Real-World Observations in Patients Receiving Infliximab for Sarcoidosis in the Home Infusion Setting

[1]Timothy P. Walton, MHS, CCRP; [1]Elizabeth Duruz, RPh, CSP, IgCP; [1]Michele Way, PharmD, IgCP, BCSCP; [1]Jordan Bruns, PharmD, IgCP; [1]Jessica Giles, RN BSN; [1]Geri Adler; [1]William Marsh; [1]James Sheets, PharmD, IgCP; [1]Randy Broyles, RPh; [1]Edward O'Bryan, MD, MBA, CPE
[1]CSI Pharmacy, Plano, TX

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BACKGROUND

Home infusion provides an alternative care setting for patients who require therapies such as biologic agents, like infliximab, allowing treatment to occur outside hospitals, clinics, or outpatient infusion centers. This model is supported by specialty pharmacies and home infusion organizations, with services delivered by clinicians who receive additional, specialized training.[1]

Delivering infusions in the home can minimize disruptions to daily life, including work, school, and family responsibilities, while offering a safe and effective substitute for traditional infusion sites and potentially lowering overall healthcare costs.[2, 3, 4] As evidence continues to demonstrate improvements in quality of life and positive clinical outcomes, the scope of therapies administered in the home setting has steadily expanded.[5]

Sarcoidosis is a chronic, immune-mediated granulomatous disease characterized by non-caseating granulomas that can affect virtually any organ system, with pulmonary involvement occurring in more than 90% of patients. Its clinical course is heterogeneous, ranging from spontaneous remission to chronic, progressive disease that may lead to pulmonary fibrosis or multisystem impairment requiring long-term immunosuppressive therapy.[6,7,8]

Biologic agents such as infliximab have emerged as important treatment options for patients with refractory sarcoidosis, demonstrating improvements in pulmonary function, extrapulmonary manifestations, and overall disease control.[9,10,11]

Home infusion providers play an essential role in the management of sarcoidosis by facilitating payer approvals, coordinating timely access to biologic therapies such as infliximab, and monitoring patient outcomes. Their involvement supports continuity of care, reduces barriers to therapy, and enables systematic tracking of adverse events and patient-reported outcomes.

Together, these observations highlight how sarcoidosis is managed in real-world practice and underscores the importance of home infusion services in optimizing long-term biologic treatment.

PURPOSE

To better understand real-world presentation and management of sarcoidosis patients in the home infusion setting, this study summarizes the demographic, clinical outcomes, and Quality of Life (QOL) of 10 patients living with sarcoidosis. Specifically, to evaluate the off-label use of infliximab within a home infusion care model, highlighting how advanced biologic therapy is delivered and managed outside traditional hospital settings.

METHODS

A retrospective review was conducted of sarcoidosis patients treated between January 2021 and November 2025 through the proprietary CSI Pharmacy, a national home infusion and specialty pharmacy provider, Clinical Outcomes 360[SM] program.

Data were obtained from this program, which captured demographics, dosing patterns, and patient-reported outcomes.

Data also included a 5-point QOL scale (1=Very Poor, 5 = Excellent). Domains evaluated included overall health, energy levels, emotional well-being, pain, and ability to engage in social activities or interact with others. Most recent Infliximab infusion responses provided a comprehensive view of patient status across physical, emotional, and social functioning, with values to be reported in detail.

Descriptive analyses were performed to summarize findings.

RESULTS

Table 1. Patient Demographics

Variable	Sarcoidosis Patients (n =10) (%)
Sex	
Female	4 (40%)
Male	6 (60%)
Age	
Median (Range)	58 (38-66)
30-39	1 (10%)
40-49	1 (10%)
50-59	4 (40%)
60-70	4 (40%)
Weight (kg)	
Median (Range)	96.39 (73.48-134.72)
73.48-83.48	4 (40%)
83.49-93.48	1 (10%)
93.49-113.48	2 (20%)
113.49-133.48	2 (20%)
133.49-143.48	1 (10%)
Ideal Body Weight (kg)	
Median (Range)	63.8 (54.7-77.6)
54.7-64.7	6 (60%)
64.8-74.7	1 (10%)
74.8-84.7	3 (30%)
Body Mass Index (BMI)	
Median (Range)	31.8 (25.77-45.42)
25.77	1 (10%)
27.44	1 (10%)
27.81	1 (10%)
29.05	1 (10%)
29.85	1 (10%)
33.72	1 (10%)
38.49	1 (10%)
38.74	1 (10%)
41.42	1 (10%)
45.42	1 (10%)
Geographical Location	
Midwest	2 (20%)
South	8 (80%)
Type of Payor	
Governmental	10 (100%)

