REVIEW PAPER



A Systematic Scoping Review of Social, Educational, and Psychological Research on Individuals with Autism Spectrum Disorder and their Family Members in Arab Countries and Cultures

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Abstract

Cultural dimensions of autism spectrum disorder (ASD) are relatively unexplored in the research literature. The current study is a systematic scoping review describing social, educational, and psychological research focused on individuals with ASD and their family members in Arab countries and cultures. Seventy studies met eligibility criteria. Most of the studies were from Jordan, Saudi Arabia, and Lebanon. Most of the identified research addressed three major domains: the prevalence of ASD and diagnosis issues, the experiences and outcomes for Arab caregivers of individuals with ASD, and social and communication behaviour of Arab individuals with ASD. There were significant gaps in research evidence base, including research on interventions and on ASD services. Overall, the included research was appraised as being of weak quality.

Keywords Education · Psychological research · Cultural variation · Arab countries and cultures · Families · ASD

Introduction

In recent decades, prevalence estimates for autism spectrum disorder (ASD) have increased (Rice et al. 2012) with recent data suggesting an ASD prevalence in the USA of 1 in 59 children (Centre for Disease Control and Prevention 2018) and 600,000 people, equivalent to a population prevalence of approximately 1%, in the UK (Buescher et al. 2014). In Arab countries, there are relatively few studies that have

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examined the prevalence of ASD (Hussein and Taha 2014). However, existing studies do suggest that ASD is a prevalent disorder in Arab countries. For example, in the Sultanate of Oman, prevalence was estimated to be 1.4 cases per 10,000 children aged 0–14 years, with the highest prevalence among 5- to 9-year-old children, and in males (2.5 times the prevalence in females) (Al-Farsi et al. 2011). In Egypt, autism is often under-diagnosed, or more frequently misdiagnosed, and research suggests that there are more than 140,000 children in Egypt who are diagnosed with autism (Haffiz 2007). In the United Arab Emirates (UAE), a representative random sample of 694 3-year-old children was assessed in a two-stage study in the community. In the first stage, using the Autism Screening Questionnaire, 58 per 10,000 children were noted to have autistic features. In the second stage using clinical interviews, the weighted prevalence was estimated to be 29 per 10,000 for a DSM-IV diagnosis of pervasive developmental disorder (Eapen et al. 2007).

The Arab world comprises 22-member countries in the Middle East and North Africa: Iraq, Egypt, Syria, Jordan, Lebanon, Palestine, Qatar, Bahrain, Saudi Arabia, the United Arab Emirates, Oman, Somalia, Sudan, Mauritania, the Comoros Islands, Djibouti, Algeria, Morocco, Libya, Tunisia, Kuwait, and Yemen; with a combined population of approximately 392 million people (World Bank 2015). Although these countries share many similar characteristics



in terms of their Arabic language and common Islamic religious backgrounds, they still vary enormously in terms of their political, ethnic, economic, social, and religious characteristics (Alkhateeb et al. 2015; Taha et al. 2013). Accordingly, different opinions about the appropriate intervention and treatment of children with disabilities might be found in the Arab countries (Taha et al. 2013). Each Arab country has its distinct individuality, with living and nutritional customs that could serve a protective or risk role in relation to developmental disorders (Hussein and Taha 2014).

Generally, Arab cultures are characterized by a higher rate of marriages among cousins, high support for nuclear families by their extended families, and therefore a high tolerance for taking care of individuals with disabilities, particularly children. Arab families may be more tolerant of behaviours in children that would be seen by Western communities as abnormal (Taha et al. 2013).

It could be argued, based on research such as that cited above, that the prevalence of ASD in Arab countries is lower than in the developed world. However, cultural factors may play a significant role in shaping some aspects of behaviour with respect to symptom recognition and response to the disorder (Taha et al. 2013). Moreover, it is often difficult to access diagnostic services for a child with ASD to be diagnosed precisely. In addition, parents prefer for their child to attend schools for typically developing children rather than being referred to special schools (Mostafa 2011). Parents may under-report the child's difficulties to assessors even though they are aware of them. In addition, paediatricians are relatively inexperienced in the diagnosis and management of psychiatric disorders compared with their Western counterparts. Therefore, both under-diagnosis and under-reporting due to paucity of awareness may play a role in the current variance in ASD prevalence between Arab countries and Western countries (Mostafa 2011).

Although ASD occurs in all cultures and countries examined by researchers to date, the majority of research in the field of ASD has been conducted in Western countries. In contrast to Arab countries, Western countries typically have at least some and certainly more extensive professional support services (Hussein et al. 2011; Sharpe and Baker 2011). ASD was not a subject of study in the Arab world until the late 1990s (Hussein et al. 2011; Hussein and Taha 2013). As a result, only small amounts of research have been conducted on ASD in the Arab world (Al-Salehi and Ghaziuddin 2009).

Four recently published literature reviews have been conducted on ASD research in Arab countries (Alnemary et al. 2017b; Alkhateeb et al. 2015; Hussein and Taha 2013; Salhia et al. 2014). Hussein and Taha (2013) conducted a review of the literature to gather all available studies published on ASD in Arab countries and summarized them to highlight which areas of research need to be addressed in future. The authors reviewed all published English language studies and their

reference lists using a limited search strategy in only one electronic database. There was no systematic attempt to evaluate the methodological quality of the included studies. The authors indicated the difficulty in accessing studies that came from different national journals in different Arab countries and restricted their review to only internationally published studies. Overall, Hussein and Taha (2013) reviewed 75 studies, published from 1992 to 2012, which addressed different fields of ASD research such as genetic, autoimmune, oxidation stress, nutritional deficiencies, environmental toxins, errors of metabolism, mitochondrial dysfunction, clinical studies, imaging, treatment outcome, and available services. Most of the studies (n = 55, 73.3%) were published in the later years of the review period 2008-2012. The most addressed issue was possible etiologies of autism (n = 42, 56.6%), while treatment outcome was the least addressed issue (n = 4, 5.3%). Hussein and Taha (2013) indicated that most of the research was published in Saudi Arabia (n = 23, 30.6%) and Egypt (n = 16, 21.3%), while 11 studies (14.7%) came from Lebanon. The authors recommended organizational efforts to support ASD research to identify efficient strategies for improving diagnosis and service delivery to individuals with ASD and their family members.

Salhia et al.'s (2014) review aimed to evaluate the current state of knowledge on the epidemiology of ASD in Arab Gulf countries: Kuwait, Qatar, Saudi Arabia, the Sultanate of Oman, Bahrain, and the UAE. The authors reviewed all published English language studies on ASD epidemiology using a limited search strategy in two electronic databases. Salhia et al. (2014) clearly described their inclusion criteria. However, their methods for data extraction were not described. Furthermore, there was no systematic attempt to evaluate the methodological quality of the included studies. Two authors did independently extract data from included studies. The authors reviewed 12 studies, published up to 2013, three of which were prevalence studies that showed a prevalence ranging from 1.4 to 29 per 10,000 persons. The remainder of the included studies reported potential risk factors or biomarkers for autism in individuals from Arab Gulf countries.

Alkhateeb et al. (2015) conducted a comprehensive review of English language studies on the inclusion of children with developmental disabilities in Arab countries. Seven electronic databases were covered, and reference lists searches were used in searching the literature from 1990 to 2014. AlKhateeb et al. (2015) clearly described their inclusion criteria and their methods for study selection and data extraction. However, there was no systematic attempt to assess the methodological quality of the included studies. The authors independently extracted data from included studies using a specifically designed data extraction form. Alkhateeb et al. (2015) reviewed 42 studies about the inclusion of children with developmental disabilities in Arab countries. Results revealed that more than two thirds of these studies were from



researchers in the UAE, Jordan, and Saudi Arabia. The majority of these studies were published in the 6 years up to 2014.

