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Burden, stigma and access to support services for caregivers of individuals with Autism Spectrum Disorder (ASD) in Morocco: A cross-sectional study

Basma Bourote
Ar-razi Psychiatric Hospital, Ibn Sina University Hospital Center
Oumnia Bouaddi
Mohammed VI Center for Research and Innovation
Afaf Affane
Collectif Autisme Maroc
Chaimaa Al Malki
Mohammed VI Center for Research and Innovation
Yassine Souidi
UNFPA Morocco
Omaima Belakbir
Ar-razi Psychiatric Hospital, Ibn Sina University Hospital Center
Hassan Kisra
Ar-razi Psychiatric Hospital, Ibn Sina University Hospital Center
Mohamed Khalis
mkhalis@um6ss.ma

Mohammed VI Center for Research and Innovation

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Abstract

Background

Globally, caregivers of individuals with Autism Spectrum Disorders (ASD) face a substantial caregiving burden affecting their social and mental well-being. In LMICs, the situation might be exacerbated by limited access to support services. In Morocco, this burden remains underexplored. Our study aims to assess the burden experienced by caregivers, with particular attention to self-stigma and the availability of support services.

Methods

We conducted a descriptive cross-sectional study among caregivers of children and adults diagnosed with ASD across three Moroccan regions, recruited via associations affiliated with Collectif Autisme Maroc and the Rabat Psychiatric Hospital. Data were collected using an adapted version of Caregiver Needs Survey, Caregiver Burden Inventory (scored and categorized as mild, moderate and severe) and selected items from Affiliate Stigma Scale. The questionnaire was validated online with caregivers and civil society actors who were subsequently trained in data collection and administered the questionnaire to participants. Data were analyzed using RStudio.

Results

Of the 269 participating caregivers, 85.9% were women and 76.6% lived in urban areas. Overall, 42% reported a moderate to severe caregiving burden, with time-dependence burden being the most prominent, primarily characterized by the need for continuous supervision (45.7%), followed by physical burden, mainly reflected by frequent physical exhaustion (24.2%), and developmental burden, characterized by emotional exhaustion (21.5%). Social burden showed moderate levels, driven by lack of appreciation from family members (23.1%), while emotional burden was the least pronounced. We found variable levels of self-stigma with 35% anticipate discrimination, and 45% report a negative impact of caregiving. Access to support services was limited, only 3.3% received childcare services and 72.5% having never benefited of psychological support. Moreover, 76.3% reported experiencing frustration in accessing services for their child.

Conclusions

Caregivers of individuals with ASD in Morocco experience a significant burden, self-stigma, and limited access to essential support services. Strengthening caregiver-child interventions through psychological support, educational accommodations, respite services, and broader psychoeducation is crucial to improve caregiver well-being and reduce burden.

1. Introduction

Affecting approximately 1 in 100 children according to the World Health Organization, autism spectrum disorder (ASD) represents a major public health problem due to its high prevalence and persistent functional impact. According to the Global Burden of Disease project, the total number of individuals diagnosed with ASD increased by 39.3% from 1990 to 2019 [1]. This rise significantly contributes to the global burden of mental disorders, particularly among children and their caregivers, and places ASD among the ten leading causes of non-fatal health deterioration in individuals under the age of 20 [2]. However, this prevalence varies across geographic regions, with higher estimates reported in high-income countries compared to low-and middle-income countries (LMICs) [3, 4]. This reported difference could be attributable to the limited ability to establish a diagnosis due to a lack of screening services, rather than a natural worldwide variation in the incidence of ASD [5].

In low-and middle-income countries, families of individuals with autism spectrum disorder not only face limited access to healthcare but also a wide range of unmet social and educational needs. Among the most pressing challenges are the shortage of specialized services [6] often restricted to major cities or capital regions [7] lack of qualified school support staff, and the limited availability of government assistance[8]. These cumulative difficulties significantly increase the burden carried by families. A systematic review of 24 studies involving 3,299 caregivers of autistic children across 10 Arab countries found that ASD has a profound negative impact on parents' mental health and well-being. Compared to parents of typically developing children or those with other disabilities, they report lower quality of life and higher rates of psychological distress. Similarly, a narrative review of 55 studies across African countries highlighted the heavy emotional and financial toll faced by families, often marked by elevated stress, anxiety, and depressive symptoms [9, 10].

