ESDM). Parent implementation version of ESDM program has proved its efficacy in improving interaction skills among ASD children. However, despite the positive association, the effect was less than what was found in intensive-treatment studies (Rogers *et al*. 2012).

Early intervention in children with ASD

Early autism intervention is based on neuroplasticity theory which hypothesizes the presence of a critical window of time in the early years in which the developing brain is more responsive than later in life (Kolb and Gibb 2011). Despite the heterogeneity of ASD neurobiological and behavioural phenotypes, evidence suggests that intervention as early as two years of age in autistic children have a positive effects on their outcomes (Krishnan *et al*. 2016, Fuller and Kaiser 2020). Undoubtedly, multiple factors are confounding the effect size including ASD-related or environmental-related factors. Examples of ASD-related factors are; severity of symptoms, intellectual and adaptive abilities and the level of spoken language at the start of the intervention. On the other hand, parent education, socioeconomic status, the dose of intervention and age at the time of diagnosis are examples of the environmental-related factors that can affect outcomes (Landa 2018).

Early intervention in children with ASD can be provided in two ways, a comprehensive approach, and targeted interventions. The comprehensive approach is encompassing interventions to help autistic children in general with an overall goal to improve symptoms of autism and help preparedness for school. The targeted interventions are usually focusing on comorbid conditions such as food selectivity and challenging behaviours (Geoffray *et al*. 2016). The main models adopted in early intervention for ASD children are ABA model utilizing discrete trial instructional format and Naturalistic Developmental Behavioural Interventions (NDBI) (Landa 2018). The NDBI is a set of interventions that use developmentally appropriate strategies to be implemented in natural settings. It uses natural incidents and involves shared control between child and therapist to teach prerequisite skills. Although NDBI is based on well-established ABA-principles, it has its unique characteristics as its core components are determined by three general concepts; the nature of the intervention targets; contexts in which the interventions are delivered; and instructional strategies (Schreibman *et al*. 2015).

Of note, different other methods were used as early intervention approaches, e.g. developmental approach, Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH), animal-assisted, technology, and sensory-based approaches. Recently, a systematic review and meta-analysis summarized the effect of the different early intervention types in achieving a range of developmental outcomes. It has been concluded that enough quality evidence was amassed by NDBI and developmental intervention approaches for supporting children with ASD (Sandbank *et al*. 2020).

Autism and Gulf Cooperation Council countries, critical analysis of the situation in Oman

Generally, there is a paucity of literature about ASD in the Gulf Cooperation Council (GCC) countries. However, the prevalence of autism in the region is ranging from 4.3 to 29 per 10,000 children (Salhia *et al*. 2014, Al-Mamri *et al*. 2019). The low prevalence rate can be attributed to lack of awareness and underdiagnosis along with lack of unified diagnostic registries (Ouhtit *et al*. 2015). Despite the great governmental interest in autism in the GCC region, many efforts are constrained by disintegration between the different stakeholders. Collaboration between different governmental sectors is challenged by variability in vision, mission, budgeting outlines, and interventional approaches. Autism is getting increasing media interest and more attention by governmental bodies, hence, many local and international non-governmental organizations and private companies are interested in providing cooperation. However, ASD can be approached differently depending on stakeholder's social and political context (Alakhzami and Huang 2020).

The Sultanate of Oman is an Arabian Gulf country that is located at the coast of the Indian Ocean. It is one of the GCC countries with a population of 4.4 million. Forty per cent of Oman's population is younger than 25 years of age. The country's economy is depending mainly on oil and gas exportation (National Centre of Statistics and Information 2014). The health system financing in Oman is mainly provided as a governmental service, where all Omani nationals are getting health care with negligible out of pocket payment. The expatriates in private and governmental sectors are covered by health insurance powered by the labour law (Ministry of Manpower 2020).

In Oman, the launching of the national autism and developmental disabilities screening program in 2017 as the first national screening project utilizing locally adapted Modified Checklist for Autism in Toddlers, Revised (M-CHAT-R) was a cornerstone in changing ASD services in the country. The program constituted a model for countries in the region to initiate similar interventions as it helped in reducing the age of diagnosis and paved the way to reaching equity and accessibility of services in different provinces (Al-Mamari *et al*. 2017).

