Needs of MS Patients At-Risk of Being Underserved

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Abstract

Analysis of data from the 2018 MS Needs Assessment sponsored by the Multiple Sclerosis Association of America examined the ways in which the needs experienced by people living with multiple sclerosis (MS) varied in relation to the extent to which they were at-risk of being underserved. Reflecting the growing literature on underserved populations in healthcare, demographic and geographic factors were used to create an index that classified respondents as having low, moderate, or high vulnerability to being underserved. Forty-eight questions about challenges and needs were divided into five subscales that measured needs related to accessing care, treatment decisions, treatment adherence, managing day-to-day life with MS, and psychosocial supports. ANOVA analyses found that respondents who were identified as having the highest vulnerability to being underserved reported significantly more needs across all domains than respondents with the lower levels of vulnerability. This finding highlights the importance of directing treatment and support efforts to individuals who, due to demographic or geographic factors, may be at greatest risk for being underserved.

Methods

This study utilized data from the 2018 MS Needs Assessment sponsored by the Multiple Sclerosis Association of America (MSAA) in collaboration with researchers at The College of Saint Rose and the North American Research Committee on MS (NARCOMS). Subjects included a random sample of 2,505 MSAA clients and NARCOMS members with oversampling for men and people of color. Responses were received from 630 subjects, for a 25.1% response rate. Surveys were distributed via email (NARCOMS and MSAA participants) and mail (MSAA participants). The survey included questions assessing symptoms, met and unmet needs, preferred communication methods, and healthcare management skills, and also included an opportunity for subjects to provide open-ended feedback. Data were analyzed using frequencies, measures of central tendency and dispersion, t-tests, and analysis of variance.

Vulnerability Index: Five variables were used to create an index to measure the extent to which subjects were vulnerable to being underserved. These variables included race, ethnicity, education, household income and self-reported access to care. Reflecting the literature on underserved populations in healthcare, being a person of color, being Latino, having less education and having a lower household income were identified as factors contributing to vulnerability for being underserved. Literature on underserved populations in healthcare also identifies geography, specifically residing in a rural or urban area, as an additional risk factor. To capture geographic risks, the index included subject's responses to a question that asked whether or not they were able to find the care they wanted in their community. Respondents who had missing data on any of these indicators were excluded from the analysis, dropping the sample from 630 to 516 participants. Final scores on the vulnerability index ranged from 2 to 16, with higher scores representing greater vulnerability to being underserved. Vulnerability scores were then used to create three groups: low vulnerability respondents (scores from 2 to 6), moderate vulnerability respondents (scores from 7 to 10), and high vulnerability respondents (scores from 11 to 16). The final sample included about 40% of respondents (n=207) in the moderate vulnerability group and about 30% of respondents in both the low vulnerability group (n=150) and the high vulnerability group (n=159).

Needs and Challenges Subscales: Forty-eight questions about challenges and needs were divided into five subscales: accessing care, treatment decisions, treatment adherence, managing day-to-day life with MS, and psychosocial supports.

ANOVA analyses were conducted to examine whether the number of needs respondents reported in each of these domains differed by respondents' vulnerability to being underserved in a healthcare context. ANOVA results are presented in Table 1.

Results

Need Domains

Respondents reported the number of needs they experienced in each of 5 need-domains.

Needs Related to Accessing Healthcare: 10 items such as not being able to afford medical care and finding physicians to coordinate MS care with other needed care.

Needs Related to Making Treatment Decisions: 6 items including needs related to communicating with physicians /staff and assessing the quality of information.

Needs Related to Treatment Adherence: 2 items, needs related to preparing for appointments and using MS medication correction.

Needs Related to Day-to-Day Life with MS: 21 items such as needs related to adaptive clothing and needs related to managing health paperwork.

Needs Related to Psychosocial Supports: 9 items such as connecting with others who have MS, coping with the day-to-day uncertainty of the disease, and managing everyday stress.

