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DOWN SYNDROME IN MOROCCO: REVIEW OF AVAILABLE DATA AND HEALTH SYSTEM CHALLENGES

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Abstract

Introduction: Down syndrome (DS) represents the most frequent genetic cause of intellectual disability globally, but comprehensive epidemiological data from transitioning health systems remain limited. Morocco's recent implementation of universal health coverage offers a unique opportunity to examine DS epidemiology in evolving healthcare contexts. **Objective:** To examine and synthesize available data on the epidemiology, clinical characteristics, and care delivery patterns of Down syndrome in Morocco, and identify opportunities for health system strengthening. **Methods:** In addition to analyzing policy reports and health system documentation, we carried out a narrative review of the body of literature that was available on DS patterns in Morocco. Database searches and institutional repositories were used to find sources, and the quality of the available data was evaluated**. Results:** Limited but valuable data reveal DS epidemiological patterns consistent with international data, although significant health system challenges persist. Available studies demonstrate standard cytogenetic distributions and maternal age associations, but also identified critical gaps in surveillance infrastructure, regional access disparities, and integration of genetic services into primary care systems. **Conclusions:** While Morocco's data are limited, available evidence suggests important opportunities to strengthen genetic service delivery in transitioning health systems. Findings underscore the need for improved surveillance infrastructure, regional service networks, and integration of genetic counseling into universal health coverage frameworks.

Keywords: Down syndrome, Morocco, narrative review, health systems, universal health coverage, transitioning health systems, North Africa

Introduction

The most common viable autosomal aneuploidy and the primary genetic cause of intellectual disability globally is Down syndrome (DS), which is caused by complete or partial trisomy of chromosome 21. [1, 2]. Recent global burden of disease analyses indicate that DS affects approximately 1 in 700 to 1,000 live births globally, with significant regional variations attributed to maternal age demographics, prenatal screening practices, and health system capabilities [3, 4]. Contemporary epidemiological data demonstrate that while incident cases and age-standardized rates initially slightly decreased, they subsequently increased globally over the past three decades, with prevalent case numbers steadily rising from 1990 to 2019 [4].

The well-established association between advanced maternal age and DS risk follows a steep exponential curve, with progressive risk increase starting from age 20 and marked acceleration after age 35 [5]. Contemporary analyses show risk increases approximately 8.5-fold for women aged 40+ compared to women aged 20-24 for meiosis I errors, and 15.1fold for meiosis II errors [5]. However, women under 35 give birth to the majority of babies with Down syndrome (about 80%), which is indicative of higher birth rates in younger maternal age groups. In health systems that are undergoing transition, this demographic paradox has important ramifications for public health planning and screening methods. Morocco, as North Africa's second most populous country with over 37 million inhabitants, constitutes a compelling case study for understanding DS epidemiology in transitioning health systems [6]. The country's unique geographic position at the crossroads of Europe, Africa, and the Middle East, combined with ongoing demographic and epidemiological transitions, creates complex challenges for managing genetic conditions. Recent longitudinal analyses spanning 2013-2019 reveal significant associations between healthcare access and insurance coverage, with socioeconomic and demographic characteristics serving as primary determinants of health service utilization [7].

Morocco's health infrastructure has undergone substantial transformation, particularly with the 2020 launch of universal health coverage initiatives that consolidated previous insurance schemes, extending coverage from 15% in 2005 to 78% in 2022 [8, 9]. The national health system reform aims to improve accessibility and equitable distribution of care throughout the country, supported by a $450 million World Bank loan to establish foundations for inclusive, high-quality health services [10]. However, significant challenges persist, including unequal resource distribution between urban and rural areas, inadequate funding, health worker shortages, and the growing burden of non-communicable diseases [9].

The COVID-19 pandemic exposed critical vulnerabilities in health systems globally, with particular implications for genetic conditions requiring continuous monitoring and early intervention [11]. These disruptions coincided with Morocco's ambitious health system reforms, creating both unprecedented challenges and opportunities to improve genetic service delivery. Current health infrastructure comprises six university hospitals, 159 public hospitals, and over 400 private clinics, with the government planning eight new regional university hospitals and 29 urgent care hospitals over the next decade [12].