The rapid increase of diagnosed cases started to exert immense pressure on intervention services. Interestingly, the prevalence of autism in Oman increased from 1.4 in 2011 to 20.4 per 10,000 children in 2018 (Al-Mamri *et al*. 2019). This further challenged the already overwhelmed intervention centres that are experiencing difficulty in staffing and training of service providers (UNICEF 2017). In Oman, an exponential paradigm shift is developing towards a multidisciplinary inclusive model of services. This is strongly reflected at the managerial level by the formation of a multi-sectoral collaboration body represented by concerned ministries to facilitate cross-sectoral referral mechanisms in early intervention, education, protection and inclusion. The growing interest of higher officials led to a dramatic increase in governmental & NGO-based pre-school intervention centres (UNICEF 2017). Furthermore, private centres contributed actively to face the increasing demands for early intervention services (Ministry of Social Development 2015).

There are currently two centres located in Muscat – the capital city- being responsible for the clinical diagnosis and follow-up of children with ASD. Thereafter, patients are referred with recommendations from the diagnostic multidisciplinary team to the Ministry of Social Development in order to carry out the intervention plan(Alakhzami and Huang 2020). There are around 23 governmental owned centres distributed all over the country that provide services to 1708 children with different disabilities including ASD. The centres are providing social and psychological rehabilitation services, speech and physiotherapy, occupational therapy along with family support (Ministry of Social Development 2020a).

At the next level, the number of government schools applying integration increased from 85 to 236 between 2010 and 2019 (Ministry of Social Development 2020a; National Centre for Statistics & Information-Oman 2020). As promogulated by Omani law, children with disabilities are supposed to be enrolled in a special education system that is integrated within the formal educational system once they reach school age, in which they can get education matching their intellectual abilities (Ministry Of Education 2017).

The number of experts in the rehabilitation and education institutions for children with ASD in the GCC region is very scarce. This is especially true for ABA certified service providers in private and governmental services in the region in general (Kelly *et al*. 2016). It is interesting to know that the only two branches of the ABA chapter in the region that are located in Saudi Arabia and the United Arab Emirates were established very late; in 2013, and have very long and sophisticated qualification procedures (Taha and Hussein 2014). For this reason, most service providers are discouraged to pursue ABA certification. According to Emam 2016, in Oman, the special education system is impaired by under training of service providers leading to segregation of some students in separate classrooms with suboptimal education to match their needs (Mohamed Emam 2016). From the caregiver's perspective, it was found that around 60% of autistic children's guardians are dissatisfied with the provided services with a significant association between the level of dissatisfaction and low socioeconomic status of the families (Al-Farsi *et al*. 2013). As for parents, proper ABA therapist-based intervention is expensive for families as it should be implemented in one-to-one therapist to case ratio. This is especially important given the continuously increasing demand for trained therapists as the prevalence of autism continues to exponentially increase (Al-Mamri *et al*. 2019).

Considering the above, it can be argued that PMI can be a game-changer in increasing accessibility to services and reducing socioeconomic impact. It was shown in previous studies that PMI can ameliorate core autism features, advance language level and improve social interaction among autistic children (Rahman *et al*. 2016). From another prospect, providing parents of children with developmental disorders with skills to cope with their children's challenges can increase their competence, reduce stress and improve family integrity (Koegel *et al*. 2002). In early intervention studies, parent-mediated intervention refers to the parent-training procedure that qualifies them to lead the intervention program. One of the practical applications of the PMI approach which incorporates ABA principles is the "WHO Caregiver Skills Training Program for Developmental Disorders or Delays" (WHO CST). The program is adopting a family-centred approach which is cheaper and comparable to paid specialist-based interventions. The program is intended to benefit a wide array of developmental disorders including children with ASD. It consists of nine core module sessions complemented by three home visits and three optional group sessions. The overall aim of the program is to enhance child development, improve social communication and behavioural skills, improve the caregiver-child relationship, boost child's participation in home and community activities and enforce parents coping

strategies and psychological-well being (Salomone *et al*. 2019).

This review aims to discuss the Strength, Weakness, Opportunities, and Threats of PMI as a supplementary approach to the pre-existing therapist-based interventions for autistic children in Oman as an example of an Arabian Gulf country.