Figures 1-5 illustrate the average number of needs on each subscale reported by respondents at low, moderate, and high levels of vulnerability for being underserved.

Needs related to accessing health care (Figure 1) were greatest among respondents who were highly vulnerable to being underserved. There was a statistically significant difference in the number of needs related to accessing healthcare for the three vulnerability levels [F(2, 516)=12.02, p=.000] with a small to medium effect size (Eta-squared = .04). Post-hoc comparisons using the Tukey HSD test indicated that the mean score for the low vulnerability group (M=.86, SD=.97) was statistically different from the moderate (M=1.40, SD=1.45) and the high (M=1.58, SD=1.51) vulnerability groups.

Needs related to treatment decisions (Figure 2) were greatest among respondents who were most vulnerable to being underserved. There was a statistically significant difference in the number of needs related to treatment decisions for the three vulnerability levels [F(2, 488)=4.93, p=.008] with a small effect size (Eta-squared = .02). Post-hoc comparisons using the Tukey HSD test indicated that the mean score for the low vulnerability group (M=2.17, SD=1.91) was statistically different from the high vulnerability group (M=2.92, SD=2.08).

Needs related to treatment adherence (Figure 3) were greatest among the most vulnerable respondents. There was a statistically significant difference in the number of needs related to treatment adherence for the three vulnerability levels [F(2, 485)=7.67, p=.001] with a small effect size (Eta-squared = .03). Post-hoc comparisons using the Tukey HSD test indicated that the mean score for the low vulnerability group (M=.33, SD=.57) was statistically different from the high vulnerability group (M=.63, SD=.71).

Needs related to day-to-day life with MS (Figure 4) were also greatest among the most vulnerable respondents. There was a statistically significant difference in the number of needs for the three vulnerability levels [F(2, 495)=12.08, p=.000] with an effect size approaching medium (Eta-squared = .05). Post-hoc comparisons using the Tukey HSD test indicated significant differences in the mean score for all three groups: low vulnerability group (M=5.80, SD=4.32); moderate vulnerability group (M=7.24, SD=4.64); high vulnerability group (M=8.47, SD=4.97) vulnerability groups.

Needs related to psychosocial support (Figure 5) were greatest among respondents who were highly vulnerable to being underserved. There was a statistically significant difference in the number of needs related to psychosocial support for the three vulnerability levels [F(2, 482)=12.12, p=.000] with an effect size approaching medium (Eta-squared = .05). Post-hoc comparisons using the Tukey HSD test indicated significant differences in the mean score for all three groups: low vulnerability group (M=3.55, SD=2.75); moderate vulnerability group (M=4.32, SD=2.82); high vulnerability group (M=5.15, SD=2.63).

Table 1. ANOVA Results, Needs by Vulnerability to Being Underserved

Need Domain	n	df	F	p
Accessing Healthcare	516	2	12.02	.000
Making Treatment Decisions	488	2	4.93	.008
Treatment Adherence	485	2	7.67	.001
Day-to-Day Life with MS	495	2	12.08	.000
Psychosocial Supports	482	2	12.12	.000

Figure 1.