This burden is further amplified by the stigma associated with the disorder. This stigma manifests in two forms: Public stigma by association (courtesy stigma) refers to prejudice and discriminatory behaviours directed at family members because of their connection to the stigmatized person. And affiliate stigma denotes parents' internalization of these social stereotypes (shame, self-blame, anticipated rejection). these forms of stigma lead some families to conceal their child's condition, consequently contributing to their social isolation and a progressive disconnection from support networks [11–14].

Although research on the impact of autism on caregivers in the Arab world has expanded over the past decade, it remains largely concentrated in high-income Gulf countries[15]. In contrast, data from North Africa remain limited. In Morocco, the lack of national epidemiological data on autism in Morocco remains a major barrier to understanding the disorder. Available studies are limited and primarily focus on the clinical profiles of children and logistical barriers to healthcare access. However, no research has quantitatively assessed the burden of care or affiliate stigma among caregivers of individuals with autism. In this context, our study aims to contribute to the scientific literature by evaluating the burden of caring for an individual with autism in Morocco, with particular attention to the self-stigma experienced by caregivers, and to assess the services available to support them.

2. Methods

Study design and setting

This is a descriptive cross-sectional study, including caregivers (parents, family members, or others) of children and adults with autism spectrum disorder, from three regions of Morocco: Tanger-Tétouan-AlHoceima, Marrakech-Safi and Rabat-Salé-Kénitra.

Study participants and recruitment

We included in the sample all caregivers of children with a clinical diagnosis of ASD following the DSM 5 criteria, who accepted to participate to the study. We excluded caregivers of children who had a diagnostic doubt or did not have a diagnosis of ASD and caregivers who refused to participate in the study and complete the questionnaire. Participants were purposefully recruited in two ways: patients benefiting from services of the network of associations affiliated to the Collectif Autisme Maroc - which is a national network of parents' associations for individuals with autism, bringing together approximately 84 associations in 8 regional collectives, whose mission is to promote the rights of people with autism; and parents of children with ASD receiving care at the Rabat-Salé Psychiatric Hospital.

Data collection

Data was collected using an adapted version of the Caregiver Needs Survey, developed by Autism Speaks to assess the needs of families affected by ASD and previously used in Southeast Europe [16]. The questionnaire included the following 4 sections: (i) general Information about caregivers, (ii) unmet needs for parents/caregivers, (iii) caregiver burden, and (iv) self-stigma. Caregiving burden was assessed using the Caregiver Burden Inventory (CBI) [17].This scale consists of five sections, each evaluating a different aspect of the burden experienced while caring for an individual with an illness or disability. The dimensions assessed include: time-dependence burden, evolutionary burden, physical burden, social burden and emotional burden. Each section includes five statements, caregivers respond to each statement by assigning a score indicating the extent to which it reflects their experience, using a 0–4 scale (0: never, 1: rarely, 2: sometimes, 3: frequently, 4: almost always). The sum of scores across sections indicates the caregiver’s overall burden, with scores between 0 and 32 reflecting a mild burden, from 33 to 64 reflecting a moderate burden, and scores above 65 reflecting a severe burden. The assessment of self-stigma was based on the Affiliate Stigma Scale [17], specifically drawing on items from its affective and cognitive dimensions.

The questionnaire was developed in French, translated and back-translated into Arabic. Members of the research team (OB and MK) organized two online sessions for the validation of the tool with parents with lived experience engaged in civil society (identified through Collectif Autisme Maroc) who also served as data collectors. The aim of the sessions was to train them on data collection and also gather their feedback on the questionnaire, in order to understand which terms are appropriate in the Moroccan

context and linguistic clarity of the questions. The finalized questionnaire was then uploaded online via Microsoft Forms in both languages. In parallel, data was also collected by BB in hospital settings.

Data analysis

Data was processed through Excel. Statistical analysis was conducted using the R software. Qualitative data were presented as percentages and frequencies. Quantitative data were summarized using means and standard deviations.

Ethical considerations

This study was conducted in accordance with the principles of the Declaration of Helsinki. The study protocol was approved by the Ethics Committee of the Mohammed VI University of Sciences and Health (CE/UM6SS/63/24). Participation in the study was entirely voluntary. All participants were informed of their right to withdraw from the study at any time, without having to provide any explanation. Verbal and informed consent was obtained from each participant before the start of each interview.