Finally, Alnemary et al. (2017b) reviewed English language literature on ASD in the Arab world between the years of 1992 and 2014. Five electronic databases were used in searching published, unpublished, and grey literature. The authors examined how much ASD research has grown, where ASD research is being conducted, what ASD research areas are being addressed, what the impact of ASD research publications is, and who funds the ASD research. Inclusion criteria, methods for study selection, and data extraction were clearly described. However, there was again no systematic attempt to assess the methodological quality of the included studies. Alnemary et al. (2017b) identified 142 publications which addressed the biology of ASD (34.5%), risk factors (28.9%), and diagnosis (14.1%). The average number of country-specific publications per year was reported as 5.7 articles. ASD research was conducted in 13 Arab countries. The majority of studies were conducted in Saudi Arabia (n = 56), Egypt (n = 44), and Oman (n = 17). Several publications were published in journals with an impact factor ≥ 5.0. Over one third of the publications included funding acknowledgments. The majority of funding sources were governmental agencies (n = 53), whereas little research was funded by private organizations (n = 9). The authors recommended that additional research is needed to address fields involving developing screening and diagnostic tools, examining the efficacy of behavioural interventions, examining the effects of policies and resources on current services provided, studying lifespan issues, and surveillance.

The existing reviews have contributed to the knowledge base on ASD research in the Arab world. However, there are a number of methodological weaknesses in these reviews, including an absence of conducting comprehensive databased searching and quality assessment of included studies, and reviewing only English language literature. At present, there is no systematic review concentrating on social, educational, and psychological (as opposed to medical/biological) research focused on individuals with ASD and their family members in Arab countries and cultures. The main purpose of the present study was to carry out a systematic scoping review with this focus, and also to include comprehensive data-based searching and quality appraisal of studies. In this review, the following questions are addressed:

- 1. What social, educational, and psychological research has been conducted on individuals with ASD in Arab countries and cultures?
- 2. What social, educational, and psychological research has been conducted on family members of individuals with ASD in Arab countries and cultures?



A protocol was written for the review and this was followed throughout the procedures described below. Although unregistered, the protocol is available from the corresponding author on request.

Search Strategy

Systematic searches were conducted in April 2016 (updated December 2017), starting with electronic searches of eight databases: PsycINFO, MEDLINE, ERIC, Social Science Citation Index, EBESCO, EMBASE, Web of Science, and Google Scholar. The search included terms for ASD combined with search terms for Arab countries' names and their recognized abbreviations. The search terms below were searched in all fields:

(Autis* OR ASD OR Asperger* OR pervasive developmental disorder*" OR PDD) AND (Arab* OR Algeria* OR Egypt* OR Libya* OR Tunisia* OR Morocco* OR Mauritania* OR Sudan* OR Somal* OR Djibouti* OR Bahrain* OR Emirates OR UAE OR Oman* OR Kuwait* OR Qatar* OR Saudi* OR KSA OR Yemen* OR Jordan* OR Syria* OR Iraq* OR Gaza OR Leban* OR Comoros* OR "West bank" OR Gulf OR "Middle East"). A comprehensive multi-point search strategy was designed to ensure that, by the end of the search process, all relevant literature was found. This strategy included electronic searches of eight databases, previous systematic reviews and literature reviews, and forwards and backwards citation searching for all included studies.

A total of 667 references were identified through the initial search process after the first reviewer removed duplicate articles (Fig. 1). Based upon title and abstract screening, two reviewers (first and third authors) excluded 593 studies (inter-rater reliability 93%) as they clearly did not meet the inclusion criteria (e.g. not specifically about ASD, not about Arab countries and cultures). The two reviewers independently applied the inclusion criteria to the remaining 74 studies after obtaining full text copies. Of those 74 studies, 31 were excluded because they did not meet inclusion criteria. The remaining 43 studies were selected by the two reviewers to be included in the review. Further, hand searches were carried out to identify publications that had not been included and indexed by electronic databases or articles from journals that were not indexed by electronic databases. In addition, hand searches can compensate for inaccurate database indexing that can result in even the most carefully constructed strategy failing to identify relevant studies (Systematic Reviews 2009). Therefore, hand searches of reference lists used Google Scholar's "cited by" feature for all included studies were carried out alongside checking of the reference lists of previous systematic reviews and literature reviews. These processes



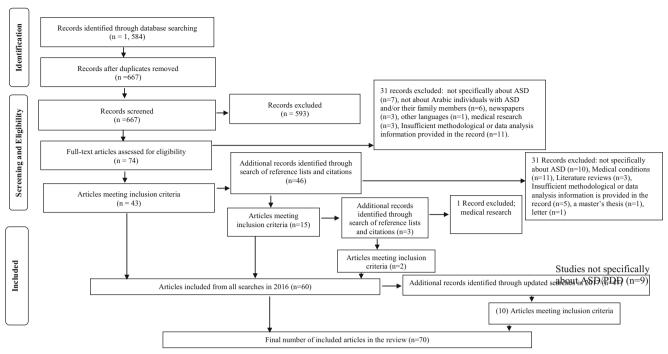


Fig. 1 A flow diagram of study selection process (adapted PRISMA "Preferred Reporting Items for Systematic Reviews and Meta-Analyses" flow diagram)

identified an additional 46 studies for consideration, and the two reviewers agreed to include 15 of these additional studies. The first reviewer searched the reference lists and checked citations of the additional 15 studies to identify more relevant studies for possible inclusion, resulting in an additional three studies, two of which were finally included. On checking the reference lists and citations of these final two studies, no more new relevant studies were found. To ensure that no recent papers were missed, the first reviewer repeated the database searches in December 2017, identifying 47 additional studies for consideration. Of those 47 papers, 10 studies were included. Ultimately, 70 studies met the inclusion criteria described below.

Study Selection

To be included within the review, an article had to meet the following criteria: (a) studies had to adopt any research design or methodology (including case series, and case studies) and report research data; (b) the study had to focus on: social, educational, or psychological issues related to individuals with ASD and their family members in an Arab country or culture; (c) participants in studies had to be Arab individuals with ASD or their family members; and (d) studies had to have been published in the English or Arabic languages.

Studies were excluded from the review for the following reasons: (a) medical studies of individuals with ASD and/or their family members including studies of medical causes (e.g. genetic factors, environmental factors, and metabolic

disorders), medical diagnosis (e.g. biological markers such as immune blood markers, immune urine markers, and laboratory tests such as genetic test, blood, and urine test), medical treatment (e.g. dietary treatment, drugs, and acupuncture therapy), and physical health condition problems (e.g. food and skin allergies, vitamins deficiency, and gluten sensitivity); (b) systematic reviews; (c) the studies were published in a research thesis, books, book chapters, meeting abstracts, or conference papers; and (d) the paper included insufficient methodological or data analysis information to understand the findings of the study.

Data Extraction and Appraisal of Study Quality

Each identified study was first assessed for inclusion/exclusion. After this, each included study was summarized by the first reviewer in terms of: (a) study reference (authors, publication date, and country where the study was conducted); (b) aims, study designs, and methods; (c) participants; and (d) main findings. The data extraction form was independently checked by the third author on a sample of included studies (20%) to verify the accuracy and completeness of the relevant data. The two reviewers agreed fully on all data extraction.

Quality appraisal tools were used for each type of study design included in the review. Three assessment tools were applied to included studies. The Critical Appraisal Skills Program (CASP) tool was used for qualitative studies. This tool includes three broad dimensions that need to be considered when appraising a qualitative study: the validity of the



study, the usefulness, and the importance of study findings (CASP 2014).

The Quality Assessment Tool for quantitative studies, which was developed by the Effective Public Health Practice Project (EPHPP) (2007) in Canada, was used for all quantitative studies in the review. This tool includes the following component ratings: selection bias, study design, confounders, blinding, data collection methods, withdrawals and dropouts, intervention integrity, and analysis.