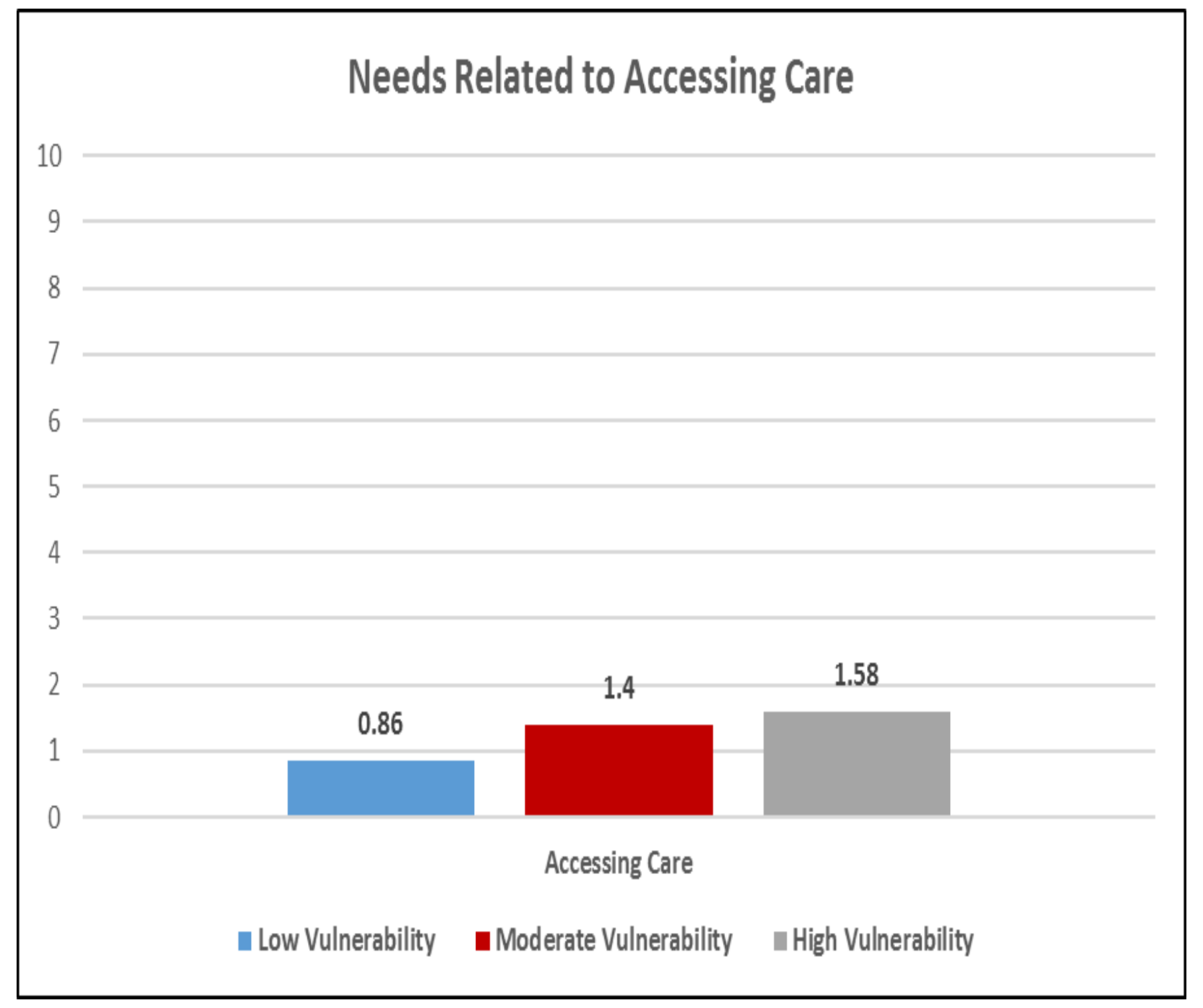


Figure 2.

