

Policy Analysis for Amyloidosis Management at MENA Region

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Abstract

Background: Amyloidosis is one of rare diseases is usually fatal. Increasingly recognized in clinical practice despite patients presenting with non-specific symptoms of cardiomyopathy for cardiac amyloidosis. Amyloidosis is a systemic illness that affects multiple organ systems, including the cardiovascular, renal, gastrointestinal, and pulmonary systems. Common manifestations include restrictive cardiomyopathy, arrhythmias, nephrotic syndrome, and gastrointestinal hemorrhage.

It is unknown whether coexisting atrial fibrillation (AF). Due to amyloidosis is considered as a rare disease according to The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. With characterization of wide diversity of symptoms and signs that vary not only from disease to disease but also from patient to patient suffering from the same disease. With all the previous features many question was raised from policy prospective like the nature of health system for disease management, system capacity and capability decision makers awareness about disease nature. Resources needed and accepility challenges. The objective for this research is policy analysis for the following items (nature of health system for disease management, system capacity and capability decision makers awareness about disease nature. Resources needed and accepility challenges).

In order to health system enhancement towards amyloidosis management for achievement better patients outcomes and efficient resources management.

Methods: Standardized survey was developed and conducted for 100 of HCPs (healthcare professionals) at the following countries (Algeria, Morocco, Egypt, KSA, UAE Iraq, Oman and Turkey) HCPs included (Physicians, nurses, pharmacists and payers).

Patient's groups are represented at the survey. Previous survey with integrated with health systems data bases and nationals health accounts analysis for these countries for previous 5 years. One way sensitivity analysis was conducted for robustness of data guaranteeing.

Results: Analysis for amyloidosis founded the following findings:

- A systemic illness that affects multiple organ systems.
- Usually fatal for cardiac amyloidosis.
- Without efficient policy it might represent burden on health system.
- Stake holders engagement represent the corner stone for system enhancement.
- Accepility challenges presented at diseases management policies.
- Clear treatment guidelines combined with effective awareness and specialized clinics might have positive impact on policy enhancement.

Conclusion: Amyloidosis management at MENA region need policy reforming in order to achieve the following:

- Patient's outcomes enhancement.
- Efficient resources utilization.
- Health system enhancement.

Keywords: *Amyloidosis Accepility; MENA; Abdalla Abotaleb Policy; Analysis*

Background

Amyloidosis is one of rare diseases is usually fatal. Increasingly recognized in clinical practice despite patients presenting with non-specific symptoms of cardiomyopathy for cardiac amyloidosis. Amyloidosis is a systemic illness that affects multiple organ systems, including the cardiovascular, renal, gastrointestinal, and pulmonary systems. Common manifestations include restrictive cardiomyopathy, arrhythmias, nephrotic syndrome, and gastrointestinal hemorrhage.

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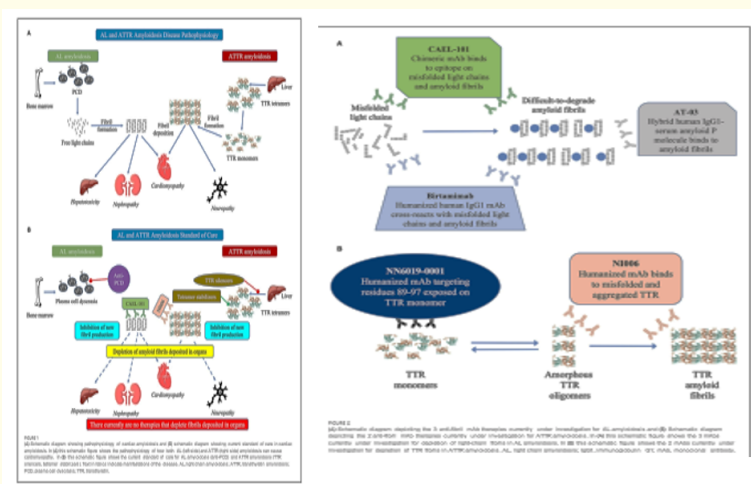