Strength

PMI programs can help in achieving better interaction and improve children's behaviour (Rogers *et al*. 2012, Krishnan *et al*. 2016). Additionally, it is potentially lowering the financial burden on the families. In a Swedish study, it was found that autistic children with intellectual disability have a total annual societal cost of around 70,000 €, of which 78% is allocated to education and intervention services (Järbrink 2007). Locally, although there are no such estimations, the out of pocket money to care for an autistic child is estimated to be around 15% of family income per month. Furthermore, the loss due to quitting jobs or unemployment among mothers can reach up to 48% (Al-Farsi *et al*. 2013). Despite the lack of formal cost-effectiveness studies, it was assumed that PMI is potentially a cost-effective intervention with great potential to reduce the total societal cost of caring for a child with autism (Järbrink 2007, Ingersoll *et al*. 2016). For instance, one of the PMI programs -Play Project Home Consultation- was found to decrease the cost of caring for an autistic child by 10 to 13 folds in an RCT study conducted in 2014 (Solomon *et al*. 2014).

Moreover, PMI was documented to improve social skills and communication among autistic children (Kasari *et al*. 2015, Nevill *et al*. 2018). This can result in increased parental satisfaction, less child-related parental stress and increased self-efficacy among parents (Keen *et al*. 2010, Factor *et al*. 2019). Although the above parental outcomes are counted as secondary outcomes, they can be of paramount importance given the tragic social and psychological implications of ASD on parents, children and families. A publication about psychosocial effects of autism on caregivers in Oman documented that they are experiencing more stress, anxiety and depression in comparison to a control group with typically developing children (Al-Farsi *et al*. 2016).

PMI can mitigate some of the weaknesses of regular therapist-based intervention, hence, could be counted as strength points. For instance, there are less than 50 behaviour analysts certified by the ABA Certification Board in GCC (Kelly *et al*. 2016). The dearth of certified trained therapists has tremendous negative impacts on interventional and educational services in the country. In addition to the quality of available services, long waiting lists for enrollment in intervention centres may constitute a major constraint. This is further complicated by the uneven distribution of centres in the country making it difficult for parents to adhere to sessions due to hardship and time lost on transportation (Ministry of Social Development 2015). It can be argued that PMI can empower parents with skills to conduct basic level interventions and prepare their children for next-level education (Afzaal *et al*. 2019).

With regards to special education, most of the educators working in rehabilitation and special education are regular teachers who were either selected by their schools or took the decision to serve in the special education system. Of those, some received training in special education of children with intellectual disabilities. Despite the appreciable efforts exerted by educators and schools, the number of special needs students and classes are increasing dramatically with no concomitant increase in the training capacity to accommodate all educators. These difficulties are reflected on the preparedness as well as the willingness of schools to provide educational services to children with disabilities (Mohamed Emam 2016). Theoretically, ensuring optimal early intervention will render autistic children better prepared for inclusion in the special education system (Eldevik *et al*. 2012, Pasco 2018).

One of the major strengths of PMI is the availability of an integrated evidence-based program that is adopted by the WHO. The WHO CST program is undergoing field testing in over 30 countries(World Health Organization 2019), and its results from different countries have suggested that it can be feasible, acceptable, and responsive to local needs (Salomone *et al*. 2019, Tekola *et al*. 2020).

Weakness

One of the main weaknesses of PMI that caregivers may vary in their implementation of intervention strategies that are delivered (Stahmer *et al*. 2017). It can be argued that paucity of evidence in this matter is originating from the inconsistency in defining the interventions, measuring scales and the outcome itself. In fact, both therapist-based interventions and PMI are sharing similar weaknesses with regards to the existence of a precise definition of intervention and identification of outcomes (Mazurek *et al*. 2020). Psycho-behavioural interventions in autism generally lack a unified measurement of outcome that can precisely identify the change in core symptoms of autism with high sensitivity. Instead, most of the available evidence relies on utilizing scales with questionable validity across different cultures or usage of improvement in intellectual abilities and developmental trajectories as desirable outcomes (Lord *et al*. 2005, Kanne *et al*. 2014). As a result, there is a scarcity of validity studies in PMI, especially, in Middle Eastern and Arabic speaking countries where there are very few validated tools and trained personnel.