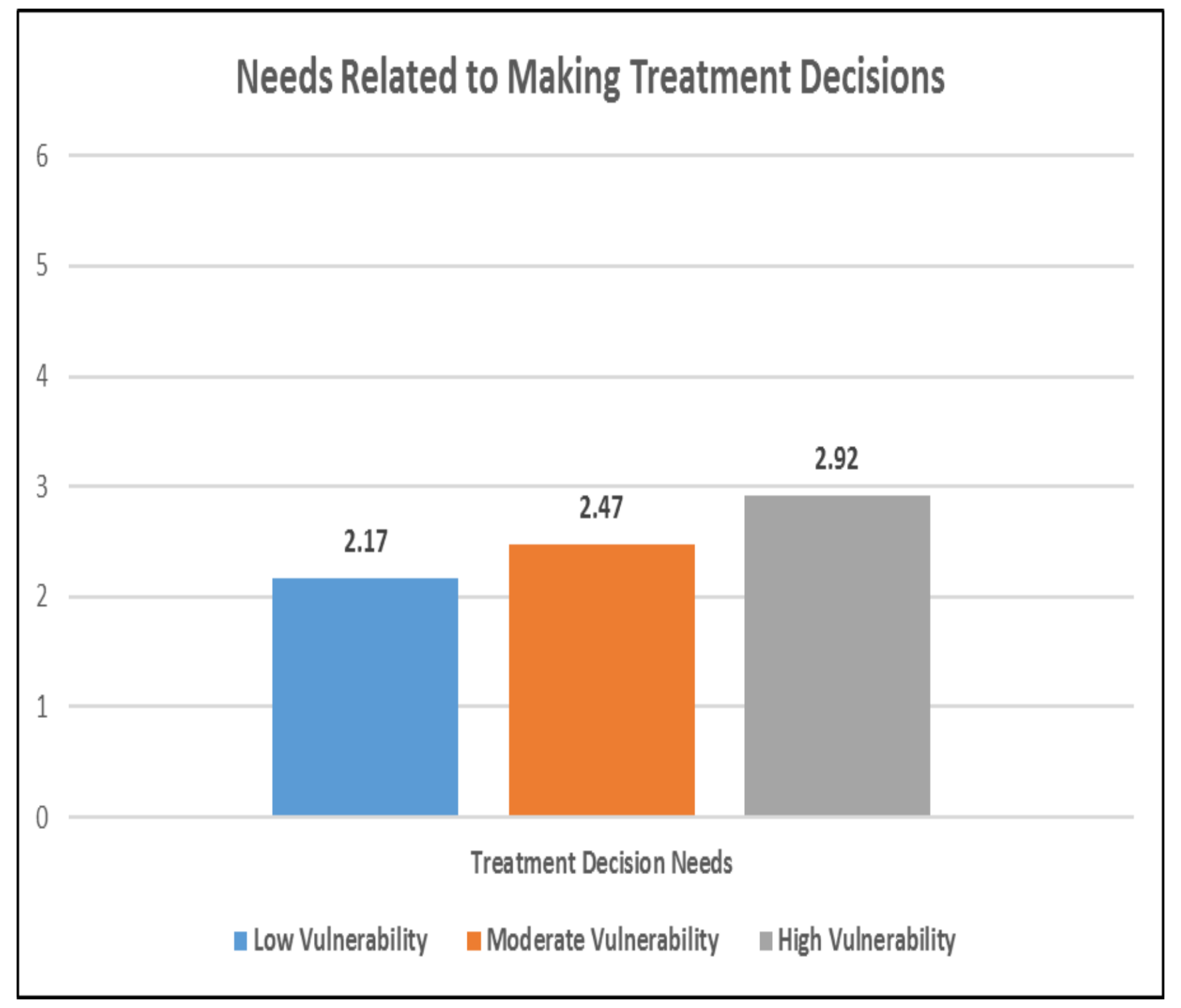


Figure 3.