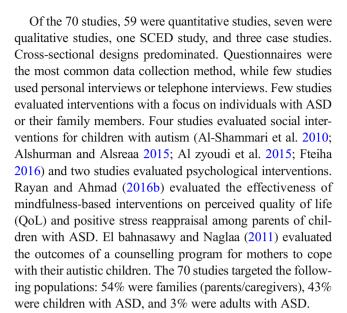
For Single-Case Experimental Designs (SCEDs), the Quality Indicators tool developed by Horner et al. (2005), was used. This tool includes several critical features that can be used to assess different aspects of SCEDs, including information on description of participants and settings, dependent variable, independent variable, baseline data, experimental control/internal validity, external validity, and social validity (Wang and Parrila 2008).

The third author independently quality assessed a sample of 20% of included studies from the searches originally conducted in April 2016 (10 quantitative studies, one qualitative study and one SCED study). Disagreements were resolved by consensus between the two reviewers. Data were summarized using a narrative synthesis approach, due to the heterogeneity of the literature and study designs.

Results

Seventy studies were found on social, educational, and psychological research including Arabic individuals with ASD and their family members in the following Arab countries: Saudi Arabia, Kuwait, Bahrain, Jordan, Lebanon, UAE, Oman, Egypt, Qatar, Libya, Iraq, West Bank, Syria, Tunisia. A small number of studies (n = 12, 17%) were conducted in non-Arab countries but with Arab populations (Baker 2017; Barnevik-Olsson et al. 2008; Dolev et al. 2016; Esler et al. 2017; Estrem and Zhang 2010; Fox et al. 2017; Kediye et al. 2009; Meiri et al. 2017; Perepa 2014; Raz et al. 2015; Sher-Censor et al. 2017; Walker-Dalhouse and Dalhouse 2015). None of the 70 studies identified were published in Arabic.

The included studies were all published in or after 2007. Most of these studies (n = 50, 71%) were conducted between 2012 and 2017. Most of the studies were from Jordan (n = 14, 20%), Saudi Arabia (n = 10, 14%), and Lebanon (n = 5, 7%). All the studies that have been published from Jordan focused on Arab caregivers of individuals with ASD. In Saudi Arabia, the largest proportions of publications addressed Arab caregivers of individuals with ASD, followed by ASD prevalence and diagnosis issues and then the social/communication behaviour of Arab individuals with ASD. While in Lebanon, ASD prevalence and diagnosis issues were the most addressed topic.



Included studies focused on research addressing three major themes: (1) the prevalence of ASD and diagnosis issues, (2) the experiences and outcomes for Arab caregivers of individuals with ASD, and (3) social and communication behaviour of Arab individuals with ASD. Tables 1, 2, and 3 contain summaries of the included studies, with full details of these studies described in the Online Resource (Tables S1–S3). The research in each of these three theme areas is summarized below. Detailed synthesis of findings is not included given the rated low quality of research in general (and thus the potential for mis-leading conclusions).

Prevalence of ASD and Diagnosis Issues

There were 23 studies that examined the prevalence of ASD or diagnosis issues in Arab countries and cultures (Table 1 and Online Resource S1). Of those 23, four studies were conducted in non-Arab countries but with Arab populations (Esler et al. 2017; Raz et al. 2015; Estrem and Zhang 2010; Barnevik-Olsson et al. 2008). The total number of Arab participants included in these studies was 916. There were six collaborative studies conducted across the Arab countries. Arab countries that contributed to this area of research were: Lebanon, Jordan, Oman, UAE, Bahrain, Libya, Egypt, and Saudi Arabia. The total number of participants for studies in this area of research was 43,846. Most of the studies used samples from hospital and specialist units that offer services for children with special needs. For example, Al-Farsi et al. (2011) recruited a sample of children aged 0-14 years from all hospitals and social institutions that provide targeted services to ASD patients in Oman, including one tertiary hospital with a child psychiatry unit and eight social centres for children with special needs distributed in all regions in the country. Results revealed that the overall prevalence of ASD was found to be 1.4 cases per 10,000 children. The male to female ratio was 3:1. Further,



 Table 1
 Prevalence of ASD and diagnosis issues

	Study reference and country	Aims, study design, and methods	Participants
1	Esler et al. 2017. Minnesota	Aims: differences across ethnic groups (included Somali children) in ASD symptoms.	Children (7–9 years) in 200
		Design: retrospective cohort.	
2	Chaaya et al. 2016. Lebanon.	Methods: Educational and medical records. Aims: prevalence of (ASD) in children in nurseries.	998 children.
•	Chaaya et al. 2010. Lebahon.	Design: cross-sectional.	998 Children.
		Methods: Modified Checklist for Autism in Toddlers.	
3	Mohamed et al. 2016. Egypt.	Aims: early screening of toddlers for ASD.	5546 toddlers
		Design: cross-sectional community based descriptive.	
ŀ	Mohammed et al. 2016. Saudi Arabia.	Methods: Modified Checklist for Autism in Toddlers. Aims: detect ASD cases within a health service, and associated risk	107 children
•	Wondinined et al. 2010. Saudi Arabia.	factors.	107 Cilidicii
		Design: cohort. Methods: Retrospective medical chart.	
5	AlAyadhi et al., 2015. Saudi Arabia.	Aims: early warning signs of ASD as perceived by ASD parents.	57 ASD cases and 84
		Design: case-control.	controls.
		Methods: Questionnaire.	
6	Raz et al. 2015. Israel	Aims: differences in ASD incidence by the major Israeli population	All children born in 1992–2009.
		groups. Design: retrospective cohort.	1992–2009.
		Methods: Data from the Israeli National Insurance Institute.	
7	Dirani and Salamoun 2014. Lebanon.	Aims: demographic and clinical variables at the first assessment of ASD or IDD children in a clinic.	209 ASD or IDD children.
		Design: cohort.	
		Methods: Autism Diagnostic Observation Schedule and Wechsler tests for cognitive functioning.	
8	Akoury-Dirani et al. 2013. Lebanon	Aims: psychometric properties of the Lebanese version of the	30 children (24 AD or
,	Though Bruin et al. 2013. Ecoulon	(CARS2-HF).	PDD-NOS and 6
		Design: cross-sectional.	(ADHD).
		Methods: Childhood Autism Rating Scale Second Edition, High	
9	Al-Ansari and Ahmed 2013. Bahrain	Functioning Version. Lebanese version.	100 AD abildran and 100
,	Al-Ansari and Anmed 2013. Banrain	Aims: prevalence of AD with the sex distribution and possible associated factors.	controls with nocturnal
		Design: case–control.	enuresis.
		Methods: Medical and social records.	
10	Al-Zahrani A 2013. Saudi Arabia.	Aims: prevalence and describe the clinical characteristics of ASDs in	22,950 Children born from
		school-age children. Design: cross-sectional.	1999 to 2004.
		Methods: The Autism Spectrum Screening Questionnaire.	
11	Hamadé et al. 2013. Lebanon	Aims: association of autism with several risk factors.	86 cases and 172 control
		Design: case-control.	children.
12	Tale at al 2012 Count's Austria and	Methods: Questionnaire	20 E
12	Taha et al. 2013. Saudi Arabia and Egypt.	Aims: outcomes of autism in a sample of Egyptian and Saudi children. Design: comparative prospective naturalistic.	20 Egyptians children and 28 Saudi.
	Lgypt.	Methods: Clinical Global Impression–Improvement Scale, Childhood	20 Saudi.
		Autism Rating Scale, Gilliam Autism Rating Scale, Vineland Adaptive	
		Behavioural Scale and Stanford Binet test.	60 LOD 1111
13	Amr et al., 2012a. Egypt, Saudi Arabia, and Jordan.	Aims: influence of sociodemographic variables on the severity of autistic symptoms and behavioural profile in children.	60 ASD children
	and Jordan.	Design: cross-sectional.	
		Methods: Arabic versions of the Wechsler Intelligence Scale for Children,	
		Indian Scale for Assessment of Autism and Child Behaviour Checklist.	
14	Amr et al., 2012b. Jordan, Egypt, and Saudi Arabia	Aims: prevalence of comorbid psychiatric disorders in a sample of ASD children.	60 ASD children.
		Design: cross-sectional.	
		Methods: Arabic versions of the Indian Scale for Assessment of Autism,	
		Wechsler Intelligence Scale for Children, Stanford Binet Intelligence Test and Semi-structured clinical interview.	
15	Zeglam and Maouna 2012. Libya	Aims: ASD prevalence in children attending a clinic.	180 children.
_		Design: retrospective cohort.	
		Methods: Children were reviewed as having ASD if they displayed	
		behavioural abnormalities consistent with DSM-IV for diagnosing	