Table 3 Signs and Symptoms Associated with hATTR Amyloidosis

Symptom ^a	Patient ^b														Total
	01	02	03	04	05	06	07	08	09	10	11	12	13	14	
Pain	×		×	×	×		×	×	×	×	×	×	×	×	12
Numbness		×	×	×	×	×	×	×	×	×	×	×	×	×	12
Fatigue, Lethargy	×	×			×		×	×	×	×	×	×	×	×	12
Weakness	×	×	×	×	×	×	×	×	×	×	×	×	×	×	10
Gastrointestinal dysfunction	×		×	×	×		×		×	×	×			×	8
Cognitive dysfunction		×	×	×	×		×		×		×	×		×	8
Paresthesia	×	×	×	×	×		×	×	×	×	×	×	×	×	8
Cardiac dysfunction		×	×	×			×		×		×	×		×	8
Loss of motor function	×		×	×			×		×		×			×	7
Loss of balance	×						×		×		×			×	6
Carpal tunnel syndrome				×	×		×		×		×	×		×	6
Dizziness				×	×		×		×					×	5
Genitourinary dysfunction	×		×		×		×		×					×	4
Ocular issues	×		×		×		×		×					×	4
Difficulty breathing			×						×		×			×	4
Swelling									×					×	3
Weight loss or difficulty gaining				×	×				×					×	3
Hot sensations	×		×											×	2
Difficulty swallowing, Choking						×								×	2
Total	11	3	13	9	6	12	5	10	9	10	7	10	5	14	

^aFourteen symptoms were mentioned by only one patient each: altered taste, back spasms, body temperature dysregulation, elevated adrenaline, heat intolerance, inability to get pregnant, insomnia, migraine, muscle tightness, nausea, perspiration, sensitivity to weather, blood pooling, and weakened voice
^bGenetic variants reported by patients: V30M (patient #s 01, 02, 03, 05, and 07), T60A (#s 11, 12, 14), A97S (#04), Y114H (#08), F64L (#09), E54G (#10), and unsure (#s 06 and 13)

Figure 1

Methods

Standardized survey was developed and conducted for 100 of HCPs (healthcare professionals) at the following countries (Algeria, Morocco, Egypt, KSA, UAE Iraq, Oman and Turkey) HCPs included (Physicians, nurses, pharmacists and payers).

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Results and Discussion

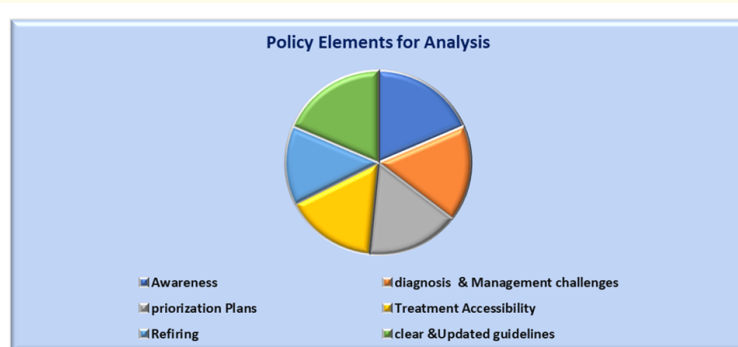
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Table 2: Outcomes and Comorbidities of Amyloidosis with and Without AF

	Amyloidosis Alone (n = 2,013)	Amyloidosis with AF (n = 984)	OR (95% CI)	aOR* (95% CI)
Stroke	7.9%	3.4%	0.39 (0.27–0.58)	0.34 (0.23–0.50)
Heart failure	30.4%	66.0%	4.47 (3.80–5.27)	4.61 (3.88–5.47)
Bleeding	2.8%	5.7%	2.10 (1.44–3.07)	2.31 (1.55–3.42)
Ventricular tachycardia	3.5%	7.5%	2.28 (1.63–3.20)	2.40 (1.68–3.41)
Heart block	2.8%	6.8%	2.60 (1.80–3.75)	2.36 (1.61–3.46)
Cardiac arrest	1.1%	1.6%	1.42 (0.75–2.71)	1.57 (0.80–3.07)
Restrictive cardiomyopathy	2.6%	5.6%	2.22 (1.51–3.27)	2.66 (1.77–4.00)
Cardiogenic shock	1.6%	5.0%	3.16 (2.01–4.98)	3.77 (2.34–6.09)
ICD/CRT/PPM placement	4.5%	14.5%	3.59 (2.71–4.74)	3.30 (2.47–4.40)
Renal failure	20.8%	29.1%	1.59 (1.33–1.90)	1.59 (1.33–1.91)
Respiratory failure	9.5%	9.8%	1.03 (0.80–1.34)	1.08 (0.82–1.41)
Inpatient mortality	5.6%	7.4%	1.34 (0.99–1.83)	1.39 (1.01–1.91)
Length of stay (includes only those patients who survived to discharge)	7.4 ± 9.2 days	7.8 ± 12.9 days	—**	—

AF: atrial fibrillation; aOR: adjusted odds ratio; CI: confidence interval; CRT: cardiac resynchronization therapy; ICD: implantable cardioverter-defibrillator; OR: odds ratio; PPM: permanent pacemaker.
 *Adjusted for age, sex, and county income.
 **Continuous variable; t-test nonsignificant (p = 0.301).