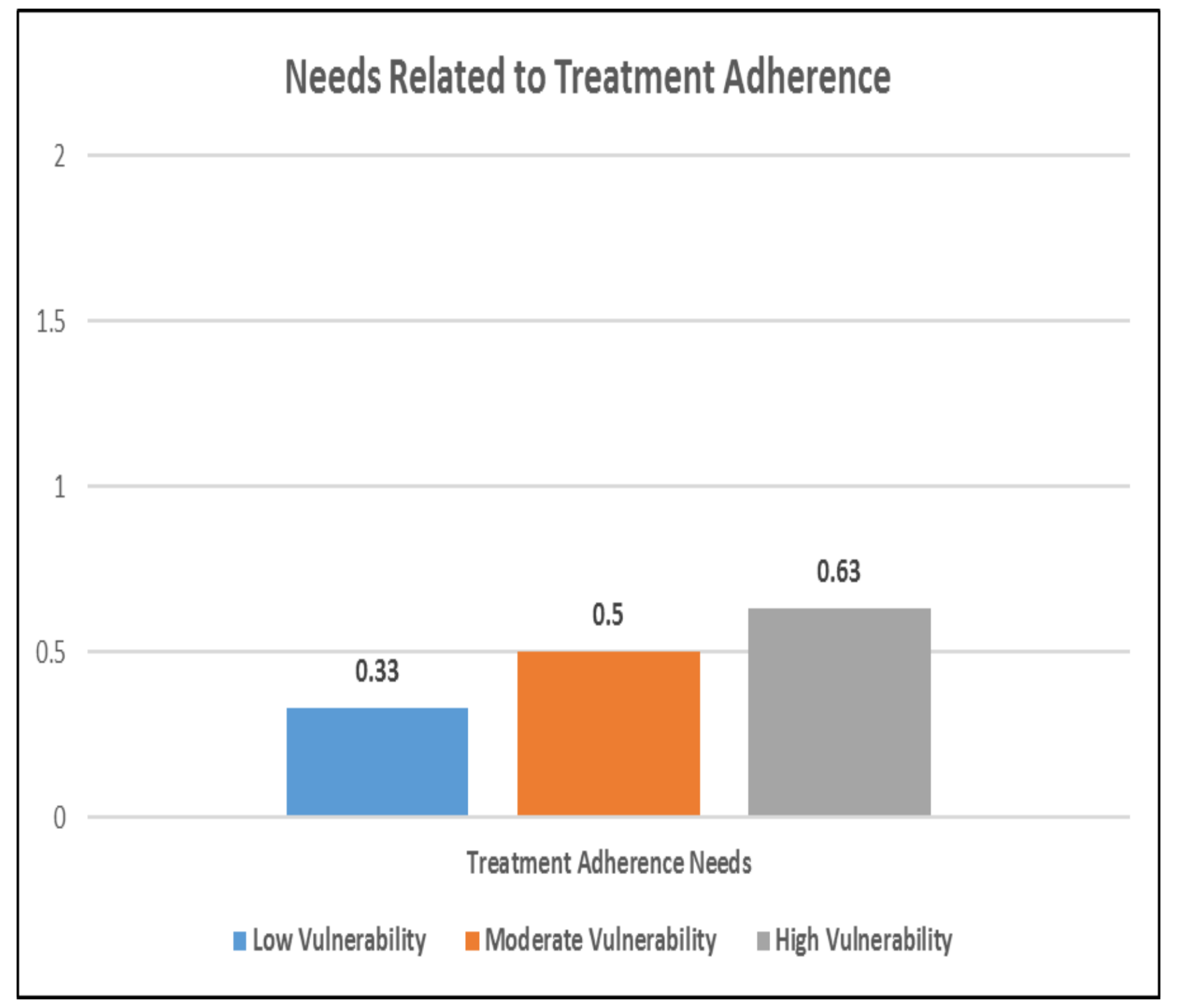


Figure 4.

