

A National Survey To Understand How Patients With Sarcoidosis Participating In Peer -Led Support Groups Engage With Their Disease & Experience Quality Of Life, Self-Efficacy, & Therapeutic Relationships

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Introduction

- Sarcoidosis is an inflammatory disease characterized by the formation of granulomas in one or more organs of the body and is estimated to impact between 150,000 and 200,000 individuals in the U.S.¹
- The Foundation for Sarcoidosis Research (FSR) is the leading international organization dedicated to finding a cure for sarcoidosis and improving care for sarcoidosis patients through research, education, and support. Since its establishment in 2000, FSR has fostered over \$7 million in sarcoidosis-specific research efforts.
- Sarcoidosis patients are faced with navigating a complex, multisystem medical condition while experiencing impaired quality of life (QOL). This study aimed to assess the impact of the Foundation for Sarcoidosis Research (FSR) peer-led support program on patients with sarcoidosis.
- The study focused on measuring various aspects of sarcoidosis patients' health understanding and comparing results for those participating in the peer-led support program with the broader cohort.

Methods

- The study utilized the Health Literacy Instrument for Adults validated survey, as well as FSR generated questions on demographics and sarcoidosis-specific disease understanding.
- The online survey was distributed in August 2024 through FSR's community communication channels to approximately 50,000 individuals affected by sarcoidosis. Patients who had attended support groups led by FSR-trained peers were self-identified.
- Metrics included assessments for disease understanding, behaviors, QOL, self-efficacy and therapeutic relationship. Descriptive statistics and confidence intervals were generated for various domains and subdomains between patients who attended a peer led support group versus those who had not. A Wilcoxon signed-rank test also examined responses compared to benchmark scores.

Conclusions

- FSR peer-led support groups appear to positively impact participants with sarcoidosis in a variety of domains (Figure 2). Focus groups will reveal whether answers to higher-scored outcomes correlated with peer-led group experience, or if individuals prone to scoring higher in those domains are more likely to choose to engage in a peer-led group.
- Learnings will be used to strategically expand and improve the FSR peer-led program, as well as enhance outreach to groups underrepresented in current program participants.