Graph 1. Prescribing Physician by Specialty

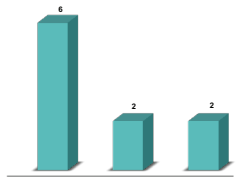


Table 2. Diagnosis and Dosing Information

Variable	Sarcoidosis Patients (n =10) (%)
Types of Sarcoidosis	
One Type	
Neurosarcoidosis	4 (40%)
Pulmonary	1 (10%)
Two Types	
Neurosarcoidosis and Pulmonary	2 (20%)
Spleen and Ocular	1 (10%)
Three Types	
Lymph Node, Liver, Lung, Skin, Joints	1 (10%)
Four Types	
Musculoskeletal, Cardiac, Gastrointestinal, Ocular, Pulmonary, Arthropathy	1 (10%)
Infliximab Dosing (mg/kg)	
Median (Range)	5 (3-10)
3	1 (10%)
5	7 (70%)
7	1 (10%)
10	1 (10%)
Infliximab Frequency	
Median (Range)	6 (4-8)
Every 4 Weeks	4
Every 6 Weeks	3
Every 8 Weeks	3
Dispensing Information	
Total Dispenses	124
Median Dispenses/Patient	8
2	2 (20%)
3	1 (10%)
6	1 (10%)
8	2 (20%)
19	1 (10%)
20	1 (10%)
25	1 (10%)
31	1 (10%)

Graph 2. Number of Patients Who Failed Treatments Prior to Infliximab

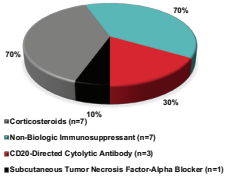


Table 3. Intake Symptoms

Variable	Sarcoidosis Patients (n =10) (%)
Musculoskeletal	Back Pain (n=1); Arm/Leg Weakness (n=2); Balance Loss (n=1); Unstable Gait (n=1); Myelitis-Related Spasticity (n=1)
Neurological/Cognitive	Memory Deficits (n=1); Confusion (n=1); Slurred Speech (n=1); Numbness (n=2); Urinary Urgency (n=1)
Ophthalmologic	Bilateral Vision Loss (n=1); Blurry Vision (n=1); Unilateral Blurred Vision (n=1); Proptosis (n=1); Eye Pain (n=1)
Respiratory	Chronic Cough (n=1); Dyspnea (n=1); Pulmonary Nodules (n=1); Scarring (n=1)
Systemic	Fatigue (n=2); Lethargy (n=1); Intermittent Dysphagia (n=1)

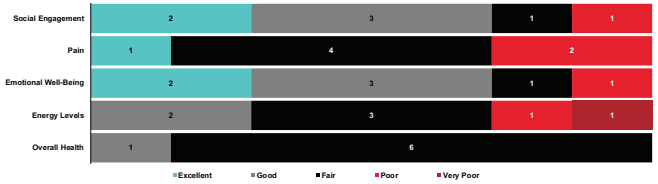
Table 4. Patient-Reported Symptom Worsening After the Most Recent Infliximab Infusion Relative to Intake

Variable	Sarcoidosis Patients (n =10) (%)
Reported Worsening of Symptoms After Most Recent Infusion of Infliximab Compared to Intake Symptoms	8 (80%)
Blurred or Lost Vision	2 (25%)
Numbness	2 (25%)
Tingling	2 (25%)
Cognitive Difficulties	1 (13%)
Gait Impairment	2 (25%)
Weakness	2 (25%)
Restricted Range of Motion	1 (13%)
Increased Dyspnea	1 (13%)
Fatigue	3 (38%)
Pain	3 (38%)