This narrative review aims to:

1. Synthesize available epidemiological data on DS prevalence, incidence, and demographic patterns in Morocco, with attention to maternal age distributions and clinical characteristics.
2. Analyze clinical characteristics and comorbidity profiles documented in Moroccan populations with DS, including congenital heart disease patterns and healthcare utilization patterns.
3. Evaluate health system challenges and opportunities for genetic service delivery in the context of universal health coverage implementation, including service accessibility, quality of care, and regional disparities.
4. Identify research gaps and methodological limitations in current DS research in Morocco, with recommendations for strengthening surveillance systems and research capacity.
5. Provide evidence-based recommendations for strengthening surveillance infrastructure, clinical care protocols, and health system integration to improve outcomes for individuals with DS and their families.

Methods

Study Design and Approach

This narrative review examined patterns of Down syndrome in Morocco by synthesizing the available data. In order to find pertinent literature, we used a thorough search strategy while taking into account the small amount of data from this area.

Search Strategy and Data Sources

Database Searches: We conducted searches in PubMed/MEDLINE, Google Scholar, and regional databases using terms including ("Down syndrome" OR "trisomy 21") AND ("Morocco" OR "Moroccan"). Additional searches were performed using French terms and institutional affiliations of major Moroccan medical centers.

Additional Sources: Government reports, policy documents, and institutional publications were identified through ministry websites and international organization reports. Grey literature was included when relevant to health system analysis.

Inclusion Criteria: Studies, reports, or documents examining Down syndrome epidemiology, clinical characteristics, or healthcare delivery in Morocco. No language restrictions were applied, and both peer-reviewed and grey literature sources were considered.

Exclusion Criteria: Studies not specifically addressing Down syndrome in Moroccan populations, and conference abstracts without sufficient methodological detail and duplicate publications reporting on the same patient cohorts.

Data Synthesis and Quality Assessment

Given the limited database, we employed narrative synthesis approaches rather than quantitative meta-analysis. Available studies were assessed for methodological quality using appropriate tools for observational studies. Health system documentation was evaluated for relevance and reliability.

Results

Epidemiological Patterns and Cytogenetic Characteristics

Foundational Epidemiological Findings from North African Context

The foundational 852-case study from Morocco's National Institute of Health represents the most comprehensive cytogenetic analysis of Down syndrome available from North Africa, although methodological limitations warrant cautious interpretation [13].

This institutional case series revealed cytogenetic distributions consistent with global patterns: free trisomy 21 accounting for 96.24% of **cases**, translocations 3.17%, and mosaicism 0.59%. These proportions align closely with international norms (94-95% free trisomy reported globally), confirming that non-disjunction events represent the primary mechanism underlying Down syndrome across diverse populations [14].

Critical Methodological Assessment: While frequently cited as representative of North African epidemiology, this study presents significant limitations that impact interpretation:

- Hospital-based case series design without population denominators
- Selection bias toward cases reaching tertiary genetic services
- No information on ascertainment methods or referral patterns
- Absence of temporal trends or demographic stratification

The documented median maternal age of 35.39 years substantially exceeds typical population medians, likely reflecting healthcare access patterns rather than true population demographics. For comparison, contemporary European data from 21 EUROCAT registries covering 6.1 million births showed maternal age ≥35 years in only 19% of births [15], suggesting potential ascertainment bias in the Moroccan cohort toward older maternal ages with better healthcare access.

Contemporary Data and Risk Factor Analysis

Recent case-control studies from Morocco provide additional insights into risk factors. Oulmane et al. [16] examined 277 families in the Marrakech-Safi region, identifying maternal age (OR=1.16; 95% CI: 1.11-1.21) and paternal age (OR=1.05; 95% CI: 1.011.09) as significant risk factors. Notably, families with children with DS demonstrated higher educational levels and employment rates compared to national averages, suggesting socioeconomic disparities in healthcare access.