Table 1 (continued)

	Study reference and country	Aims, study design, and methods	Participants
		autism, (PDD-NOS), including atypical autism, or Asperger disorder.	
16	Al-Farsi et al. 2011. Oman.	Aims: ASD prevalence among children. Design: cohort.	113 ASD children (0–14 years).
		Methods: Questionnaire and Childhood Autism Rating Scale questionnaire.	•
17	Amr et al. 2011. Egypt, Saudi Arabia, and Jordan.	Aims: sex differences in autistic symptoms and coexisting behavioural problems.	37 M and 23 F with ASD.
		Design: cross-sectional. Methods: Socio-demographic questionnaire, Indian Scale for Assessment of Autism and Arabic version of Child Behaviour Checklist.	
18	Hussein et al. 2011. Egypt and Saudi Arabia.	Aims: characteristics of autism in two groups of Egyptian and Saudi children.	20 Egyptian ASD children and 28 Saudi.
		Design: comparative. Methods: Arabic versions of Gilliam autism rating scale, Stanford Binet test and Vineland Adaptive Behavioural Scale.	
19	Raddad et al. 2011. Jordan	Aims: contributions of demographic variables and intellectual correlates among AD children.	22 AD children.
		Design: cross-sectional. Methods: Semi-structured questionnaire, Arabic versions of the Indian Scale for Assessment of Autism, Child Behaviour Checklist and	
		Wechsler Intelligence Scale of Intelligence.	
20	Estrem and Zhang 2010. Minnesota.	Aims: prevalence of children who received autism SES between 2001 and 2008.	All children (birth to 21 years) in
		Design: retrospective cohort. Methods: Data from the Minnesota Department of Education.	public schools.
21	Barnevik-Olsson et al. 2008. Stockholm	Aims: prevalence of autism in Somali children and a	501 AD or PDD-NOS chil-
	county, Sweden.	non-Somali group. Design: cohort.	dren aged 7–17 years.
22	Seif Eldin et al. 2008 Egypt, Kuwait,	Methods: Records of Somali children with AD or PDD-NOS. Aims: feasibility of using Modified Checklist for Autism in Toddlers.	122 ASD cases and 106
	Jordan, Lebanon, Oman, Qatar, Saudi Arabia,	Design: cross-sectional. Methods: Modified Checklist for Autism in Toddlers was translated.	TD controls.
	Syria, and Tunisia.		
23	Eapen et al. 2007. UAE	Aims: prevalence and correlates of PDDs in preschool children. Design: cross-sectional.	694 3-year-old children.
		Methods: Autism Screening Questionnaire, Denver Developmental Screening Test and Child Behaviour Check List.	

in Libya, of 38,508 children seen in the neurodevelopment clinic of Al-Khadra Hospital in Tripoli, 128 children were diagnosed with ASD: 99 (55%) children had classic autism, 21(12%) had pervasive developmental disorder not otherwise specified, 6 (3%) had Asperger syndrome, and 2 (1%) had Rett syndrome. The prevalence of ASD was 1 in 332 children seen at the paediatric outpatient department, approximately 3 per 1000 children (Zeglam and Maouna 2012).

Other studies attempted to determine the prevalence of ASD in samples from preschools. For example, in Lebanon, a sample of 998 children from both genders and all ethnic groups, aged 18–30 months, were recruited from 177 nurseries in the capital city, Beirut and Mount Lebanon by using the Modified Checklist for Autism in Toddlers (M-CHAT). Results revealed that ASD prevalence was 1 in 66 children. The male to female ratio was 1:05 (1 in 65 for males and 1 in 67 for females) (Chaaya et al. 2016).

There were few studies that attempted to validate screening and diagnostic tools for use in Arab countries. A recent study from Lebanon (Akoury-Dirani et al. 2013) employed forward and backward translation of the English version of Childhood Autism Rating Scale Second Edition, High-Functioning Version (CARS2-HF), into Arabic and evaluated its psychometric properties. It was reported that the Lebanese version of the CARS2-HF had a high degree of internal consistency, interrater reliability, and test-retest reliability. These data suggest that the CARS2-HF can be used in screening and assessing for ASD in high-functioning Lebanese- and Arab-speaking individuals (Akoury-Dirani et al. 2013). A study was also conducted in nine Arabic speaking countries aiming to validate the Modified Checklist for Autism in Toddlers (M-CHAT) as an Arabic tool for the screening of autism. The analysis included 228 children (122 of whom screened positive for ASD). Results indicated that the new translated M-CHAT is an effective tool to



 Table 2
 The experiences and outcomes for Arab caregivers of individuals with ASD

	Study reference and country	Aims, study design, and methods	Participants
1	Al-Kandari 2017. Kuwait	Aims: coping strategies of mothers of children with ASD. Design: cross-sectional.	198 mothers.
2	Al-Dababneh et al. 2017. Jordan	Methods: Questionnaire. Aims: parents' beliefs of children with ASD, ID and LD about the causes of their child's disability. Design: Qualitative. Methods: Interviews.	63 parents.
3	Alnemary et al., 2017a. Saudi Arabia	Aims: characteristics associated with use of ASD services. Design: cross-sectional. Methods: Survey.	205 parents.
4	Baker 2017. USA	Aims: language-development-related knowledge of paired mothers and educators of three Somali American boys with autism. Design: case study. Methods: Interview.	3 mother/educator pairs
5	Eid et al. 2017. Saudi Arabia	Aims: effectiveness of learning skills from observing other parents being taught using behavioural skills training. Design: experimental. Methods: Multiple-probe.	6 parents of children with ASD.
6	Fox et al. 2017. UK	Aims: Somali families affected by autism, and how services can support them. Design: qualitative. Methods: Interview.	15 parents.
7	Hemdi and Daley 2017. Saudi Arabia	Aims: efficacy of a self-help psychoeducation intervention delivered via WhatsApp. Design: RCT. Methods: Pre-intervention, intervention, post-intervention.	62 mothers of children with ASD.
8	Sher-Censor et al. 2017. Israeli	Aims: interplay of mothers' coherent representations of their ASD child and emotional availability to the child in Arab-Israeli families. Design: cross-sectional. Methods: The Five-Minute Speech Sample, Reaction to Diagnosis Interview, The Emotional Availability Scales, Vineland Adaptive	46 mothers and their 2—8-year-old sons.
9	Dolev et al. 2016. Israel	Behavior Scales and Demographic Questionnaire. Aims: maternal resolution of the child's diagnosis with Arab-Israeli mothers and its associations. Design: cohort. Methods: Reaction to diagnosis interview, Maternal sensitivity scale, Vineland adaptive behaviour scales, Brief Symptom Inventory, Family support scale and Demographic Questionnaire.	46 mothers and their 2—8-year-old ASD sons.
10	Rayan and Ahmad, 2016a. Jordan	Aims: assess psychological distress and examine the correlation between PRC and psychological distress in ASD parents. Design: cross-sectional. Methods: Depression, Anxiety and Stress Scale, Positive Reappraisal Coping Subscale of the Cognitive Emotion Regulation Questionnaire and Demographic Questionnaire.	104 parents.
11	Rayan and Ahmad, 2016b. Jordan	Aims: effectiveness of mindfulness on QoL and stress among parents of ASD children. Design: quasi-experimental, with non-equivalent control. Methods: Demographic survey, World Health Organisation Quality of Life Assessment-Brief, positive stress reappraisal subscale of the Cognitive Emotion Regulation Questionnaire and Mindful Attention Awareness Scale	104 parents (52 intervention and 52 control).
12	Zaki and Moawad 2016. Egypt	Aims: autism awareness and psychological wellbeing of mothers caring for their autistic children. Design: cross-sectional. Methods: A structured interviewing questionnaire, Parents stress scale, and Psychological Well-Being Scale.	60 children and their mothers.
13	Ahmad and Dardas 2015. Jordan	Aims: characteristics of fathers of ASD children predicting QoL. Design: cross-sectional.	101 fathers.



