

Background

Medication non-adherence is a significant challenge in sarcoidosis, yet its drivers remain poorly understood.

Qualitative work from our group suggests adherence is driven primarily by **perceived lack of efficacy** and **medication side effects** rather than access barriers.

The Sarcoidosis Advanced Registry for Cures (FSR-SARC), maintained by the Foundation for Sarcoidosis Research, provides a unique opportunity to examine patient-reported adherence and its correlates at scale.

Key factors hypothesized to influence adherence include quality of care, mental health, fatigue, self-efficacy, and financial burden, but their relative contributions have not been systematically evaluated.

Objective: To evaluate how patient-reported quality of care, medication side effects, and demographic and financial factors relate to medication adherence among FSR-SARC Registry participants.

Methods

Population: Members of the FSR-SARC registry—a longitudinal patient-reported registry collecting demographics, disease characteristics, and treatment data at baseline and annually.

Survey instruments administered:

- MARS-5 (Medication Adherence Report Scale)
- ACCC (Assessment of Care for Chronic Conditions)
- KSQ-M (King's Sarcoidosis Questionnaire–Medication domain)
- PHQ-8 (Patient Health Questionnaire — depression)
- PROMIS Self-Efficacy for Managing Chronic Conditions–Symptoms)
- PSS (Perceived Stress Scale)
- SAT-F (Sarcoidosis Assessment Tool–Fatigue)

Financial covariates: Insurance type, income, and self-reported financial impact of sarcoidosis.

Analysis: Univariate and multivariable negative binomial regression models were used to identify predictors of MARS-5 score.

Results

Age – median (IQR)	60 (52-66)	Annual gross income - n(%)	
Race – n (%)		<\$35k	69 (14%)
Black	51 (10%)	\$35k-\$85k	129 (25%)
White	401 (79%)	>\$85k	184 (36%)
Other	17 (3%)	Missing	124 (25%)
Missing	37 (7%)	How has diagnosis affected family finances? – n(%)	
Organ involvement – n (%)		No financial impact	130 (26%)
Lung	384 (76%)	Slightly affected	167 (33%)
Joints	225 (44%)	Greatly affected	103 (20%)
Skin	189 (37%)	Severely affected	56 (11%)
Heart	158 (31%)	Missing	50 (10%)
Eye	145 (29%)	Health Insurance - n(%)	
Brain	129 (25%)	Private	268 (53%)
Taking sarcoidosis medication – n (%)		Government	147 (29%)
Yes	369 (73%)	None	14 (3%)
No	131 (26%)	Missing	77 (15%)
Missing	6 (1%)		

	Scale Range	Median (IQR)	Missing
MARS 5	5 – 25	24 (23-25)	138
ACCC	1 – 5	2.4 (1.6-3.2)	12
KSQ-Med	0 – 100	67 (47-81)	138
PHQ-8	0 – 24	9 (4-14)	17
PROMIS self efficacy	22.67 – 63.85	43 (34 – 53)	22
PSS	0 – 40	18 (11- 25)	8
SAT Fatigue (T score)	0 – 100	63 (54-69)	91

Univariate Outcomes

Every 20% increase in perceived quality of care (ACC) was associated with a 22% (9%-32%) increase in medication adherence (MARS-5)

Every 1% increase in medication related quality of life (KSQ Med) was associated with a 0.7% (0.1-1.3%) increase in medication adherence (MARS-5))

For every 1% increase in self efficacy (PROMIS self efficacy) was associated with a 1.5% increase in medication adherence (MARS-5)

Univariate associations not significant in multivariate models including race, organ involvement, ACC, KSQ-med, self-efficacy, PSS, fatigue and PHQ-8

Discussion

Of 506 survey completers, **368 reported current medication use** and were included in the analysis

In univariate analyses, higher adherence (MARS-5) was associated with:

- Higher patient-reported quality of care (ACCC) ✓
- Greater self-efficacy for symptom management (SECC-S) ✓
- Less fatigue (SAT-F) ✓
- Less depressive symptoms (PHQ-8) ✓
- Less Perceived stress (PSS) ✓

Financial variables (insurance, income, financial impact) were not significantly associated with adherence

In variable selection analyses, **self-efficacy (SECC-S) emerged as the strongest predictor of adherence**

In a multivariable model (n=260 complete cases) adjusting for race, organ involvement (neurologic, cardiac, joint), SECC-S, PSS, SAT-F, and PHQ-8 — no individual covariate reached statistical significance after adjustment.

Conclusions

1. In univariate and multivariate analysis financial barriers were not associated with adherence, suggesting a distinction between access and adherence. Univariate analyses suggest psychosocial factors and medication side effects may be relevant targets for adherence interventions, though further work is needed to clarify their independent contributions.
2. The absence of significant independent predictors in multivariable modeling likely reflects substantial overlap among self-efficacy, mental health (stress, depression), and symptom burden (fatigue, medication side effects). Disentangling these interrelated constructs will be an important goal for future work.

References

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