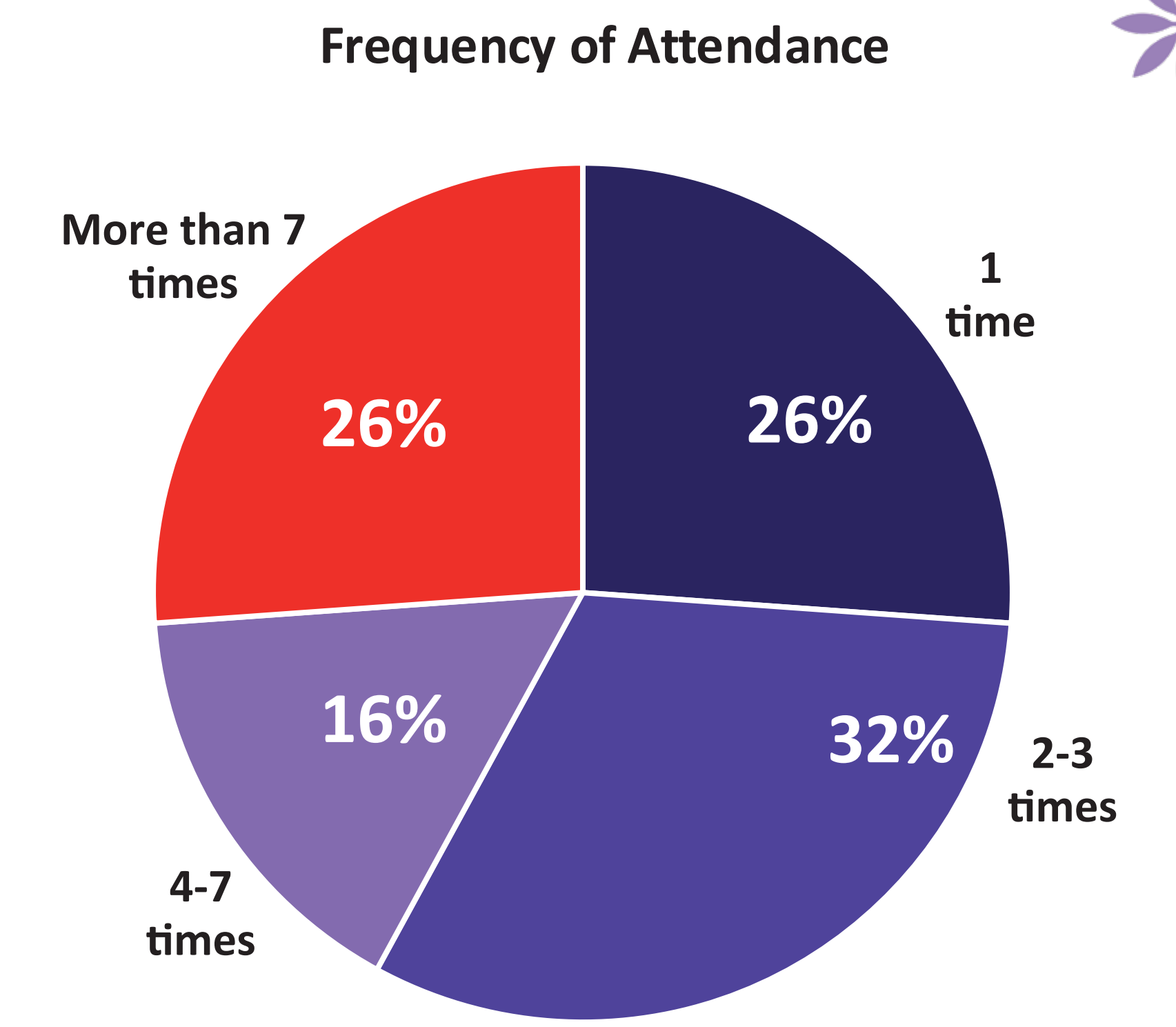
Results

Table 1: Participant Characteristics

	Peer to Peer Support Group Attendees (n=88)	Support Group Non-attendees (n=444)	Full Cohort (n=532)
Gender			
- Female	74 (84)	310 (79)	384 (72)
- Male	12 (14)	131 (30)	143 (27)
- Non-binary	2 (2)	3 (1)	5 (1)
Race/Ethnicity			
- White	58 (66)	361 (81)	419 (79)
- Black or African American	22 (25)	47 (11)	69 (13)
- Hispanic/Latino	2 (2)	7 (2)	9 (2)
- Asian, South Asian, or Pacific Islander	1 (1)	2 (1)	3 (1)
- American Indian or Alaska Native	3 (3)	7 (2)	10 (2)
- Middle Eastern	0 (0)	2 (1)	2 (1)
- Another race	2 (2)	11 (3)	13 (3)
- Multiple races	0 (0)	7 (2)	7 (2)
Education Level			
- High School Graduate or lower	3 (3)	67 (15)	70 (13)
- Associate's Degree or Trade School	24 (27)	115 (26)	139 (26)
- Bachelor's Degree	35 (40)	129 (29)	164 (31)
- Master's Degree	23 (26)	88 (20)	111 (21)
- Professional or Doctorate Degree	3 (3)	40 (9)	43 (8)
Living Area			
- Urban	20 (23)	121 (27)	141 (27)
- Suburban	49 (56)	190 (42.8)	239 (45)
- Rural	14 (16)	98 (22)	112 (21)
- Combination	5 (6)	35 (8)	40 (8)
Employment Status			
- Employed full-time	19 (22)	124 (28)	143 (27)
- Employed part-time	9 (10)	38 (9)	47 (9)
- Retired	33 (38)	171 (39)	204 (39)
- Receiving disability benefits	13 (15)	59 (13)	72 (14)
- Unemployed	7 (3)	28 (6)	35 (7)
- Student	2 (2)	3 (1)	5 (1)
Partnership Status			
- Married	59 (67)	290 (65)	349 (66)
- Divorced	12 (14)	75 (17)	87 (16)
- Single (never married)	10 (11)	36 (8)	46 (9)
- Widowed	5 (6)	31 (7)	36 (7)
- Separated	2 (2)	10 (2)	12 (2)

Those participating in the peer-led groups were more likely to be African American (25% compared to 11%) and to hold a bachelor's degree or higher (69% compared to 58%)