3. Results

Socio-demographic characteristics of study participants

A total of 269 caregivers participated in the study. Of these, 38.7% resided in the Rabat-Salé-Kénitra region, 38.3% in the Tangier-Tétouan-Al Hoceima region, and 23% in the Marrakech-Safı region. The majority of participants were women (85.9%), while men accounted for 14.1%. Regarding place of residence, 76.6% lived in urban areas and 23.4%in rural areas. In terms of their relationship to the autistic child, 83.3% were mothers, 12.3% were fathers, and a small proportion were other family members, including sisters (0.4%) and brothers (0.7%). The mean age of parent caregivers was 40.7 ± 8.72 years (Table 1). Individuals with ASD had a mean age of 10.83 ± 4.33 years, most were male (77.7%), while 22.3% were female.

Table 1
Socio-demographic characteristics of study participants

Variable	Distribution (Mean ± SD / Count (%))
Parent's age (years)	40.7 ± 8.72
Gender	
Female	231 (85.9)
Male	38 (14.1)
Residence	
Urban	206 (76.6)
Rural	63 (23.4)
Region	
Rabat-Salé-Kénitra	104 (38.7)
Tangier-Tétouan-Al Hoceima	103 (38.3)
Marrakech-Safi	62 (23.0)
Relationship to child	
Mother	224 (83.3)
Father	33 (12.3)
Sister	3 (0.4)
Brother	2 (0.7)
School educational assistant	1 (0.4)
Other	6 (2.2)

Caregiver burden

Caregivers reported substantial levels of burden across all dimensions of the Caregiver Burden Inventory. Time-dependence burden was the most pronounced dimension (M = 2.00 ± 1.26), with 40.5% of caregivers reporting frequent or near-constant assistance with daily activities, 45.7% indicating the need to supervise the care recipient continuously, and 24.2% reporting little to no break from caregiving duties. Physical burden was also evident (M = 1.34 ± 1.25), as 24.2% reported being physically tired frequently or almost always and 22.0% indicated that their health had suffered. Developmental burden reflected disruptions in personal functioning and well-being (M = 1.25 ± 1.24), with 20.8% reporting that they were missing out on life and 21.5% feeling emotionally drained frequently or almost always. Emotional burden was comparatively lower (M = 1.04 ± 1.06), 18.3% endorsed embarrassment related to the care receiver's behaviour and 10.7% reported feelings of shame. Social burden showed moderate levels (M = 1.15 ±

1.13), with 23.1% reporting that their caregiving efforts were not appreciated by family members and 15.6% reporting marital problems frequently or almost always. Overall burden severity was predominantly mild (58.0%), while 32.7% reported moderate burden and 9.3% severe burden (Table2).

Table 2
ASD caregiver burden

Categories	Distribution N (%)				
	Never	**Rarely**	**Sometimes**	**Frequently**	**Almost always**
Time dependence burden (Mean ± SD)	2.00 (1.26)				
My care receiver needs my help to perform many daily tasks	47 (17.5)	28 (10.4)	85 (31.6)	55 (20.4)	54 (20.1)
My care receiver is dependent on me	49 (18.2)	40 (14.9)	77 (28.6)	44 (16.4)	59 (21.9)
I have to watch my care receiver constantly	46 (17.1)	31 (11.5)	69 (25.7)	48 (17.8)	75 (27.9)
I have to help my care receiver with many basic functions	45 (16.7)	57 (21.2)	66 (24.5)	52 (19.3)	49 (18.2)
I don't have a minute's break from my caregiving chores	100 (37.2)	50 (18.6)	54 (20.1)	28 (10.4)	37 (13.8)
Emotional burden (Mean ± SD)	1.04 (1.06)				
I feel embarrassed over my care receiver's behavior	107 (39.8)	41 (15.2)	72 (26.8)	23 (8.6)	26 (9.7)
I feel ashamed of my care receiver	183 (68.0)	29 (10.8)	28 (10.4)	13 (4.8)	16 (5.9)
I resent my care receiver	175 (65.1)	38 (14.1)	25 (9.3)	14 (5.2)	17 (6.3)
I feel uncomfortable when I have friends over	123 (45.7)	39 (14.5)	55 (20.4)	28 (10.4)	24 (8.9)
I feel angry about my interactions with my care receiver	101 (37.5)	59 (21.9)	74 (27.5)	16 (5.9)	19 (7.1)
Physical burden (Mean ± SD)	1.34 ± 1.25				
I'm not getting enough sleep	97 (36.1)	48 (17.8)	69 (25.7)	26 (9.7)	29 (10.8)
My health has suffered	123 (45.7)	33 (12.3)	54 (20.1)	29 (10.8)	30 (11.2)
Caregiving has made me physically sick	128 (47.6)	45 (16.7)	50 (18.6)	21 (7.8)	25 (9.3)
I'm physically tired	91 (33.8)	52 (19.3)	61 (22.7)	32 (11.9)	33 (12.3)
Developmental burden (Mean ± SD)	1.25 (1.24)				