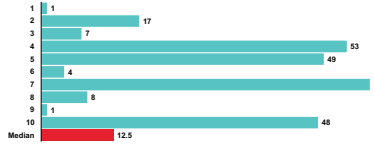
Table 5. Patient-Reported Efficacy Following the Most Recent Infliximab Infusion Relative to Intake

Variable	Sarcoidosis Patients (n =10) (%)
Reported Efficacy After Most Recent Infusion of Infliximab Compared to Intake Symptoms	10 (100%)
Mobility	1 (10%)
Gait Stability	1 (10%)
Lower Extremity Strength	1 (10%)
Reduced Dyspnea	2 (20%)
Decreased Inhaler Use	1 (10%)
Extremity Pain	1 (10%)
Extremity Numbness	1 (10%)
Extremity Tingling	1 (10%)
Skin Lesions	1 (10%)

Graph 3. 5-Point Quality of Life Scale (Note: Only 7 out of 10 Completed this QOL)



Graph 4. Months On Infliximab with Specialty Pharmacy at Time of Data Collection/Patient



DISCUSSION

This real-world review reinforces the complexity of sarcoidosis and the substantial variability in clinical presentation, organ involvement, and treatment response. The cohort demonstrated a wide spectrum of disease phenotypes, ranging from isolated pulmonary or neurologic involvement to extensive multisystem disease affecting up to six organ systems. Such heterogeneity mirrors the broader sarcoidosis population and underscores the need for individualized therapeutic strategies, particularly for patients with refractory or progressive disease.

Across the 10 patients actively receiving infliximab, improvements were observed in multiple symptom domains, including mobility, gait stability, respiratory function, neurological complaints, dermatologic manifestations, and overall, well-being. These findings are consistent with prior reports supporting the use of infliximab for refractory sarcoidosis, particularly neurosarcoidosis and pulmonary disease. At the same time, persistent or worsening symptoms, such as fatigue, pain, sensory disturbances, and visual changes, highlight the chronic, relapsing nature of sarcoidosis and the limitations of biologic therapy in fully controlling systemic symptom burden.

Patient-reported outcomes provided additional insight into the lived experience of individuals receiving infliximab. Despite targeted improvements, many patients continued to rate their overall health, energy, and pain levels as fair or poor. Emotional well-being and social engagement were more preserved, suggesting that while physical symptoms remain challenging, patients may adapt psychosocially over time. These findings emphasize the importance of comprehensive, multidimensional assessment beyond organ-specific metrics.

The home infusion setting played a meaningful role in enabling access to therapy and supporting ongoing monitoring. Structured data collection through this home infusion providers clinical outcomes program allowed for systematic capture of symptoms, functional status, and quality of life indicators, elements that are often underrepresented in traditional clinical documentation. This model may help bridge gaps in real-world evidence by providing longitudinal, patient-centered insights that complement clinical evaluations. However, the small sample size (n=10) represents a key limitation, restricting the validity and generalizability of these findings and underscoring the need for larger studies and more frequent outcome measures to confirm these observations.

CONCLUSION

This analysis demonstrates that infliximab administered through a home infusion model is a feasible and effective therapeutic approach for patients with complex, multisystem sarcoidosis. Improvements were observed across functional, respiratory, neurological, and dermatologic domains, although many patients continued to experience substantial residual symptoms, reflecting the chronic and heterogeneous nature of the disease. Patient-reported outcomes revealed ongoing challenges with fatigue, pain, and overall health perception, underscoring the need for continued symptom management and supportive care. Given the small cohort size, these findings should be interpreted cautiously, and broader dose optimization studies are needed to validate the trends observed.

Home infusion providers play a critical role in facilitating access to biologic therapy, coordinating care across specialties, and capturing meaningful patient-reported data. Broader integration of standardized outcome measures within home infusion programs may enhance real-world monitoring, inform treatment optimization, and ultimately improve the lived experience of individuals managing chronic sarcoidosis.

Abbreviations: kg (kilogram); mg (milligram)

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Contact Details: timothy.walton@csipharmacy.com

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