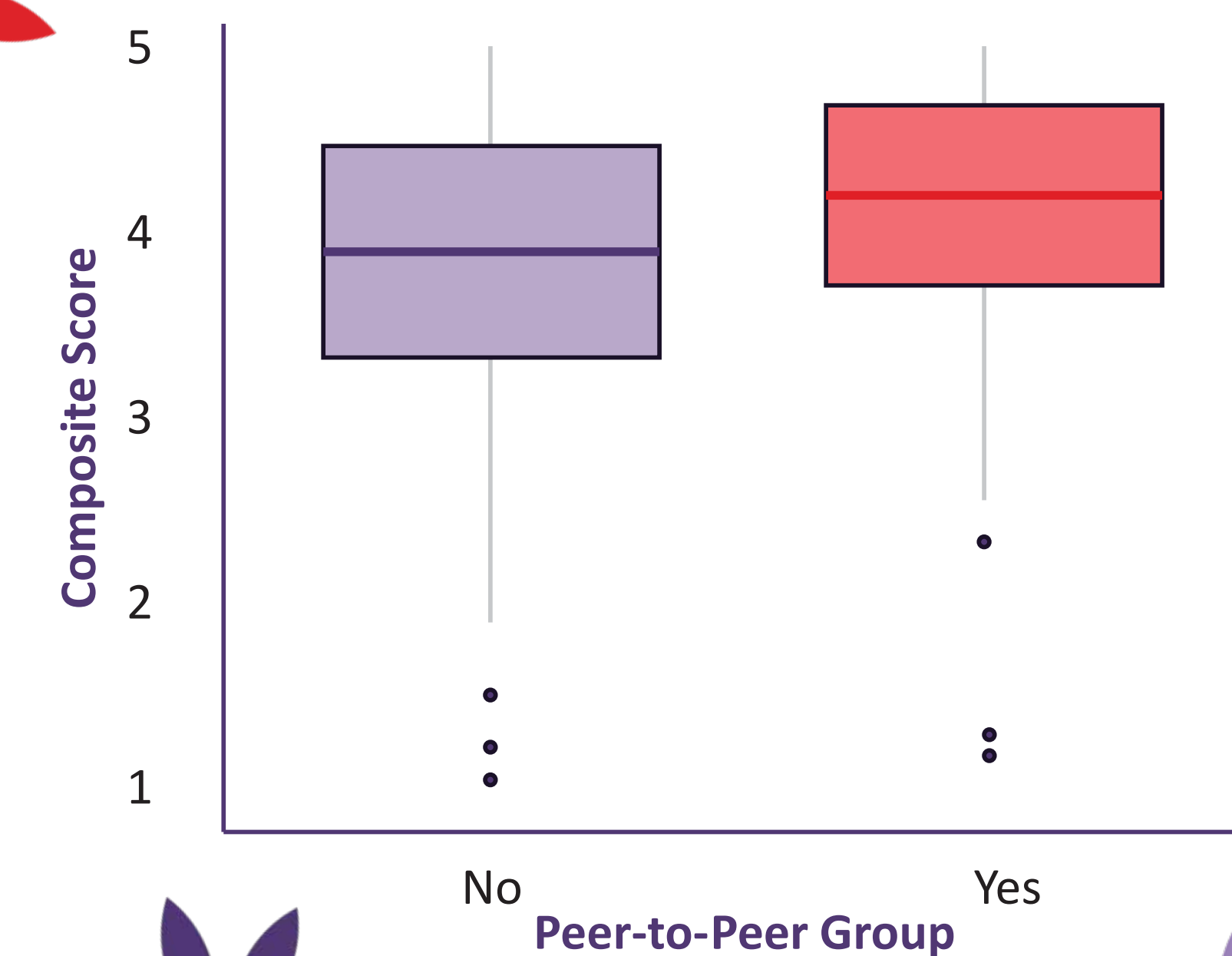
Figure 1: Support Group Attendance and Structure