Intervention fidelity is another factor that can be a challenge to PMI programs. Fidelity of intervention is defined as "the degree to which programs are implemented as intended by program developers" (Proctor *et al*. 2011). It is considered an important measure as it can affect the intervention outcome. As far as PMI is concerned, fidelity itself can be subdivided into the trainer and parent-related fidelity. In literature, research was mainly focused on exploring the trainer fidelity with the scantiness of evidence when it comes to parent adherence to intervention programs(Oono *et al*. 2013). The parent adherence to implementing an intervention is challenging to address and requires close follow-up and supportive supervision to ensure appropriateness (Shire *et al*. 2019). A Cochrane review about PMI documented the lack of consistency in follow-up methodology as methods ranged from questionnaires, diaries, videotaping to direct observation. Most of the trials, though, have not addressed fidelity at all (Oono *et al*. 2013). According to Lovass, fidelity has to be set at more than 90% in order to attain desired outcomes in early intensive behavioural intervention, which is difficult to achieve without close monitoring and evaluation (Lovaas 2003). It was documented that the accuracy and consistency of intervention by implementors plays a major role in the variability of children's outcome (Symes *et al*. 2006). Undoubtedly, achieving fidelity level as high as 90% in NDBI programs can be challenging and requires close monitoring, an area that is being under research. Regarding the WHO CST program, the development team adopted two scales for fidelity measure; namely, ENhancing Assessment of Common Therapeutic (ENACT) and Adult/Child Interaction Fidelity Scale. The WHO CST team prerequisites 25% of the program content to be rated through fidelity tools, however, no data have been published yet (Salomone *et al*. 2019).

Opportunities

The good infrastructure of the health system in Oman and the even distribution of primary health care facilities across the country can play a tremendous role in providing the venue, channels of communication and monitoring and evaluation checkpoints (National Centre for Statistics and Information 2017). Furthermore, in the last few years, autism has gained a lot of public and governmental interest which was culminated by establishing a national autism screening program in all the primary health care facilities of the country (Al-Mamari *et al*. 2017). The success of autism screening program can be the starting point to gain community consensus on the PMI. This is especially true for the non-governmental and private sector motivation to support autism activities given the current community interest in autism and governmental support (UNICEF 2017; Oman LNG 2020). Most importantly, the endorsement of Omani child law in 2014 that included a statement on the right of children with disabilities to undergo early detection and receive appropriate intervention was a cornerstone for autism-related projects implemented over the last few years (World Health Organization 2014).

On another scale, the availability of WHO CST program as an application of PMI can ensure cost-effectiveness, improve accessibility and guarantee more governmental support which in turns can safeguard sustainability (WHO 2019). Paradoxically, the current dissatisfaction about existing services and the obstacles faced by the caregivers would constitute an opportunity for this program to be accepted from the parents' perspective (Al-Farsi *et al*. 2013).

Threats

Social acceptability of some strategies and activities of PMI can compose a threat to its applicability. For example, WHO CST program is utilizing different strategies to achieve engagement, incorporation of the child in home-routine and play, promotion of communication, and problem-solving skills. One of the most important WHO CST strategies are dependent on child-caregiver play activities. Herewith, the concept of a parent playing with their children is difficult to be accepted in some rural areas and as a result, it could exert additional social pressure on parents of autistic children (Tekola *et al*. 2020).

As per the child's law in Oman, all children with disabilities have the right for early and appropriate intervention (World Health Organization 2014). Despite that, many autism cases in Oman are receiving intervention in private centres as the governmental centres are overwhelmed by the increasing number of patients with different disabilities. For eligible children who do not have the chance to get enrolled in public intervention centres, the government is outsourcing these services by paying to private centres to accommodate those children in the intervention (Ministry of Social Development 2020b). Consequently, additional hypothetical threat is the market competition for current therapist-based intervention centres.

Autistic children and their families are experiencing enormous pressure due to stigma attributed to poor community awareness. Interestingly, autism was attributed to parental maltreatment or negligence by 62% of teachers and 23% of general medical practitioners in Oman (Al-Sharbati *et al*. 2015, Al-Farsi *et al*. 2016). Subsequently, in addition to the self-isolation that ensues due to autism itself, parents tend to hide and isolate their children to avoid stigmatization which can negatively impact their psychological wellbeing (Al-Adawi *et al*. 2002).

