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Palestine and Autism

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Historical Background

Since the end of the British mandate over Palestine in 1948 and the creation of Israel, the region has witnessed continuing territorial disputes, protracted violence, and political instability between the Arab Palestinians and the Israeli Jews. After the Oslo Accord signed in Washington, DC, in 1993, the Palestinian Authority was installed in the West Bank and Gaza Strip in a yet complicated peace process envisaging a two-state solution. Today, Palestine is a nonsovereign state that has been accepted as the 195th Member State by the United Nations Educational, Scientific and Cultural Organization (UNESCO) in 2011 (UNESCO 2011). Palestine still holds a non-member observer state in the United Nations. The West Bank of Palestine is a landlocked area surrounded by Israel and bordered to the East by the Hashemite Kingdom of Jordan, while the Gaza Strip is 25 miles long and 4–5 miles wide land bounded by Israel and Egypt. The majority of

the West Bank is controlled by Israel and a blockade has been in place since long limiting entry to and exit of Palestinians from the Gaza Strip. There are nearly 3 million Palestinians living in the West Bank and about 1.85 million living in the Gaza Strip.

Attention to autism spectrum disorders (ASDs) in Palestine has increased recently. This could be attributed to the increasing exposure to mass media, in part, and to the disseminated research carried out in the region and elsewhere around the world (Ashbee 2016; Dababnah and Bulson 2015; Dababnah and Parish 2013). This might have led to increasing the awareness of both healthcare professionals as well as laypersons on the issue of ASDs (Basha 2014). Tracking down the history of ASDs in this particular region of the world would be a difficult task in the absence of disseminated case reports. In addition, the incidence and prevalence of ASDs in Palestine are still unknown due to the absence of large epidemiological studies carried out for these objectives. Furthermore, Palestinian refugees in neighboring countries were excluded from studies conducted to determine the prevalence of ASDs, notably the one conducted in Lebanon although the number of Palestinian refugees in Lebanon registered by the United Nations Relief and Works Agency for Palestine Refugees in 2010 was approximately 440,000 (Chaaya et al. 2016). Recently, there have been calls to prioritize

research needs in mental health in Gaza Strip and ASDs were among these priorities (Abu-El-Noor and Aljeesh 2014).

Probably, light was shed on ASDs when the Palestinian Bureau of Statistics has conducted its first specialized national disability survey in 2011 which included ASDs within the category of “learning difficulties” when the Palestinian Central Bureau of Statistics has conducted its first specialized national disability survey in 2011 which included ASDs within the category of “learning difficulties” (PCBS 2011). Prior to this disability survey, the Child Statistics survey made no mention of ASDs. However, next year (2012), the Child Statistics survey alluded to ASDs which were included within “learning disability/difficulty” (Ashbee 2016; PCBS 2012). Another light shedding event was the organization of the first conference related to ASDs which was held in April 2012 in Bethlehem to coincide with the World Autism Day (Ashbee 2016). The conference was well attended and policies were discussed. In April 2016, the An-Najah Child Institute of An-Najah National University took a next step and held another conference on “Autism Spectrum Disorder, Evidence Based Practices in Palestine.”

In Palestine, there are four main providers of healthcare to the Palestinians. These providers are: (a) the Ministry of Health (the public sector), (b) the private sector, (c) nongovernmental organizations (NGOs), and (d) refugee services operated by the United Nations Relief and Works Agency (UNRWA). NGOs provide many services including psychosocial support and rehabilitation for physical as well as mental disabilities. Utilization of the services provided by the NGOs accounts for 11% of the overall healthcare utilization in the West Bank (World Bank 2006). In spite of the reported dearth of services for children with ASDs in Palestine, some not-for-profit and NGOs provide services to individuals with intellectual disability and ASDs.

An-Najah National University, which is the largest university in Palestine, has established An-Najah Child Institute in 2013. This institute provides clinical, training, and research services related to ASDs. A comprehensive and

multidisciplinary assessment approach is applied for the diagnosis of ASDs at this institute using internationally accepted tools which were translated into Arabic, adapted to culture, tested, and formally validated in Palestine. Currently, there is a kindergarten catering to the needs of children with ASDs. Once admitted, children are assessed, monitored, and individualized educational and skills acquiring plans are made for every child. Children with ASDs are grouped in small groups, each group of about five children and children with high functioning ASDs are later included in classes with the mainstream educational programs along with other children without ASDs. The institute has many research initiatives and plans to use evidence-based practice in catering to the needs of children with ASDs.

