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Hidden Burden of Hereditary Transthyretin Amyloidosis (ATTRv) in Four Gulf Countries: A Burden-of-Disease Modeling Study

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INTRODUCTION

Hereditary transthyretin amyloidosis (ATTRv) is a rare, progressive, and life-threatening disease caused by pathogenic variants in the transthyretin gene. (1,2) The disease has heterogeneous manifestations, including polyneuropathy (ATTRv-PN), cardiomyopathy (ATTRv-CM), and mixed phenotypes, which often contribute to delayed diagnosis and misdiagnosis. (3,4)

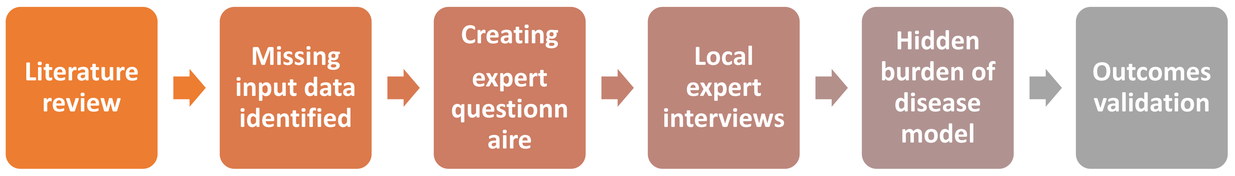
OBJECTIVE

The study aims to estimate the hidden societal burden of ATTRv in four Gulf countries (the United Arab Emirates (UAE), Oman, Kuwait, and Bahrain) in 2025.

METHODS

A bottom-up burden-of-disease model was developed to estimate the hidden burden of ATTRv. Patients were stratified by phenotype (ATTRv-PN, ATTRv-CM, and mixed) and diagnostic status (diagnosed vs misdiagnosed/undiagnosed). Humanistic burden was assessed using Disability-adjusted life years (DALYs), while indirect costs captured productivity losses among patients and caregivers. Patient numbers were estimated using published epidemiological data and refined through expert validation.

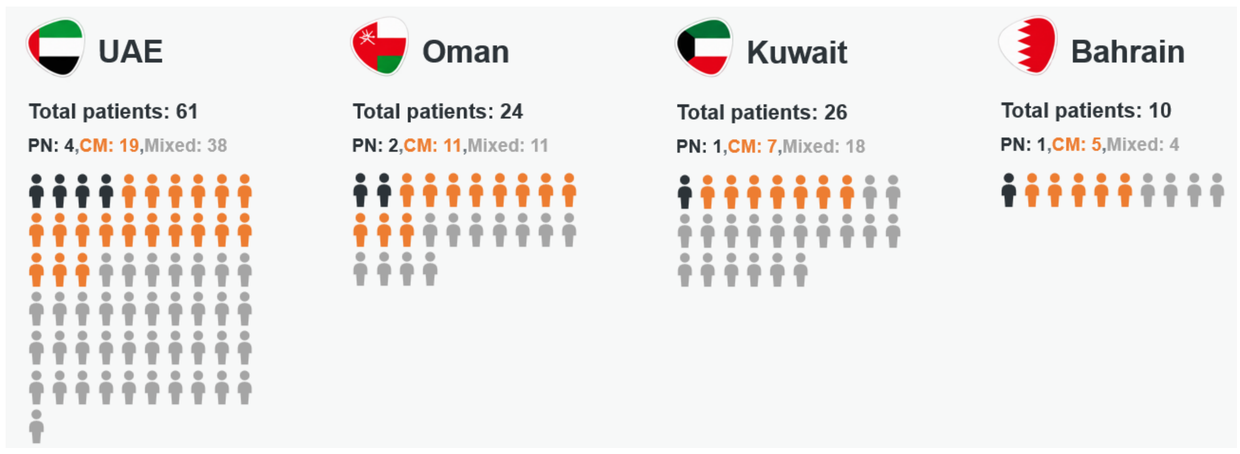
Figure 1: ATTRv burden of disease study steps