More importantly, language could potentially emerge as a major barrier as most of the autism intervention service providers in Oman are Arabic speaking with

only a few having post-graduate university degrees (UNICEF 2017). Despite the fact that autism does not respect geographical boundaries or linguistic abilities of its patients, its outcome does. It was found that families with English speaking abilities have better outcomes in terms of social and communication skills in comparison to non-English speaking families (St. Amant *et al*. 2018). This is attributed to the fact that most of the diagnostic, educational and interventional strategies and tools were designed in the English language followed by translation to other languages at different rates of completion (Zuckerman *et al*). In regards to WHO-CST program, no data have been published about validation and Arabic adaptation yet.

Main recommendation

Defining intervention outcome

The lack of unified follow-up protocol and definition of outcomes among different PMI programs can be addressed by different approaches. Firstly, clear targets should be set at the child's assessment point and a specific tool to be selected that can measure each behaviour. Thereafter, to re-test the specific behaviour in isolation of general improvement or deterioration (Lord *et al*. 2005). Secondly, for the measurement of general improvement, it can be argued that setting the core symptoms of autism as a target outcome can be acceptable. Autism Diagnostic Observation Schedule (ADOS) is considered the gold standard test to document the core features of autism (Lord *et al.* 2012, Wiggins *et al*. 2019). Hence, multiple authors adopted the repetition of ADOS pre- and post-intervention as a good indicator of program performance (Lord *et al*. 2005, Oono *et al*. 2013, Solomon *et al*. 2014). Concerning the WHO-CST program, the outcome was set to target the child's social communication and adaptive skills, enhance the caregiver-child relationship and child's participation and include the child in community activities. The program has a secondary target toward caregiver's psychological well-being, parenting skills, and coping strategies (Salomone *et al*. 2019).

Fidelity

Regarding fidelity of trainers, videotaping is suggested to ensure robust application of the training protocol with continuous monitoring and evaluation by an external expert. This was found to increase the adherence to intervention protocol to 80% (Chang *et al*. 2016). As PMI is utilizing many NDBI strategies, project planners can use some of the tools created to monitor NDBI activities. It is worth mentioning that different tools are being innovated to operationalize activities related to NDBI which can improve the quality of provided services (Frost *et al*. 2020). Surly, having local experts for project implementation and monitoring process is expected to improve sustainability.

Different languages and community adaptation

With regards to language, a proper translation, validation, and adaptation to each community's norms and standards are strongly advised. With regards to the WHO CST program, the tool is available in multiple languages but the Arabic version is still not available on the WHO website (WHO 2019). However, community adaptation was done in India, Pakistan and Ethiopia with other studies still ongoing in other parts of the world (Rahman *et al*. 2016, Tekola *et al*. 2020), which can include Arab speaking countries. As a matter of fact, Oman's team that developed and established the autism screening program went through a similar experience in translating and adapting the Modified Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHAT-R/F)^{TM} to the Omani community (Idris *et al*. 2016).

From a different perspective, increasing community awareness is likely to reduce stigmatization and increase accessibility and acceptability to interventional services (Yamaguchi *et al*. 2011). In view of that, targeting community awareness about autism by multiple approaches would be a prerequisite for starting any community-based interventional program. The autism media campaign should target main messages which include; basic psychoeducation, community acceptability and participation along with family-centred approach intervention. The media campaign can help in fundraising, building capacity, changing attitudes of care providers and empower children with autism and their parents (World Health Organization 2013).

Conclusion

PMI programs can decrease the cost of caring for children with ASD. By adopting the PMI approach, some of the weaknesses of regular therapist-based interventions can be mitigated, hence, it can serve as a supplement to the early intervention process in Oman. The WHO Caregiver Skills Training Program (WHO CST) is an application of PMI which has proven its feasibility, acceptability, and appropriateness to local needs in many countries. In order to ensure better fidelity, videotaping is suggested to increase adherence to the intervention protocol. In the last few years, Oman has achieved great success in advocating for autism and initiated the first screening program for autism in the region. What has been achieved in Oman so far is creating the necessary conditions to move the services for autistic children to the next level.

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