Table 2 (continued)

	Study reference and country	Aims, study design, and methods	Participants
		Methods: Parenting Stress Index–Short Form, WCCL, and World	
		Health Organization Quality of Life Assessment –Brief Self-Administered Instrument.	
14	Dardas and Ahmad, 2015a.	Aims: coping strategies as mediators and moderators between stress	184 parents.
	Jordan	and QoL among parents of ASD children.	
		Design: cross-sectional. Methods: Parenting Stress Index—Short Form, Revised Ways of Coping Checklist and World Health Organisation Quality of Life Assessment-Brief.	
15	Obeid and Daou 2015. Lebanon	Aims: effects of coping styles, social support, and child's behavioural symptoms on the well-being of mothers	65 ASD mothers and 98 TD mothers.
		of ASD children. Design: case-control. Methods: Brief COPE Scale, Indian Scale for Assessment of ASD, General Health Questionnaire, and	
		Demographic questionnaire.	
16	Abu-Hamour and	Aims: attitudes of parents towards the inclusion of ASD students in	148 parents.
	Muhaidat 2014. Jordan	public schools. Design: cross-sectional.	
		Methods: Survey.	
17	Al Jabery et al. 2014.	Aims: perceptions and experiences of parents of autistic children	60 parents.
	Jordan	regarding services. Design: cross-sectional.	
		Methods: Questionnaire	
18	Al-Khalaf et al. 2014. Jordan	Aims: effectiveness of an education program for mothers of ASD children to improve their coping skills and reduce stress levels. Design: cohort.	10 mothers.
		Methods: Pre-interviews, an education program, post-interviews.	
19	Dardas and Ahmad, 2014a.	Aims: relationship between parents' characteristics and	184 parents.
	Jordan	coping strategies. Design: cross-sectional.	
		Methods: Parenting Stress Index-Short Form, World Health	
		Organization Quality of Life Assessment-Brief	
		Self-Administered Instrument and Ways of Coping Checklist-Revised.	
20	Dardas and Ahmad, 2014b.	Aims: differences in the QoL between fathers and mothers	184 parents.
	Jordan	of AD children.	
		Design: cross-sectional. Methods: World Health Organization Quality of Life	
		Assessment-Brief Self-Administered Instrument, Parenting	
		Stress Index-Short Form, and Ways of Coping	
21	Dardas and Ahmad, 2014c.	Checklist-Revised. Aims: mediation and moderation effects of coping in the	101 fathers.
	Jordan	relationship between fathers' parenting stress and QoL.	
		Design: cross-sectional. Methods: Parenting Stress Index-Short Form, Ways of Coping	
		Checklist-Revised and World Health Organization Quality of	
		Life Assessment-Brief Self-Administered Instrument.	
22	Dardas and Ahmad, 2014d. Jordan	Aims: psychometric properties and theoretical structure of the PSI-SF with parents of AD children.	184 parents.
	Jordan	Design: cross-sectional.	
	D 1 141 12014	Methods: Exploratory factor analysis.	70.0.1
23	Dardas and Ahmad, 2014a. Jordan	Aims: predictors of QoL for fathers and mothers of AD children. Design: cross-sectional.	70 fathers and 114 mothers.
	Jordan	Methods: Parenting Stress Index–Short Form and World Health	mourers.
		Organization Quality of Life Assessment-Brief	
24	Dardas L 2014. Jordan	Self-Administered Instrument. Aims: psychosocial impact of raising AD children.	184 parents.
	_ man = _ in volumi	Design: cross-sectional.	paramo
		Methods: Parenting Stress Index-Short Form, Ways of Coping	
		Checklist-Revised and World Health Organization Quality of	
		Life Assessment-Brief Self-Administered Instrument.	



Table 2 (continued)

	Study reference and country	Aims, study design, and methods	Participants
		Design: cross-sectional. Methods: World Health Organization Quality of Life Assessment-Brief Self-Administered Instrument.	
26	Al-Farsi et al. 2013. Oman	Aims: socioeconomic status and challenges of nurturing ASD children. Design: cross-sectional.	150 caregivers.
27	AL Mansour et al. 2013. Saudi Arabia	Methods: Questionnaire. Aims: depression and anxiety in parents of ASD children. Design: case-control. Methods: A questionnaire and Hospital Anxiety and Depression scale.	50 parents of ASD child and 50 Parents of TD child.
28	Dababneh and Parish 2013. West Bank	Aims: knowledge, attitudes, burdens and coping strategies related to caring for an ASD child. Design: qualitative.	24 parents.
29	Fido and Al Saad 2013. Kuwait	Methods: Interview and focus group. Aims: prevalence of parental depression in families of autistic children and in control families. Design: case-control. Method: Beck's Depression Inventory.	120 parents of autistic children and 125 parents of TD children
30	Alqahtani, 2012. Saudi Arabia	Aims: beliefs of parents of autistic children. Design: qualitative. Methods: A semi-structured interview.	47 parents.
31	Kheir et al., 2012a. Qatar	Aims: concerns of caregivers about the child's life, future and care. Design: case-control. Methods: Demographic information and Standard Recall Form –36.	56 caregivers of ASD child and 48 caregivers of TD child.
32	Kheir et al., 2012b. Qatar	Aims: impact of having an autistic child on the lives of the caregivers. Design: case-control. Methods: Standard Recall Form-36.and Demographic information.	56 caregivers of an autistic child and 42 caregivers of a TD child
33	Elbahnasawy and Naglaa, M. 2011. Egypt	Aims: effect of counselling for mothers on coping. Design: cohort (single group pre-post-test). Methods: Family Impact of Childhood Disability Scale and Medical records.	90 mothers.
34	Al-Eithan et al. 2010. Saudi Arabia	Aims: whether ASD/PDD children are more likely to have parents from maths or engineering backgrounds, than children with other DDs. Design: case-control. Methods: Data from medical records	57 parents of ASD/PDE children and 40 parents of DDs children
35	Al-Kandari and Al-Qashan 2010. Kuwait	Aims: perceptions of maternal self-efficacy, and correlates, among mothers of DD children. Design: cross-sectional. Methods: Demographic Questionnaire and Kandari caregiver self-efficacy scale.	33 mothers of DD children and 41 mothers of DS children, and 21 mothers of ASD children
36	Kediye et al. 2009. Canada	Aims: stress factors related to raising an ASD child in Somali-Canadian families. Design: qualitative.	10 mothers.
37	Crabtree S 2007. UAE	Methods: Focus group interviews. Aims: family caregiving of DD children. Design: qualitative. Methods: Ethnographic approach	15 parents.

use in the early screening of autism in Arab countries. Maternal health problems during pregnancy and labour were more significant for ASD mothers than for controls. Paediatric health problems were significantly more evident among ASD individuals than among controls (Seif Eldin et al. 2008).