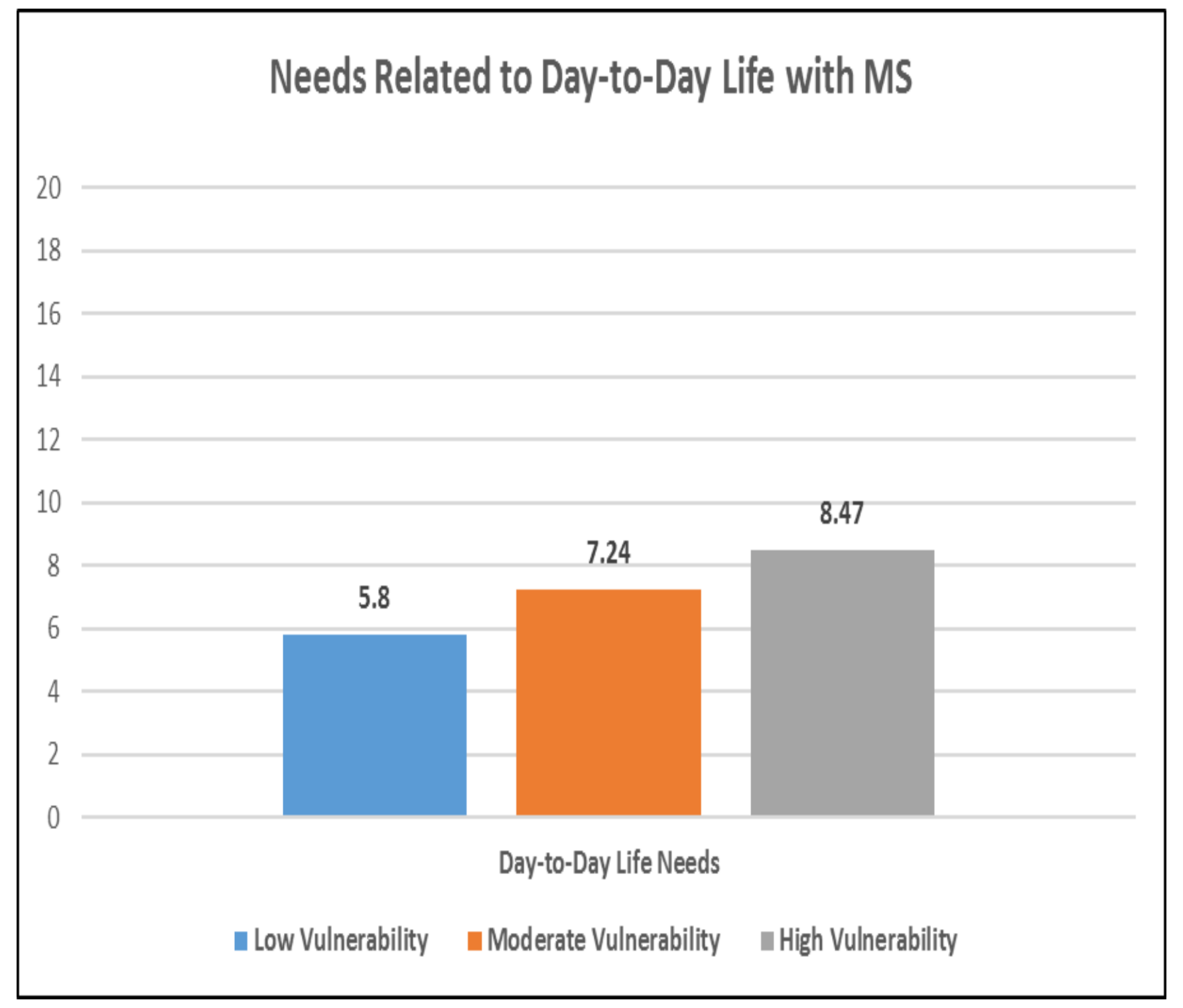
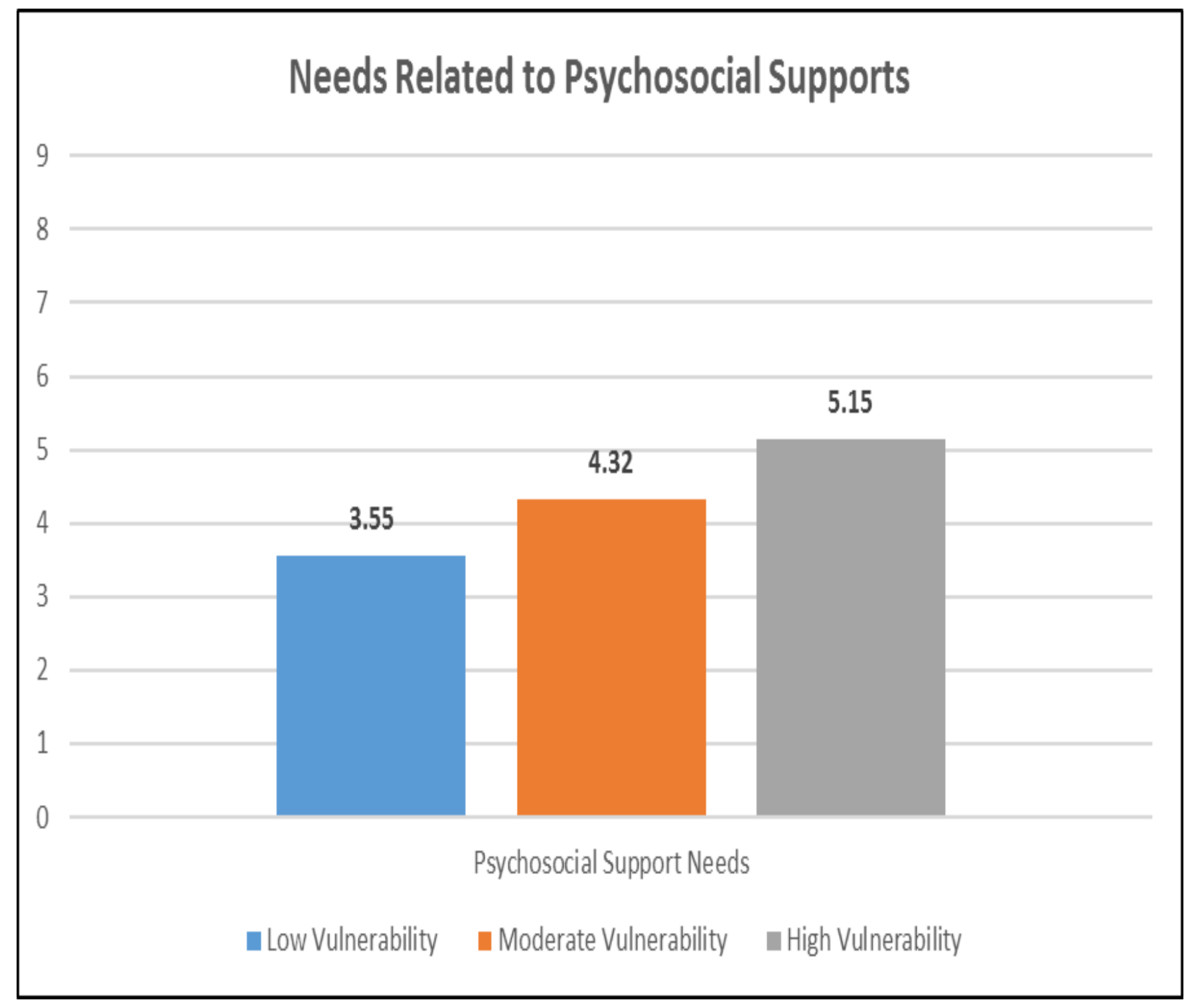


Figure 5.



Implications

Findings from this study highlight how the needs of MS patients differ depending upon their vulnerability to being underserved by the healthcare system. The most vulnerable respondents consistently reported the greatest number of needs while those least vulnerable to being underserved reported the fewest needs. This pattern was consistent across all need domains examined: accessing care, treatment decisions, treatment adherence, managing day-to-day life with MS, and psychosocial support.

These findings suggest the importance of outreach efforts to identify people living with MS who are at the greatest risk of being underserved by the healthcare system. Once identified, vulnerable individuals would benefit from case management or navigation services, education and support. While such an undertaking would present multiple challenges, it would enable a high-needs group to access care, make better treatment decisions, improve their treatment adherence, and have more skills managing both the day-to-day and psychosocial aspects of the disease.

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