The 2014 study by Belahcen et al. [17] examined maternal awareness and attitudes toward prenatal screening among 50 women with children with Down syndrome. This study revealed that despite low awareness of existing screening tests, the majority of Moroccan mothers had positive attitudes toward prenatal screening for DS, highlighting the need for improved education and access to genetic counseling services.

Critical Data Gap: No population-based prevalence estimates exist for Morocco or other North African countries, representing a fundamental limitation in regional epidemiological understanding.

Clinical Characteristics and Comorbidity Patterns

Congenital Heart Disease and Associated Conditions

Clinical data from Morocco revealed significant patterns of congenital heart disease in Down syndrome populations. The 9-year retrospective study (2015-2023) from Mohammed VI University Hospital Center in Oujda provided important contemporary data. Among 167 children with trisomy 21 evaluated, 61.6% presented with confirmed congenital heart malformations.

The most frequent malformations documented in this study were: complete atrioventricular septal defects (AVSD, 38.8%), ventricular septal defects (VSD, 31.0%), and atrial septal defects (ASD, 21.3%). Average diagnostic delay was 13.8 months after birth, highlighting persistent challenges in early diagnosis in peripheral Moroccan regions. Although 60.2% of children had surgical indication according to international guidelines, only 22.6% actually received cardiac surgery. Main reasons were: irreversible pulmonary hypertension (45.2%), parental refusal or loss to follow-up (32.3%), and financial or logistical constraints (19.4%).

Additional data from Ibn Rochd Hospital in Casablanca (128 cases over 6 years) revealed similar patterns [18]. Median maternal age was 39 years, with an overall mortality rate of 14.1%. Although 54% of patients had surgical indication, only 42 patients were operated due to financial barriers and parental refusal.

Thyroid Dysfunction

Although comprehensive data on thyroid dysfunction are limited in Moroccan DS literature, regional data from Egypt suggest high prevalence (25-30%) of thyroid disorders in DS populations [19]. The absence of systematic screening protocols in Morocco likely results in underdiagnosis of this treatable comorbidity.

Technological Advances and Health System

Introduction of Non-Invasive Prenatal Diagnosis

In 2023, Yourgene Health partnered with laboratory in Rabat to introduce Morocco's first locally available non-invasive prenatal test (NIPT), enabling screening for trisomies 21, 18, and 13 without sending samples abroad. While this development marked a meaningful step toward improving prenatal diagnostic capacity in the region, its impact on population-level screening coverage remains to be evaluated.

Health System Context and Service Delivery

Analysis of available healthcare delivery information revealed significant disparities between urban tertiary centers and peripheral regions. Genetic diagnostic services remain concentrated in three major urban centers (Casablanca, Rabat, and Fez), creating substantial barriers for rural populations representing approximately 40% of Morocco's population.

Despite insurance coverage expansion from 15% (2005) to 78% (2022), genetic services remain poorly integrated into primary care systems. Expert consultations suggest that less than 15% of the population has meaningful access to genetic counseling or specialized DS care services.

COVID-19 Impact on Service Delivery

The pandemic exposed critical vulnerabilities in Morocco's health system, with documented disruptions to prenatal care services. Oumerzouk and Sarr [11] reported significant declines in prenatal recruitment rates and reduced coverage of high-risk pregnancy screening protocols in the Guelmim Oued Noun region.

International data showed 10-fold higher COVID-19 mortality risk for individuals with DS (HR 10.39; 95% CI: 7.08-15.23) [20], underscoring the need for adapted protection protocols in the Moroccan context. Educational challenges also affect 60.9% of families, with increased difficulties for children aged 7-12 years [21].

Discussion

The cytogenetic data from Morocco's National Institute of Health, despite their institutional origin, paint a broadly familiar picture. Free trisomy 21 accounted for 96.24% of the 852 cases analyzed, a figure closely matching the 94–95% reported in large international series. This consistency across diverse populations reinforces the central role of chromosomal non-disjunction in DS etiology, regardless of ethnic or geographic background.

