Deepening Understanding Through Focus Groups: Exploring Quality of Life and Engagement Among Sarcoidosis Patients in FSR Peer-Led Support Groups

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Introduction

- Patients with sarcoidosis face the challenge of managing a complex, often multi-organ disease with impactful effects on their daily quality of life and uncertain disease progression.
- Building on prior qualitative findings, this qualitative follow-up study utilized focus groups to gain deeper insight into how participation in the Foundation for Sarcoidosis Research (FSR) peer-led support programs influence patients' understanding of their health, self-efficacy, and experiences with care.
- Analysis was completed by FSR in partnership with the FSR Global Sarcoidosis Clinic Alliance Patient Advisory Leadership Committee.

Methods

- In August 2024, an online survey was distributed through FSR communication channels to 532 individuals with sarcoidosis, including 88 (17%) who reported participation in FSR peer-led support groups.
- To deepen understanding of the those who participated in FSR peer-led support groups,three virtual focus groups were conducted in Spring 2025 with 10 participants of the original survey, aged 32–68 and representing varied phenotypes and disease durations.
- Transcribed discussions (nearly 37,000 words) were thematically analyzed to explore experiences before and after joining peer groups.

Meaningful benefits from engagement in FSR peer-led support groups

Substantially enhanced mental and emotional well-being	Sense of belonging and emotional safety fostered through shared experience	Exchanges within the groups strengthened participants' ability to self-advocate in clinical encounters.

Participants also noted the value of non traditional support groups (podcasts) as their ongoing support program.

Participants reported improved understanding of sarcoidosis

> **"What I was seeking were other people like me … I didn't know there were other people out there who were like me … it felt like I found a family."**

> **"She [a fellow peer group member] had figured out how to deal with it … I realized I was going to be okay."**

Participants reported improved care decision-making

> **"It [self-advocacy] went up tremendously once we could share in the group … that's when I found out how different we all are."**

> **"You have symptoms from the medication, or it's not working… You go in and tell the doctor this is this is what's happening, and you have to have a change. And so that was a big eye opener. And when I started doing that, advocating for myself."**

Novel finding

Focus group participants often did not initial attend for their own benefit, but rather to help others; however, after attending many support and resources helpful to their journey.

Conclusions

- Peer-led support enhanced emotional well-being, disease understanding, and self-advocacy among individuals with sarcoidosis.
- Participants described increased confidence in communicating with clinicians and managing treatment decisions.
- Findings emphasize the value of peer connection in improving patient engagement and quality of life. Insights will inform FSR program strategies, including enhanced peer leader training, tailored discussion content, and expanded access to supportive networks across the sarcoidosis community.

Acknowledgements and Resources

FSR Homepage | FSR Local Support Group | FSR Virtual Support Group | FSR Sarc Fighter Podcast

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