The Jerusalem Princess Basma Centre for Disabled Children was established in 1965 initially as a home for children with physical disabilities. Later the center was opened to include both children with disabilities and those without disabilities. Today, the center offers services related to physical therapy, occupational therapy, speech therapy, and special education. Since 2011, the center offers services to children with ASDs (Jerusalem Princess Basma Centre for Disabled Children 2017). The center is unique in the Palestinian context. The staff at the center are well-resourced and trained in approaches for working with children with ASDs. The staff includes teachers and occupational and speech therapists. Unfortunately, Palestinians in the West Bank face difficulties accessing and utilizing the services offered at this center as it is located in East Jerusalem. Palestinians need to obtain a travel permit (a *laissez-passé*) from the Israeli authorities to enter Jerusalem. For Palestinians of the Gaza Strip, it is nearly impossible to utilize the services of the center as they are restricted to travel to Jerusalem by Israel (Dababnah and Bulson 2015).

Other centers catering to the needs of children with ASDs in Palestine include the Star Mountain Center which was started as a hospital and now offers services and cater to the needs of children with low-functioning ASDs and intellectual disabilities (Star Mountain 2017). Parents of children with ASDs established a community-based

program known as Friends of Autistic Children Society (Friends of Autistic Children Society 2017). This center was established particularly for children with ASDs. Families of children with ASDs are closely involved. No formal training was provided to the staff; instead, they turned to the internet to seek guidance (Ashbee 2016).

Although the number of projects and programs that cater to the special educational needs of individuals with physical, intellectual, and learning disabilities ran by not-for-profit organizations and NGOs has grown, many parents questioned the quality of the services provided and claimed the costs were unaffordable to a considerable percentage of those interviewed (Dababnah and Bulson 2015; Dababnah and Parish 2013; Nasir-Tucktuck et al. 2017). Rigorous data on the quality of screening, diagnosis, therapy, and other services available and accessible to individuals with ASDs in Palestine are still needed (Dababnah and Bulson 2015). In best practice, diagnosis of ASDs requires a comprehensive assessment which is carried out with the help of a multidisciplinary team using formally validated tools. Recent studies reported healthcare professionals lacking awareness and knowledge of ASDs (Dababnah and Bulson 2015; Dababnah and Parish 2013; Shawahna et al. 2017). In many cases, parents of children with ASDs reported noticing signs and symptoms of ASDs on their children before pediatricians. Parents also reported that pediatricians did not use any formal screening tools. Parents of children suspected of having ASDs struggle finding healthcare professionals trained to perform the diagnosis. Receiving inaccurate diagnosis and information on ASDs and being recommended to use treatments without a solid evidence for effectiveness have also been reported (Dababnah and Bulson 2015).

Traveling outside the country is a common practice by Palestinians seeking diagnosis and/or treatments of disorders including ASDs (Dababnah and Bulson 2015; Habash and Fteiha 2015). Obtaining a referral from the Palestinian Ministry of Health and a travel permit (a *laissez-passé*) from the Israeli authorities is often required for Palestinians to be allowed to visit Israeli hospitals and healthcare centers. Palestinians also

often seek diagnosis and/or treatment in Jordan. Al Jabery and colleagues reported services including physical, occupational, and speech therapies available for individuals with ASDs in Jordan (Jabery et al. 2014). They also reported treatment services using hyperbaric oxygen and special nutritional plans. Extensive barriers to utilizing these services were reported, most notably, the cost. Geographic and political barriers also exist. Parents also reported challenges related to checkpoints and transportation limiting their access and utilization of services related to ASDs. Beyond cost and geographic and political barriers, individuals with ASDs and their families often face a heavy burden of social and cultural barriers to access and utilize services pertaining to ASDs (Dababnah and Bulson 2015).

Legal Issues, Mandates for Service

The passage, in 1998, of the Right of Education for All law by the Palestinian Authorities led to reforms in teacher training programs and educational facilities to accommodate the different needs of students, including those with disabilities (Palestinian Ministry of Education 2000). Prior to this law, schools did not cater to the needs of school children with physical, intellectual, and/or learning disabilities (Nasir-Tucktuck et al. 2017). Following the passage of this law, progress has been witnessed in regards to changing the attitudes and perception of providing equitable education to school children with disabilities. In the last two decades, many grant-funded teacher training projects have been administered in the Palestinian territories and many new schools accepted students with learning disabilities and mild disabilities. Despite these efforts of inclusion, unfortunately many children with disabilities in Palestine skip education. According the Palestinian Central Bureau of Statistics, more than 1 out of 3 people with disabilities aged 15 and above had never been enrolled in any educational system and out of those who did enroll, nearly 1 out of 5 dropped out as a result of their disabilities (Ashbee 2016; PCBS 2011).