There were few studies comparing issues related to ASD diagnosis/characteristics across two or more Arab countries. For instance, Amer et al. (2011) investigated autistic symptoms and coexisting behaviour problems in 37 boys and 23 girls with ASD from three Arab countries (Egypt, Saudi



 Table 3
 Social and communication behaviour of Arab individuals with ASD

	Study reference and country	Aims, study design, and methods	Participants
1	Meiri et al. 2017. Israel	Aims: report development of a database of autism from an ethnically diverse population. Design: cohort. Methods: DQ, Autism Diagnostic Observation Scale-2, Bayley Scales of Infant and Toddler Development-III or Wechsler Pre-school and	296 children (Jewish and Arab Bedouins).
2	Etaila M 2016 IIAE	Primary Scale of Intelligence.	12 autistis alililusu
2	Fteiha M 2016. UAE	Aims: effects of using assistive technology to improve language skills. Design: controlled clinical trial.	12 autistic children.
		Methods: Pre-, post-, and follow-up tests	
3	Alshurman and Alsreaa 2015. Saudi Arabia	Aims: peer teaching for developing non–verbal communication. Design: case-control.	5 experimental and 5 control children with ASD.
		Methods: Peer teaching sessions and non-verbal communication scale.	
4	Al zyoudi et al. 2015. UAE	Aims: video modelling to improve social skills. Design: series of 5 A-B case studies. Methods: A videotape presented two individuals	5 autistic children.
		interacting in a role-play setting.	
5	Mashat et al. 2015. Saudi	Aims: use of Facebook by ASD adults and the role of	7 ASD adults.
	Arabia, Kuwait, and the	photos on their communication and interactions.	
	UAE	Design: cross-sectional. Methods: Framework for Autistic Arabs' Social Communication and Interaction Technology (FAASCIT)	
6	Walker-Dalhouse and Dalhouse 2015. USA	Aims: school and home experiences of an autistic student to help promote his literacy development. Design: case study.	one 6-year-old autistic boy
7	Perepa 2014. UK	Methods: Observations and unstructured interviews Aims: cultural influence on parents' understanding of appropriate social behaviour. Design: qualitative.	63 parents.
		Methods: Semi-structured interview.	
8	Abd El-haliem et al. 2013.	Aims: eating habits of autistic children.	112 autistic children.
	Egypt	Design: cross-sectional. Methods: Questionnaire.	
9	Huwaidi and Daghustan	Aims: sexual behaviours of autistic adolescents from	15 HFA adolescents and 17
	2013. Saudi Arabia	the perspective of both parents and teachers.	LFA.
		Design: cross-sectional.	
		Methods: Sexual Behaviour Scale, Social-Sexual Skills Scale and A Screening Questionnaire for Asperger Syndrome and Other High Functioning ASD.	
10	Al-Shammar et al. 2010. Kuwait	Aims: an intervention to improve the inappropriate social behaviours of an autistic student.	One male autistic student.
		Design: case study. Methods: LISTEN strategy (L for learn, I for interact, S for study, T for training, E for emulate, and N for normalize) was developed.	

Arabia, and Jordan). Results indicated that boys had poor emotional responsiveness and the girls had more cognitive problems. Boys exhibited significantly more delinquent behaviour problems. Another study by Hussein et al. (2011) compared characteristics of autism in two groups of 20 Egyptian and 28 Saudi children with respect to demographic

and clinical characteristics. Results revealed that there was no difference of statistical significance between the two groups in type of autism. Hyperactivity was found in 50% of Egyptian children in comparison to 60.7% of Saudi children. Further, epilepsy was found in 25% of Saudi children versus 5% of Egyptian children. Psychiatric comorbidities were reported in



71.4% of Egyptians and 67.5% of Saudi children. Egyptian autistic children were characterized by delayed language development, earlier age at start of treatment intervention, high preference for behavioural and phonetic therapies, higher paternal and maternal education, higher employment among parents, and higher family concern. In contrast, the Saudi group were characterized by delay in all developmental milestones, severe and profound communication defects, more stereotypes and developmental deficits, younger age at detection of abnormality and older age at start of treatment intervention, with a marked difference between the two (being around 2 years), higher percentage of missing examinations, older birth order, and significantly higher preference for drug treatment (Hussein et al. 2011).

Experiences and Outcomes for Arab Caregivers of Individuals with ASD

Arab caregivers of individuals with ASD were the focus of 37 studies, 53% of the included research (Table 2 and Online Resource S2). Of those 37, five studies were conducted in non-Arab countries but with Arab populations (Baker 2017; Dolev et al. 2016; Fox et al. 2017; Kediye et al. 2009; Sher-Censor et al. 2017). The total number of Arab participants included in these studies was 120. There were no collaborative studies conducted across the Arab countries. Fourteen studies were conducted in Jordan and the rest of the studies were conducted in Saudi Arabia, Kuwait, Qatar, Lebanon, UAE, Iraq, West Bank, Egypt, and Oman. There were 4074 participants included in research from this theme. Topics researched included the following: (a) quality of life (QoL) of caregivers of children with ASD and (b) psychological impacts of parenting a child with ASD. Studies on QoL of caregivers of children with ASD were carried out in Jordan, Iraq, and Qatar (Dardas and Ahmad 2014d; Kareem and Ali 2014; Kheir et al. 2012b). Only one study (Rayan and Ahmad 2016b) examined the impact of an intervention program on improving the QoL and positive reappraisal coping among parents of children with ASD. This study implemented a mindfulness-based intervention with parents of children with ASD for 5 weeks. Results showed that parents had significant improvements in measures of the psychological health domain of QoL, the social health domain of QoL, mindfulness, and positive stress reappraisal with medium to large effect sizes. Studies on coping strategies as mediators and moderators between stress and QoL among parents of children with ASD were carried out in Jordan by Dardas and Ahmad (2015a, 2015b). Dardas and Ahmad (2015a) found that "accepting responsibility" mediated the relationship between stress and QoL, while "seeking social support" and "escape avoidance" were moderators. Dardas and Ahmad (2015b) investigated the possible mediation and moderation effects of coping in the relationship between fathers of children with autism's parenting stress and QoL. None of the investigated coping strategies were found to mediate or moderate the stress-QoL relationship among the participating fathers. Dardas and Ahmad (2014b) examined six predictors of QoL for parents of children with ASD: Parental Distress, Parent–Child Dysfunction Interaction, Difficult Child Characteristics, household income, and the child with ASD's age and number of siblings. Only parental distress emerged as a significant predictor of both mothers' and fathers' QoL, whereas difficult child characteristics, household income, and number of siblings were found to predict mothers' QoL.

There were in total 12 studies on psychological impacts of parenting a child with ASD (Al-Khalaf et al. 2014; Alqahtani 2012; Al-Farsi et al. 2013; Crabtree S 2007; Dababnah and Parish 2013; Dardas and Ahmad 2014c; Dardas L 2014; El bahnasawy and Naglaa 2011; Fido and Al Saad 2013; Kediye et al. 2009; Rayan and Ahmad 2016a; Zaki and Moawad 2016). Fido and Al Saad (2013) examined the prevalence of parental depression in families of children with autism and in control families. The Arabic version of the Depression Inventory was used to assess the psychological status of 120 parents of children with autism and a matched control sample of 125 parents of intellectually able children. Results revealed that mothers of autistic children had a significantly higher levels of problems for all dimensions of depression (Fido and Al Saad 2013). Al-Khalaf et al. (2014) implemented an education program for mothers of preschool age children with ASD. Following the education program, results showed that the mothers reported a statistically significant reduction in stress levels, an increase in coping skills, and an improvement in mother-child interaction.

There were two studies conducted in Lebanon and Egypt in which the well-being of mothers of children with ASD were examined. Zaki and Moawad (2016) assessed the influence of autism awareness on the psychological well-being of Egyptian mothers caring for their children (n = 60) with autism. Results concluded that about two thirds of the studied sample had poor awareness regarding autism and there was a highly statistical significant relationship between awareness, stress, and psychological well-being among mothers of children with autism. In Lebanon, Obeid and Daou (2015) examined and compared the effects of coping styles, social support, and their child's behavioural symptoms on the well-being of 65 mothers of children with ASD and 98 mothers of typically developing children. Results showed that disengagement and distraction coping predicted poor well-being, whereas cognitive reframing showed a correlation with better well-being levels. There was a significant correlation between the child's behavioural problems and maternal well-being. Mothers of children with ASD differed in terms of coping styles used and showed lower levels of perceived social support. Well-being was significantly better for mothers of typically developing children.