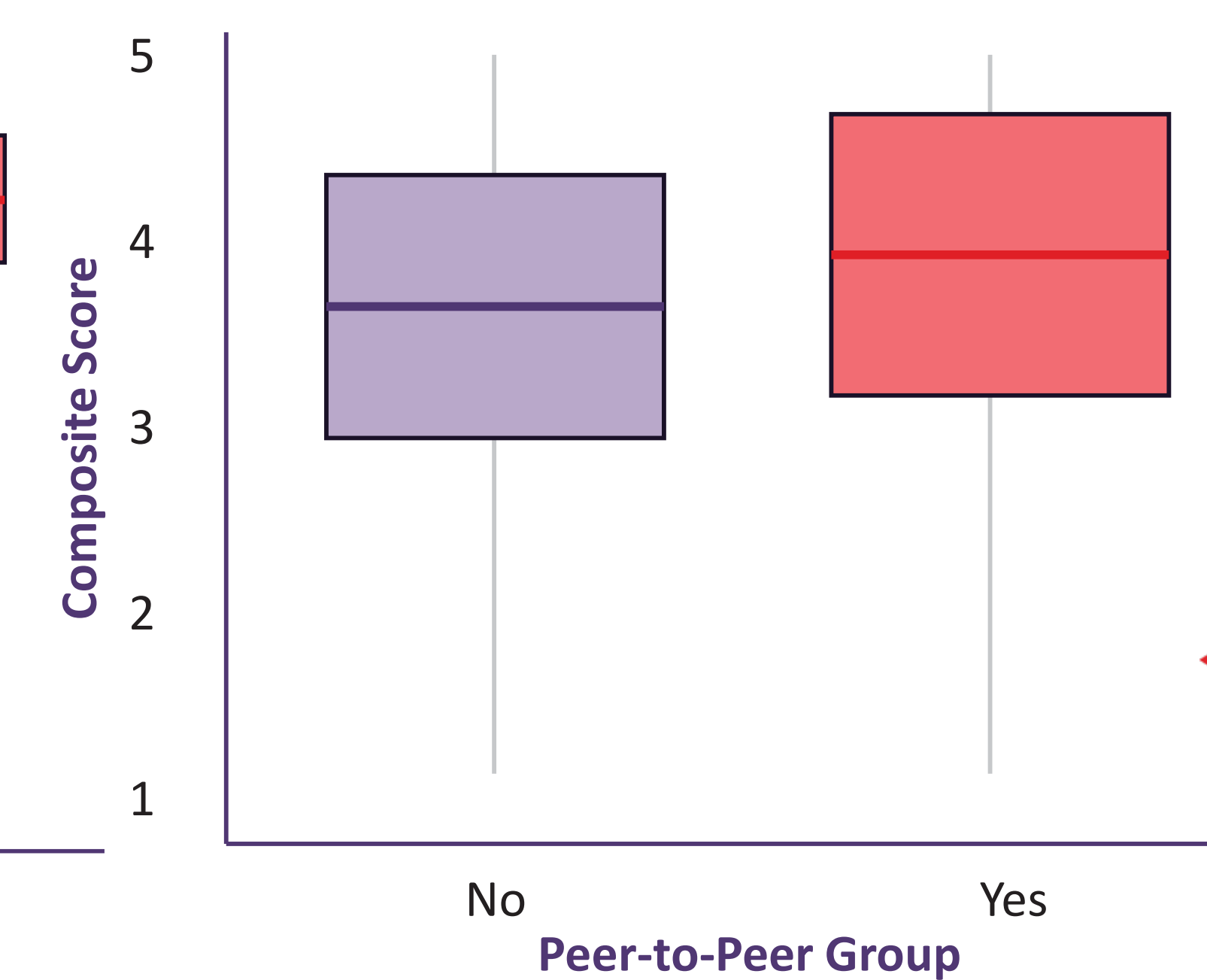
80% attended virtual support groups, with 16% reporting attending both virtual and in-person

Figure 2: A comparison of outcome domains between those participating in a peer-led group and those not participating