Financial assistance to individuals with ASDs and their families is limited. In Palestine, any person with disability is eligible to apply for support from the Ministry of Social Affairs. Eligibility for financial support is decided following an extensive scrutiny. Support consists of an amount equivalent to about \$215 every 3 months. This amount is hardly enough to cover the cost of diagnosis of ASDs. Financial restraints related to caring for children with ASDs in regard to treatment, vitamins, tests, diapers, costly specialty items, speech therapy were reported by parents (Dababnah and Bulson 2015).

Overview of Current Treatments and Centers

Despite the dearth of services offered to individuals with ASDs in Palestine, the number of centers offering services to individuals with ASDs has grown recently. Some centers are striving to apply evidence-based approaches. Currently, the national mental health thematic group is developing the national policy for the diagnosis and treatment of ASDs. The policy was recently drafted and the formal approval is underway. Initiatives by parents and community-based programs have started and probably would be growing in the near future. Ambitious plans have been envisaged to create a village for individuals with ASDs (Ashbee 2016). However, these plans are beyond realization in the near future due to lack of funds and governmental support. Probably, this has come after the growing awareness of the importance of exposure to peers and acquiring of social skills.

Overview of Research Directions

Unfortunately, research programs are underdeveloped. Recently, some qualitative studies reported access to ASDs-related services as well as parents' perspectives of raising children with ASDs (Dababnah and Bulson 2015; Dababnah and Parish 2013). Another study investigated the awareness and knowledge of pharmacists on ASDs (Shawahna et al. 2017). A study

investigated a possible link between iron deficiency and ASDs (Al-Ali et al. 2015). Another study sequenced whole exome and revealed complex inheritance patterns and identified two gene mutations implicated in ASDs and intellectual disability (Khalaf-Nazzal et al. 2016).

Large clinical trials are completely absent in Palestine as laws prohibited conduction of such trials. Recently, a law was passed which permits the conduction of clinical trials in Palestine. The passage of this law would probably open new avenues for therapeutic interventions and research. Obviously, there is a dearth of interventional research in Palestine.

Overview of Training

The importance of training teachers to cater to the needs of children with ASDs has recently been recognized (Ashbee 2016). The Palestinian Ministry of Education has promised more commitment to develop in the field of education for children with ASDs. Resource rooms have been established in some schools to support children with additional needs. Some schools like the Friends school in Ramallah are including pupils with ASDs in the mainstream environment. The Jerusalem Princess Basma Centre for Disabled Children offers training to professionals in the West Bank in a trial to share experience and transfer know-how to their peers. More efforts are needed to accelerate the formal approval of the national policy for the diagnosis and treatment of ASDs and setting healthcare agenda in relation to ASDs.

Social Policies and Current Controversies

In a survey conducted in the West Bank by the Palestinian Central Bureau of Statistics, 1.6% of children aged 0–17 years were reported to have either physical or intellectual disability (PCBS 2011). It is important to mention that disabilities in the region are underreported and therefore, these figures should be interpreted with caution. Families with individuals with

ASDs were reported to hide their afflicted siblings (Ashbee 2016).

Unfortunately, there is stigma in regards to individuals with disabilities in general. Social stigma and discrimination were reported by parents of children with ASDs (Dababnah and Bulson 2015; Dababnah and Parish 2013). Denial, depressive symptoms, poor coping, social isolation, and increased burden on siblings were also reported by parents of children with ASDs (Dababnah and Bulson 2015; Dababnah and Parish 2013). Parents were able to cope with these challenges by religious practices, social support, and access to information. Fortunately, there is a growing body of information freely available on the internet that parents can access and learn about ASDs.

In Arabic speaking regions, words to denote disability are reported to be derogatory and pejorative. They are also used to swear. It is not uncommon for families to hide their children with disabilities fearing that the community will reject them.

A report by the Palestinian Central Bureau of Statistics on children and disability found that there is a tendency to blame the mother for her child's perceived disability (PCBS 2012). ASDs were often blamed as a "punishment from god." Recently surveyed pharmacist lacked adequate awareness and knowledge of and believed in myths in regard to ASDs (Shawahna et al. 2017).

Interestingly, today there is a louder parent voices demanding better governmental services for their children with ASDs. Increasing awareness and education might have an impact on reducing stigma and dispelling myths about individuals with ASDs.

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See Also

- ▶ DSM-III
- ▶ DSM-III-R
- ▶ ICD-10

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