Social and Communication Behaviour of Arab Individuals with ASD

There were few studies that explored the social and communication behaviour of Arab individuals with ASD (n = 10, 14%) (Table 3 and Online Resource S3). Of those 10, three studies were conducted in non-Arab countries but with Arab populations (Meiri et al. 2017; Perepa 2014; Walker-Dalhouse and Dalhouse 2015). The total number of Arab participants included in these studies was 44. There was one collaborative study conducted across Arab countries. Arab countries that contribute to this area of research were the following: Kuwait, UAE, Egypt, and Saudi Arabia. The total number of participants for studies in this area of research was 539. Most of the studies investigated the impact of intervention strategies on improving social and communicational skills of Arabic children with ASD (Al-Shammar et al. 2010; Alshurman and Alsreaa 2015; Al zyoudi et al. 2015; Fteiha 2016). For instance, Fteiha (2016) examined the effects of assistive technology on improving communication skills of children with autism (n = 12) who were randomly assigned to either experimental groups or a control group (n = 4 per group). A language skills scale was administered to them as a pre-, post-, and follow-up tests. Results revealed that there were statistically significant differences between the average grade level of children with autism in the two experimental groups. The children in the two experimental groups gained more language from pre- to post-test than those in the control group.

In addition, a study was conducted in Saudi Arabia to identify the common sexual behaviours of 32 male autistic adolescents 15 of whom were described as having "high-functioning" autism and 17 "low-functioning" autism from the perspective of both parents and teachers, taking into consideration the adolescent's functional level (which may impacts on sexual behaviour). Both parents and teachers reported inappropriate sexual behaviour expressed by the autistic adolescents. There were also significant correlations between both

the social-sexual skills and reported sexual behaviours in all sub-tests and total scores. The high-functioning adolescents with autism displayed significantly less inappropriate sexual behaviour and significantly more social-sexual skills when compared to adolescents with low-functioning autism (Huwaidi and Daghustani, 2013). Interestingly, Abd Elhaliem et al. (2013) conducted a study to investigate the eating habits of (112) children with autism in Egypt. Results showed that children with autism had a less varied diet feeding behaviour and limited interests and difficulty in accepting change and types of foods that affected their weight.

Quality Appraisal Results

Ratings of the methodological quality of the qualitative studies are provided in Table 4. Six of the seven qualitative studies were rated as valuable research (Al-Dababneh et al. 2017; Algahtani 2012; Dababnah and Parish 2013; Fox et al. 2017; Kediye et al. 2009; Perepa 2014). The main area of weakness for the qualitative studies was in providing enough information of how ethical issues had been taken into consideration. The main strengths were in addressing the stated research aims and selecting an appropriate methodology for addressing the research aims. One qualitative study (Crabtree S 2007) was rated as not valuable research because of a lack of clear reporting of data analysis, ethical issues, and findings. Table 5 presents the quality assessment results for the only Single-Case Experimental Design study included in the review (Al zyoudi et al. 2015). The study met the applicable quality indicators, with exception of the indicator of external validity. The quality assessment results for quantitative studies (n = 59)(see Table 6) revealed that two studies were rated as moderate in quality, while the remaining were rated weak. The two main areas of weakness were selection bias and data collection methods. For example, 21 (30%) of quantitative studies had a lack of clear reporting of validity and reliability for data collection methods that were used.

 Table 4
 Quality assessment of methodology for included studies using a qualitative design: CASP–The Critical Appraisal Skills Program (2014)

	CASP Questions	References						
		Dababnah and Parish 2013	Perepa 2014	Crabtree S 2016	Alqahtani 2012	Kediye et al. 2009	Al- Dababneh et al. 2017	Fox et al. 2017
1	Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2	Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3	Was the research design appropriate to address the aims of the research?	No	Yes	Yes	Yes	Yes	Yes	Yes
4	Was the recruitment strategy appropriate to the aims of the research?	No	Yes	Yes	Yes	Yes	Yes	Yes
5	Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes



Table 5 Quality assessment of methodology for Al-Zyoudi et al. (2015)'s single-case experimental design study: the quality indicators tool developed by Horner et al. (2005)

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Description of Participants and Setting

- Yes
- Participants are described with sufficient detail to allow others to select individuals with similar characteristic; (e.g., age, gender, disability, diagnosis).
- The process for selecting participants is described with replicable precision.
- Critical features of the physical setting are described with sufficient precision to allow replication
- 2 Dependent Variable

Yes

- Dependent variables are described with operational precision.
- Each dependent variable is measured with a procedure that generates a quantifiable index.
- Measurement of the dependent variable is valid and described with replicable precision.
- Dependent variables are measured repeatedly over time.
- Data are collected on the reliability or inter observer agreement associated with each dependent variable, and IOA levels meet minimal standards (e.g., IQA = 80%; Kappa = 60%).
- 3 Independent Variable

Yes

- Independent variable is described with replicable precision.
- Independent variable is systematically manipulated and under the control of the experimenter.
- Overt measurement of the fidelity of implementation for the independent variable is highly desirable
- 4 Baseline

Yes

- The majority of single-subject research studies will include a baseline phase that provides repealed
 measurement of a dependent variable and establishes a pattern of responding that can be used to
 predict the pattern of future performance, if introduction or manipulation of the independent
 variable did not occur.
- Baseline conditions are described with replicable precision.
- 5 Experimental Control/internal Validity

Yes

- The design provides at least three demonstrations of experimental effect at three different points in time.
- The design controls for common threats to internal validity (e.g., permits elimination of rival hypotheses).
- The results document a pattern that demonstrates experimental control.
- 6 External Validity

No

- Experimental effects are replicated across participants, settings, or materials to establish external validity.
- 7 Social Validity

Yes

- The dependent variable is socially important.
- The magnitude of change in the dependent variable resulting from the intervention is socially important.
- Implementation of the independent variable is practical and cost effective.
- Social validity is enhanced by implementation of the independent variable over extended time periods, by typical intervention agents, in typical physical and social contexts.

Yes = the study meets the criterion. No = the study does not meet the criterion

Discussion

The current review has provided an overview of the current state of the field of social, educational, and psychological research focused on individuals with ASD and/or their family members, in Arab countries and cultures. Seventy studies met the inclusion criteria for the review. The results revealed that there is growing interest in recent years in social, educational, and psychological research focused on individuals with ASD and/or their family members in some Arab countries, especially in Jordan, Saudi Arabia, and Lebanon. The lack of literature

from other parts of the Arab world, for instance the Maghreb (consisting of the countries Algeria, Morocco, Tunisia, Libya, and Mauritania) may be due to the fact that there may be published research on ASD in other languages than English and Arabic. For instance, Algeria, Morocco, and Tunisia were an important part of the French Empire in the nineteenth and early twentieth centuries and despite gaining independence, the French language continues to be an important language in many areas of life (Aitsiselmi and Marley 2008). Accordingly, there might be some published literature on ASD in Arab countries in the French language.