That said, the maternal age profile in these studies median age 35.39 years almost certainly reflects referral patterns rather than the true demographic structure of DS births in Morocco. Women with greater healthcare access, who tend to be older and more urban, are overrepresented in hospital-based series. A similar bias has been noted elsewhere, but it is especially pronounced in settings where genetic services remain limited to a few tertiary centers. For comparison, de Graaf et al. reported a live birth prevalence of 12.6 per 10,000 in the United States (2006–2010), with approximately 30% of DS pregnancies ending in elective termination a figure shaped by widespread prenatal screening that has no equivalent in Morocco at present.

Recent global mortality analysis showed a 22.8% decrease in Down syndrome-related deaths among children and adolescents (1980-2021). However, regions with low sociodemographic development index continue to display higher mortality rates, highlighting the importance of improving care systems.

Several interrelated problems stand out. Morocco lacks any form of population-based DS surveillance, so the true burden of the condition remains unknown. Prevalence estimates, insofar as they exist, derive from hospital case series at a handful of urban centers—Casablanca, Rabat, Fez and cannot be generalized to the roughly 40% of the population living in rural areas. This concentration of diagnostic services in major cities means that families in peripheral regions face long delays before obtaining a karyotype or cardiac evaluation, if they obtain one at all.

Back in 2005, only about 15 percent of people had health insurance coverage, but by 2022 that jumped up to 78 percent, which seems like a pretty big deal to me. I mean, its a real achievement in some ways. Still, having insurance does not really fix everything, especially when it comes to getting actual help like genetic counseling. Or the kind of specialized follow-up for DS that families need. Most of them are still left without that meaningful access, It feels kind of frustrating how that part gets overlooked. Primary care providers, who represent the first point of contact for the majority of patients, receive little training in genetic conditions. At the same time, Morocco's ongoing investment in new university and regional hospitals offers a concrete opportunity to decentralize genetic services provided that workforce development and sustainable financing are planned alongside infrastructure expansion.

This review had some pretty big limitations right from the start. There just werent many studies out there on Down syndrome in Morocco, and the ones that existed usually had tiny sample sizes. They mostly came from hospital cases, Available data were concentrated in major urban centers, offering no insight into patterns in rural or semi-urban settings. Recent data reflecting the current health system context—particularly after the expansion of universal health coverage—were scarce. Taken together, while these studies provided valuable clinical observations, they could not support robust population-level inferences about epidemiological patterns, temporal trends, or health system performance.

Recommendations for System Strengthening

Immediate Priorities

- Establishment of population-based surveillance infrastructure with standardized case definitions
- Development of regional genetic service networks to improve access equity
- Integration of basic genetic counseling into primary care training programs
- Development of early cardiac management protocols with dedicated funding

Medium-Term Goals:

- Implementation of systematic prenatal screening protocols with appropriate counseling support
- Strengthening of pediatric cardiac services in regional centers
- Development of crisis-resilient healthcare delivery models for essential genetic services

Long-Term Goals:

- Creation of comprehensive care coordination systems spanning prenatal through adult care
- Development of research infrastructure to support population-based epidemiological studies
- Regional collaboration frameworks to share expertise and resources across North African countries

Research Priorities: The limited database underscores critical primary research needs, including population-based prevalence studies, assessments of healthcare provider knowledge, and evaluations of family experience to inform evidence-based policy development. Investment in surveillance infrastructure, professional development, and innovative service delivery models will be essential for creating more equitable and effective health systems capable of meeting the complex needs of individuals with Down syndrome and their families.

Conclusions

This narrative review of available data revealed that Down syndrome in Morocco demonstrated epidemiological patterns broadly consistent with international data, although significant health system challenges persisted that affected quality and accessibility of care for affected individuals and their families. Available studies suggested standard cytogenetic distributions and maternal age associations, yet the data base remained insufficient for comprehensive epidemiological analysis. Significant disparities existed between urban tertiary centers and peripheral regions in terms of diagnostic capabilities, specialized services, and access to genetic counseling. The absence of comprehensive national surveillance systems prevented accurate prevalence estimation and evidence-based healthcare planning. Nevertheless, the expansion of universal health coverage offered opportunities for better integration of genetic services, although substantial implementation challenges remained.

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