RESULTS

Number of patients

Figure 2: Number of ATTRv patients in each phenotype

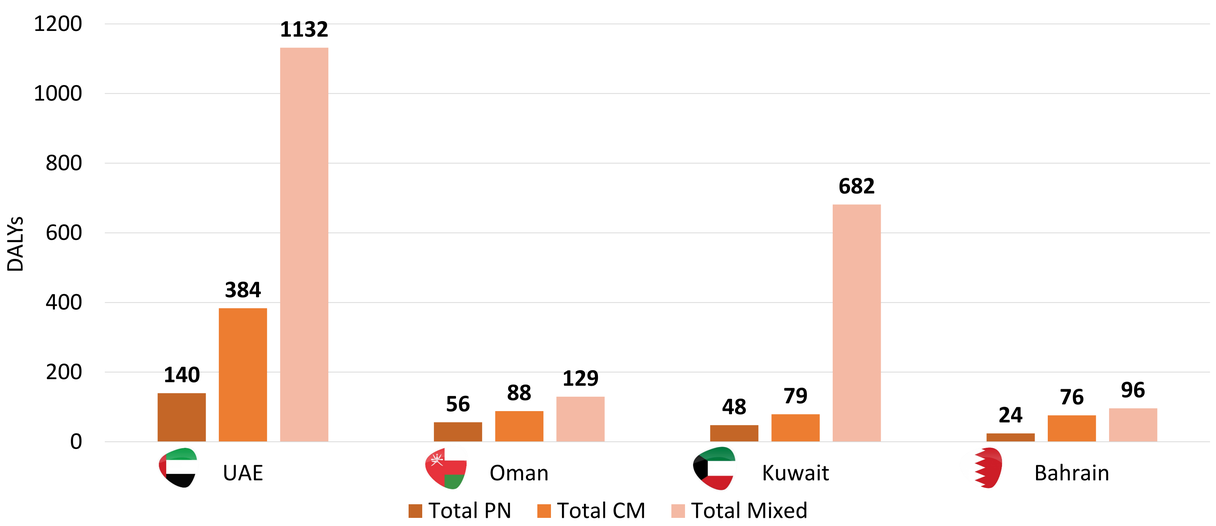


Across all countries, the mixed phenotype was the most prevalent presentation. The model highlighted a substantial diagnostic gap, with approximately 71–80% of patients estimated to be undiagnosed or misdiagnosed.

Humanistic burden

The combined lifetime humanistic burden for patients and caregivers was 1,655 DALYs in the UAE, 273 in Oman, 808 in Kuwait, and 196 in Bahrain.

Figure 3: Lifetime DALYs for patients and caregivers



The monetary value of DALYs lost was estimated by multiplying annual DALYs lost across ATTRv patients and caregivers by country-specific gross domestic product (GDP) per capita. Annual DALYs lost were derived from the lifetime DALYs divided by the expected survival duration. This resulted in monetary value of AED 9.7 million in the UAE, OMR 132.2 thousand in Oman, KWD 224.4 thousand in Kuwait, and BHD 92.6 thousand in Bahrain.

Indirect costs

The indirect costs associated with productivity losses among patients and caregivers were estimated at AED 8,116,777 in the UAE, OMR 119,286 in Oman, KWD 145,646 in Kuwait, and BHD 23,867 in Bahrain.

Table 1: Annual indirect cost for patients and caregivers (in thousands of local currency)

ATTRv phenotype	UAE		Oman		Kuwait		Bahrain	
	Patients Thousand AED	Caregivers Thousand AED	Patients Thousand OMR	Caregivers Thousand OMR	Patients Thousand KWD	Caregivers Thousand KWD	Patients Thousand BHD	Caregivers Thousand BHD
ATTRv-PN	207	273	31	7	2	3	1	1
ATTRv-CM	0	647	0	41	0	18	0	5
Mixed ATTRv	4,400	2,590	0	41	75	47	13	4

Annual productivity losses in each country's own currency. Columns are not directly comparable across markets. Zero values reflect no indirect costs.

Indirect costs were attributed to both patients and caregivers in ATTRv-PN and mixed ATTRv. For ATTRv-CM, costs were mainly related to caregivers, as patients are usually diagnosed at older ages; therefore, patient productivity losses were not included in the analysis. Similarly, productivity losses were not considered for mixed ATTRv patients in Oman due to older age at diagnosis.

Total hidden burden

The annual hidden burden, incorporating humanistic and productivity losses, was estimated by monetary values at AED 17.82 million, OMR 0.25 million, KWD 0.37 million, and BHD 0.12 million, respectively, largely driven by mixed phenotype and undiagnosed/misdiagnosed patients.

Table 2: Total ATTRv hidden burden (in millions of local currency)

ATTRv phenotype	UAE	Oman	Kuwait	Bahrain
	Million AED	Million OMR	Million KWD	Million BHD
ATTRv-PN	1.07	0.05	0.01	0.01
ATTRv-CM	3.56	0.10	0.07	0.05
Mixed ATTRv	13.18	0.10	0.29	0.06
Total ATTRv	17.82	0.25	0.37	0.12

Values in millions of each country's own currency. Columns are not directly comparable across markets. Totals may differ slightly due to rounding of presented values.

CONCLUSION

ATTRv imposes a substantial hidden burden in the Gulf region, highlighting the need for improved disease awareness, earlier detection strategies, multidisciplinary management pathways, and stronger regional evidence generation.

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