Categories	Distribution N (%)				
	Never	Rarely	Sometimes	Frequently	Almost always
I feel that I am missing out on life	110 (40.9)	53 (19.7)	50 (18.6)	28 (10.4)	28 (10.4)
I wish I could escape from this situation.	161 (59.9)	32 (11.9)	29 (10.8)	25 (9.3)	22 (8.2)
My social life has suffered	131 (48.7)	39 (14.5)	46 (17.1)	29 (10.8)	24 (8.9)
I feel emotionally drained due to caring for my care receiver	116 (43.1)	43 (16.0)	52 (19.3)	27 (10.0)	31 (11.5)
I expected that things would be different at this point in my life	96 (35.7)	45 (16.7)	51 (19.0)	39 (14.5)	38 (14.1)
Social burden (Mean ± SD)	1.15 (1.13)				
I don't get along with other family members as well as I used to	133 (49.4)	45 (16.7)	47 (17.5)	23 (8.6)	21 (7.8)
My caregiving efforts aren't appreciated by others in my family	117 (43.5)	43 (16.0)	47 (17.5)	36 (13.4)	26 (9.7)
I've had problems with my marriage	167 (62.1)	38 (14.1)	22 (8.2)	18 (6.7)	24 (8.9)
I don't do as good a job at work as I used to	123 (45.7)	57 (21.2)	45 (16.7)	22 (8.2)	22 (8.2)
I feel resentful of other relatives who could but do not help	125 (46.5)	33 (12.3)	34 (12.6)	37 (13.8)	40 (14.9)
Caregiver burden severity					
Mild burden	156 (58.0)				
Moderate burden	88 (32.7)				
Severe burden	25 (9.3)				

Table 2. ASD caregiver burden *(please insert here the table provided at the end of the document)*

Self-stigma among caregivers

Concerning self-stigmatization in parents and adults with ASD, opinions were mixed. For example, 37.2% strongly disagreed with feeling helpless, while 26.8% disagreed and 23% agreed (Table 3). A majority (47.2%) strongly disagreed with being concerned about others knowing they had a child with autism, and 33.5% disagreed. Regarding perceived discrimination, 32.3% strongly disagreed, though 29% agreed. Concerning happiness and personal success, 37.9% of parents strongly disagreed with the idea that

caring for an autistic child would prevent them from being happy, while 39% disagreed. Concerning the perceived impact on personal success, 37.2% of parents strongly disagreed with the notion that caring for an autistic child would prevent them from being a successful person, and 41.6% disagreed. Finally, 32% agreed and 10% strongly agreed that having a family member with ASD imposes a negative impact on the caregiver.

Table 3
Self-stigma among caregivers of individuals with ASD

Item	Distribution N (%)			
	Agree	Strongly agree	Disagree	Strongly disagree
Having a family member with ASD imposes a negative impact on me.	86 (32.0)	27 (10.0)	71 (26.4)	85 (31.6)
I think I cannot be a successful person because I take care of a child with autism	47 (17.5)	10 (3.7)	112 (41.6)	100 (37.2)
I think I cannot be happy because I take care of a child with autism	48 (17.8)	14 (5.2)	105 (39.0)	102 (37.9)
Other people would discriminate against me because I have a child with autism	78 (29)	24 (8.9)	80 (29.7)	87 (32.3)
I worry if other people know that I have a child with autism	41 (15.2)	11 (4.1)	90 (33.5)	127 (47.2)
I feel helpless for having a child with autism	62 (23.0)	35(13.0)	72 (26.8)	100 (37.2)

Caregivers' unmet support needs

The assessment of service needs dedicated to supporting parents revealed very limited access to childcare facilities. Only 3.3% of parents reported benefiting from nursery or after-school care, whereas 41.3% and 59.1%, respectively, had never accessed such services, and 55.4% and 37.5% reported no need for them (Table 4). Weekend childcare services were almost non-existent in our sample (0.7%). With regard to psychological support, the majority of respondents (72.5%) reported never having received psychotherapeutic assistance, while 22.7% had access to such support. Finally, the vast majority of parents reported experiencing frustration in their efforts to obtain services for their child (76.3%), while only 23.8% expressed satisfaction with the services received.