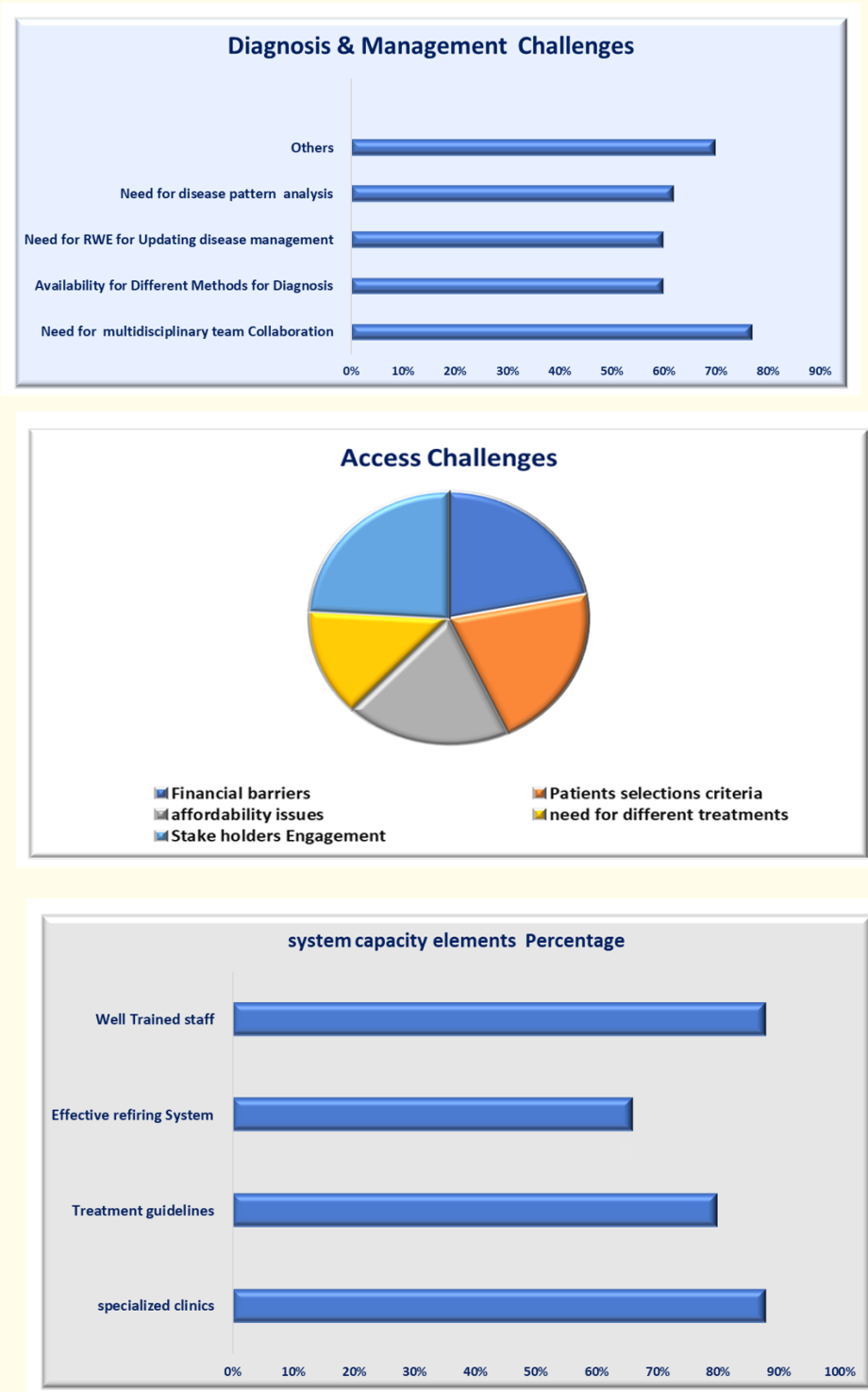


Figure 2

Conclusion

Amyloidosis management at MENA region need policy reforming in order to achieve the following:

- Patient's outcomes enhancement.
- Efficient resources utilization.
- Health system enhancement [1-17].

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