Sarcoidosis-Related Understanding



Therapeutic Relationship



Decision-Making/ Behavioral Intention

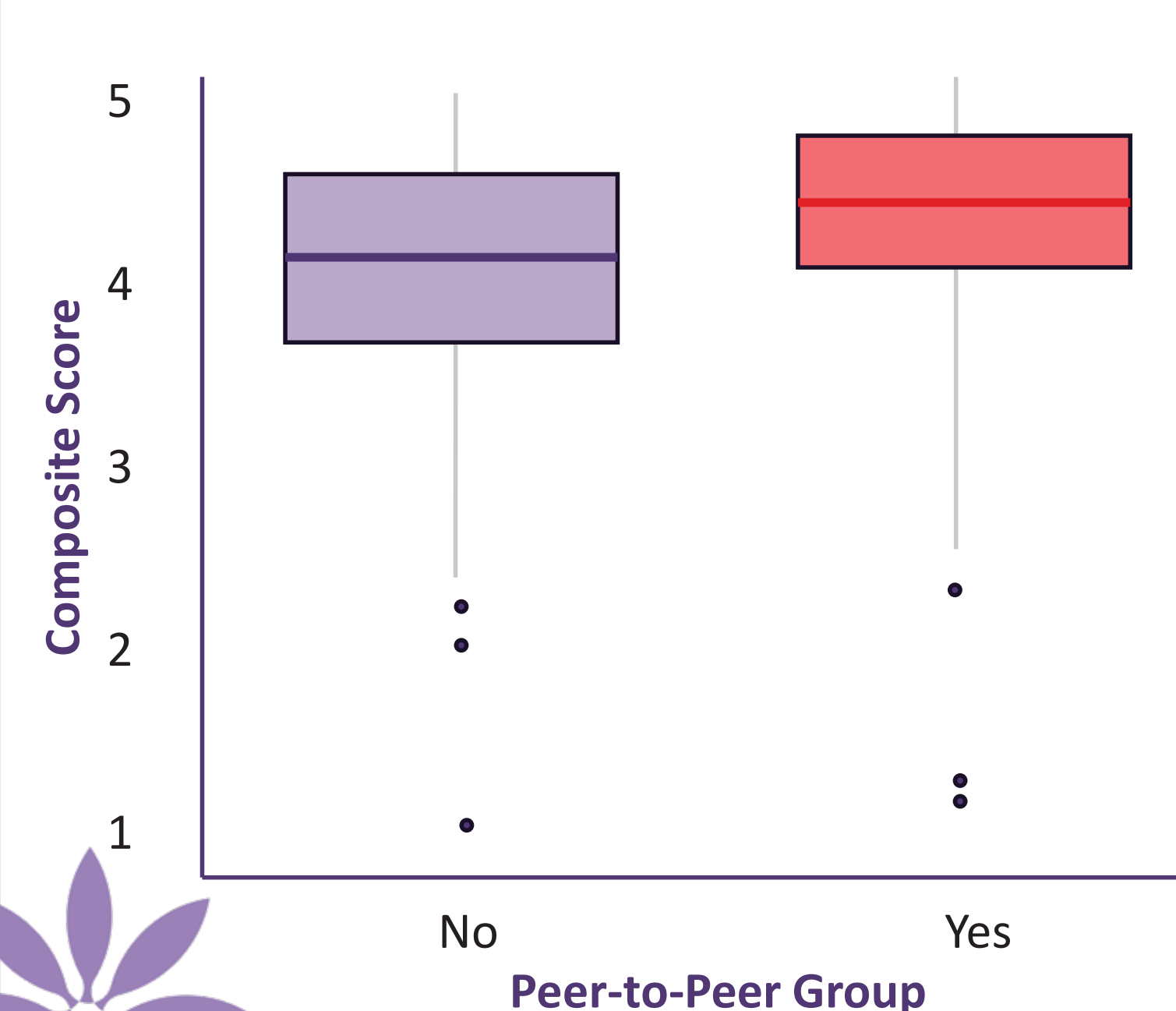


Figure 1: Support Group Attendance and Structure

Race/ Ethnicity	Domain	W	p-value	Effect Size	Magnitude	
Black or African American	Therapeutic Relationship	317.5	.010	.310	Moderate	
	General Health Status	465	.507	.081	Small	
	Self-Efficacy	453.5	.417	.098	Small	
	Access to Information	310.5	.007	.324	Moderate	
Other Races	Therapeutic Relationship	12940.5	.874	.007	Small	
	General Health Status	13433	.742	.015	Small	
	Self-Efficacy	12852.5	.881	.007	Small	
	Access to Information	11894	.229	.056	Small	
Marital Status	Domain	W	p-value	Effect Size	Magnitude	
	Not Married	Therapeutic Relationship	2098	.607	.038	Small
		General Health Status	2264	.907	.009	Small
		Self-Efficacy	2213	.941	.006	Small
Access to Information		1735	.056	.141	Small	
Married	Therapeutic Relationship	7434.5	.113	.085	Small	
	General Health Status	8285	.703	.020	Small	
	Self-Efficacy	7923	.438	.042	Small	
	Access to Information	7377.5	.094	.090	Small	
Household Income	Domain	W	p-value	Effect Size	Magnitude	
	Below \$60,000	Therapeutic Relationship	2796	.786	.020	Small
		General Health Status	3018	.655	.032	Small
		Self-Efficacy	2772	.727	.025	Small
Access to Information		2610.5	.380	.063	Small	
Above \$60,000	Therapeutic Relationship	5595.5	.028	.122	Small	
	General Health Status	6304	.302	.057	Small	
	Self-Efficacy	6227.5	.280	.060	Small	
	Access to Information	5391	.011	.141	Small	

Higher domain scores on therapeutic relationship and access to information were reported by African American support-group participants and those with higher household incomes.

P2P = Peer-to-Peer support group. Domains were assessed on a scale of 1-5 (5 being a better/more positive outcome). Those participating in peer-led groups reported statistically significant ($p < .05$) higher scores on various aspects of disease understanding (particularly reading and access to information), decision-making/behavioral intention, and therapeutic relationship.

References

1. <https://www.stopsarcoidosis.org/what-is-sarcoidosis/>

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Acknowledgements and Resources

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FSR Homepage
StopSarcoidosis.org



FSR Virtual Support Group



FSR-GSCA Community Groups