Table 4
Caregivers' unmet support needs

Service	Distribution N (%)		
	Not receiving	Currently receiving	No need
Childcare services	111 (41.3)	9 (3.3)	149 (55.4)
After-school childcare services, for school-aged children	159 (59.1)	9 (3.3)	101 (37.5)
Week-end childcare services	133 (49.5)	2 (0.7)	134 (49.8)
Psychological support	206 (76.6)	34 (12.6)	29 (10.8)

4. Discussion

The objective of this study was to explore the burden associated with caring for an individual with autism in Morocco, with particular emphasis on the self-stigma experienced by caregivers and on the availability of services dedicated to supporting them. To the best of our knowledge, this is the first study in Morocco to examine the caregiver burden of individuals with ASD and the stigma caregivers experience. We found that 42% of our sample reported a moderate to severe level of burden, and an equal proportion indicated that having a family member with ASD had a negative impact on them. In addition, our findings highlighted the limited availability of respite services for individuals with ASD, as well as the insufficient psychological support provided to their caregivers, with nearly three-quarters of parents reporting that they had never received psychotherapeutic care.

Consistent with our findings of relatively high caregiving burden, similar studies conducted in African countries and in the MENA region often demonstrate a significant negative caregiving burden that varies by country, with predominantly mild levels in Saudi Arabia [18], mild to moderate levels in South Africa [19] and high levels in Egypt [20] and Nigeria [21]. Multiple determinants of caregiver burden in ASD have been identified and can be grouped into three interconnected domains. First, child-related factors include ASD severity and the presence of problem behaviours such as irritability, social withdrawal, stereotyped behaviours, and hyperactivity [22, 23]; Second, caregiver-related characteristics such as gender, coping strategies, intolerance of uncertainty, and spiritual well-being; [24–27]; And third, environmental influences, particularly social support and access to care, further contribute to variations in caregiver strain. In the Arab region, religious coping emerges as the predominant adaptation strategy. [10, 22, 28].

Beyond overall burden prevalence, the affiliate self-stigma profile provides a nuanced understanding of Moroccan caregivers' subjective experience. In our study, affiliate self-stigma did not present uniformly, but rather showed heterogeneous expression, with variable distributions across the assessed dimensions. The findings indicate a predominance of items reflecting perceived personal negative

impact, anticipated discrimination, and feelings of helplessness, whereas broader self-devaluing beliefs, such as questioning one's personal achievement or happiness were reported less frequently. This pattern suggests a form of self-stigma that is more situational and socially mediated, rather than reflecting a deeply internalized and generalized cognitive devaluation.

These findings are consistent with regional evidence indicating that autism-related parental stigma is prevalent and closely associated with caregiving burden. In Riyadh, Alshaigi et al. reported that more than one-third of parents of children with ASD (33.7%) experienced stigma, with mothers more frequently experiencing such experiences than fathers.[29] In Egypt, a multicenter study indicated that half of the parents reported substantial stigma and highlighted interrelations among increased burden and stigma, reduced quality of life, and parental mental health difficulties [30], aligning with the internationally observed association among stigma, psychological distress, and family impact.

From an explanatory standpoint, the literature provides plausible mechanisms that may account for this convergence. Autism-related stigma is primarily shaped by public understanding of the condition in combination with interpretations of visible autistic traits [31]. Thus, given the not-readily-apparent nature of autism and the "normal" outward appearance of many autistic individuals, disruptive behaviors risk being construed as disobedience or poor parenting, exposing the family to courtesy stigma and explaining the greater stigma observed in ASD relative to other neurodevelopmental disorders [32]. According to Dehnavi and al., internalized stigma accounts for 25% of the variance in mental health [33] therefore, stigma stems not solely from the child's characteristics but from a social process in which others' reactions play a major role in shaping parental burden.[34]