Table 6 Quality assessment of methodology for included studies using a quantitative design: EPHPP quality assessment tool for quantitative studies (Effective Public Health Practice Project (2007))

References		Global ratings	Refe	erences	Global Ratings
1	Al-Eithan et al. 2010	Weak	35	Seif Eldin et al. 2008	Weak
2	Hamadé et al. 2013	Weak	36	Akoury-Dirani et al. 2013	Weak
3	Al-Farsi et al. 2011	Weak	37	Al-Farsi et al. 2013	Weak
4	Hussein et al. 2011	Weak	38	Dardas and Ahmad, 2014a	Weak
5	Amr et al., 2012a	Weak	39	Fteiha M 2016	Weak
6	Kheir et al., 2012a	Weak	40	Rayan and Ahmad, 2016a	Weak
7	Dirani and Salamoun 2014	Weak	41	Dardas and Ahmad, 2014b	Weak
8	Almansour et al. 2013	Weak	42	Zaki and Moawad 2016	Weak
9	Raz et al. 2015	Weak	43	Al-Zahrani A 2013	Weak
10	Al-Ansari and Ahmed 2013	Moderate	44	Rayan and Ahmad, 2016b	Weak
11	Mohammed et al., 2016	Weak	45	Fido and Al Saad 2013	Weak
12	Al-Kandari and Al-Qashan 2010	Weak	46	Dardas L 2014	Weak
13	Dardas and Ahmad, 2014a	Weak	47	Abd El-haliem et al. 2013	Weak
14	Al Jabery et al. 2014	Weak	48	Ahmad and Dardas 2015	Weak
15	Abu-Hamour and Muhaidat 2014	Weak	49	Taha et al., 2013	Weak
16	Estrem and Zhang 2010	Weak	50	Mashat et al. 2015	Weak
17	Barnevik-Olsson et al. 2008	Weak	51	Dardas and Ahmad, 2014d	Weak
18	Chaaya et al. 2016	Weak	52	Elbahnasawy and Naglaa 2011	Weak
19	Zeglam and Maouna 2012	Weak	53	Esler et al. 2017.	Weak
20	Eapen et al. 2007	Weak	54	Al-Kandari 2017.	Weak
21	Dardas and Ahmad, 2014b	Weak	55	Alnemary et al., 2017a	Weak
22	Dardas and Ahmad, 2014c	Weak	56	Eid et al. 2017	Weak
23	Kareem and Ali 2014	Weak	57	Hemdi and Daley 2017.	moderate
24	Kheir et al., 2012b	Weak	58	Sher-Censor et al. 2017.	Weak
25	Dolev et al. 2016	Weak	59	Meiri et al. 2017.	Weak
26	Mohamed et al. 2016	Weak			
27	Amr et al. 2011	Weak			
28	Huwaidi and Daghustan 2013	Weak			
29	Amr et al., 2012b	Weak			
30	AlAyadh et al. 2015	Moderate			
31	Al-Khalaf et al. 2014	Weak			
32	Obeid and Daou 2015	Weak			
33	Alshurman and Alsreaa 2015	Weak			
34	Raddad et al. 2011	Weak			

The most commonly applied methodologies were quantitative (59), with four of these studies only being randomized controlled trials (RCTs) or other controlled comparisons of interventions. There were also seven qualitative, one single-case experimental design study, and three case studies. Most of the studies used cross-sectional designs. Questionnaires were the predominant data collection method. The use of cross-sectional designs can be useful for estimating the prevalence of a behaviour or condition in a population (Sedgwick 2014), and for exploring associations between potential risk factors and outcomes of interest. However, these designs are limited by the fact that they are conducted at one timepoint

and thus give no indication of the sequence of events. Therefore, it is impossible to infer causality (Levin 2006). In addition, most of the included studies that used cross-sectional designs gave minimal consideration to possible confounding variables, and there was rarely an indication of the validity and reliability of measures used. Studies evaluating interventions also had a number of limitations leading to their low-quality ratings. Thus, using the current evidence base to inform future ASD research and policies in the Arab world should be done with caution. Parents/caregivers of individuals with ASD were the most targeted populations in the included studies. A few studies were conducted in non-Arab countries (e.g. USA, UK,



Israel, Canada, and Sweden) but with Arab populations. Most of these studies focused on experiences and outcomes for caregivers of individuals with ASD.

There has been research in three broad domains: (1) the prevalence of ASD and diagnosis issues, (2) the experiences and outcomes for Arab caregivers of individuals with ASD, and (3) social and communication behaviour of Arab individuals with ASD. One third of the reviewed studies explored prevalence of ASD and diagnosis issues. Samples from hospital, specialist units, and preschools were commonly used. The range in prevalence in the included studies was 0.014-4.7%. However, given that the research was generally rated as low quality, it is not appropriate to draw any strong conclusions about the likely prevalence rate for ASD in Arab countries. In addition, there were few screening and diagnostic tools that had been validated for the Arabic context. The experiences and outcomes for Arab caregivers of individuals with ASD were the majority of the reviewed studies (53%). There was a focus on psychological impacts of parenting a child with ASD which reflects a significant impact on quality of life that Arab caregivers are increasingly experiencing. Therefore, there is growing interest in understanding better care and management practices to avoid this burden. However, studies on quality of life of caregivers of individuals with ASD arose from only three Arab countries, that is, Jordan, Iraq, and Qatar. The least researched domain was the social and communication behaviour of Arab individuals with ASD (14%). The focus of these studies was on the impact of intervention strategies on improving social and communicational skills of Arab children with ASD.

Our review indicated that there were significant gaps in research evidence base. For instance, research on interventions, particularly educational interventions, was scarce. In addition, there were few data on ASD services in terms of their organization, effectiveness, or consumer perspectives. Only one study (Al Jabery et al. 2014) investigated the perceptions and experiences of parents of children with ASD regarding provided services in Jordan.

Among the intervention studies published, there were very few RCTs and only one study used a single-subject experimental design. However, RCTs and single-subject experimental designs are commonly used to define the effectiveness of behavioural and educational interventions for autism (Dounavi and Dillenburger 2013). The very few RCTs that have been published had very limited sample sizes and a lack of evaluation of long-term impact. Current evidence is insufficient to provide the required information to plan appropriately for effective intervention strategies for individuals with ASD in Arab countries.

Further research is needed to explore the most effective and efficient strategies for improving intervention and service delivery to Arab individuals with ASD and their family members in the context of a given country, culture, and governmental system. Arab countries still vary enormously in terms of their political, ethnic, economic, social, and religious characteristics (Al-khateeb et al. 2015; Taha et al., 2013; Hussein and Taha 2013) and so contextually relevant research is needed. Future research should be conducted to address areas including developing or adapting screening and diagnostic tools as there were few screening and diagnostic tools that had been validated for the Arabic context. Overall, the quality of the vast majority of included research studies was weak. Thus, a priority is likely research training and building the research infrastructure for ASD and related research in Arab countries. Moreover, research on adults with ASD is a high priority as there were few studies that focused on adults with ASD. In addition, none of the included studies from the searches mentioned non-Arab participants living in Arab countries. Therefore, future research should also consider non-Arab populations living in Arab countries.

Limitations

This review has certain limitations that need to be taken into consideration. The most apparent limitation is language bias as all included studies were published in English (although the inclusion criteria included the Arabic language). Consequently, this review may have missed some articles published in the Arabic language. However, it is very difficult to access Arabic literature because Arabic electronic databases are still lacking (Al-Khateeb and Al-Khateeb 2014). Additional elements of the search strategy identified a significant number of studies not previously identified in searches. However, according to the Systematic Reviews (2009), conducting forwards and backwards citation searching (checking reference lists of included studies; checking citations of included studies, and checking reference lists of other reviews on the topic) aim to identify publications that have not been included and indexed by electronic databases or from journals that are not indexed by electronic databases. In addition, CRD (2009) indicated that such additional searches can compensate for inaccurate database indexing that can result in even the most carefully constructed strategy failing to identify relevant studies. There were also not enough studies with similar research questions to enable meta-analytic summaries of the research evidence. However, this is a priority in future when sufficient evidence has been amassed.

Conclusions

The findings of this systematic scoping review highlight that there is growing interest in recent years in social, educational, and psychological research focused on individuals with ASD



and/or their family members in some Arab countries. However, there were significant gaps in research evidence base, including research on interventions and on ASD services. These areas would be priorities for future research, especially given the need to inform services with culturally relevant evidence. Overall, the included research was appraised as being of weak quality. There is a need for additional, high-quality, culturally sensitive research on ASD in Arab countries and cultures.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest

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