Consequently, caregivers of autistic individuals may adopt active strategies to reduce the impact of experienced stigma and to enhance adaptation to their child's specificities. In the study by Arab et al., Moroccan families' participation in training and awareness workshops organized by a civil society actor facilitated access to medical, psychological, and legal resources, supported public disclosure of their children's different identities, and promoted the affirmation of neurodiversity as a legitimate form of human diversity. Families progressed through three stages of social stigma: denial, resistance, and recognition[35] Similarly, in the study by Mak and Kwok, social support emerged as a differentiated factor in parental stigma: while all forms of support contributed to improved psychological well-being among parents of children with ASD, only support from friends and significant others exerted a direct protective effect on internalized stigma.[36]

Our results also highlighted limited access to services for families of individuals with ASD. The very low use of respite services -particularly weekend respite- reflects not only the absence of appropriate infrastructure but also a social model in which care rests almost exclusively on the family. Prior studies showed that this scarcity of formal services is often offset by recourse to family or community solidarity; however, such informal support may not restore the psychological relief afforded by structured respite, although culturally salient [37].

The lack of psychological support observed in our sample with approximately three-quarters of caregivers had never received psychosocial support shows the insufficient integration of caregiver mental health into ASD care pathways. Consistent with our findings, data from the MENA region indicate that most caregivers rated family guidance, parent training, and interventions as unsatisfactory, despite comparatively better ratings for diagnostic components, suggesting a model of care more centred on the child than on caregiver support [38]. Among Arab populations, parents also tend to underutilize formal psychological services and favor informal support, which delays specialized help-seeking [39].

In Morocco, the literature describes a service system for ASD that remains insufficiently structured: access is hindered by financial barriers, limited availability of information, and urban/rural disparities, resulting in modest overall caregiver satisfaction and a limited integration of parent-focused interventions within care pathways [6, 15]. Public-sector services are frequently characterized by long waiting lists and uneven professional training, prompting many families to seek costly private care. Civil society organizations play a critical supportive role, yet their capacity is constrained by limited funding and restricted coverage[6].

Another key finding is that the majority of frustration (76%) with procedures for obtaining services reflects an experience of structural powerlessness. This frustration is not merely administrative dissatisfaction but a cumulative emotional burden arising from repeated encounters with an under-resourced system. In Morocco, a survey of 131 caregivers indicated that satisfaction remains modest due to unavailability of services or waiting lists, lack of information, and high costs, with heterogeneity between rural and urban settings [15].

This study has several strengths and limitations. It contributes novel quantitative data on caregiver burden and affiliate stigma among caregivers of individuals with autism in Morocco, a context in which such evidence remains limited. The inclusion of caregivers from multiple regions enhances the geographic diversity of the sample, and the participation of caregivers of both children and adults with autism spectrum disorder allows caregiving experiences to be considered across the lifespan. However, recruitment through civil society organizations and a public psychiatric hospital may have influenced the composition of the sample, potentially underrepresenting caregivers who are not connected to formal services or advocacy networks. In addition, the cross-sectional design restricts conclusions regarding temporal or causal relationships, and reliance on self-reported measures may have introduced recall or social desirability bias, particularly for sensitive constructs such as stigma. Finally, despite regional inclusion, caregivers from rural or remote areas may remain insufficiently represented, which may affect the generalizability of the findings.

5. Conclusions

Our study highlights a moderate to severe caregiving burden, the persistence of self-stigma particularly affective dimensions, and a shortage of dedicated support services among caregivers of individuals with ASD in Morocco. These findings argue for an integrated, caregiver-child model of care that combines

caregiver focused psychological support, tailored educational accommodations, easy access to respite care services, and population-level psychoeducation in order to improve caregiver well-being and reduce their burden.

Abbreviations

ASD
Autism Spectrum Disorder
CBI
Caregiver Burden Inventory
DSM
Diagnostic and Statistical Manual of Mental Disorders
LMICs
low-and middle-income countries
MENA
Middle East and North Africa

Declarations

Declaration of competing interest

The authors declare no competing interests.

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Author Contribution

Conception and design of the study: OB, CE, BB and MK. Data collection: BB, AA, OB and HKData analysis: OB and MK. Funding: YS. First draft : BB. Critical revision of the article and supervision: OB and MK. All authors reviewed and approved the final version

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Data Availability

The data used and analyzed in the study can be made available upon reasonable request from the corresponding.

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