Abstract: P1445

Title: THE IMPACT OF ILLNESS PERCEPTION AND STIGMA ON PATIENT-REPORTED OUTCOMES IN SICKLE CELL DISEASE

Abstract Type: Poster Presentation

Session Title: Sickle cell disease

Background:

Stigma and illness perceptions surrounding adolescents and young adults (AYA) with sickle cell disease (SCD) are not well-studied. The psycho-social and emotional factors may have implications on overall patient-reported outcomes, including health-related quality of life (HRQOL) and adherence behavior.

Aims:

(1) Evaluate the impact of patients' perceptions of SCD and their medications on HRQOL and adherence **(2)** Examine the relationship of illness perception and stigma among AYA with SCD

Methods:

In this year-long, single-institution study, participants were enrolled from outpatient hematology clinics. Patients age range was between 10 to 25 years old, English-speaking, and taking hydroxyurea, voxelotor and/or crizanlizumab for SCD treatment. Participants completed the Brief-Illness Perception Questionnaire (B-IPQ), Patient Reported Outcomes Measurement Information System (PROMIS) HRQOL Domains, Measure of Sickle Cell Stigma Questionnaire (MoSCS), and Adherence to Refills and Medications Scale 7 (ARMS-7) every 3 months. Patient statistics were evaluated utilizing Wilcoxon rank-sum tests, spearmen rho correlations (*r*s), and chi-square analysis. The data presented in this abstract represent baseline analysis for study participants

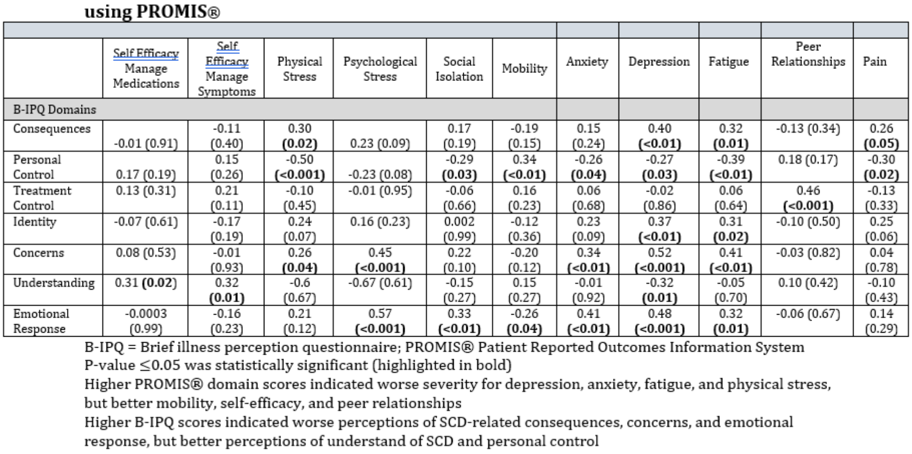
Results:

Sixty-one participants completed study assessments (93% Black; 52% Female) with a median age of 14 years old (IQR 12-18) and 77% HbbSS, homozygous hemoglobin S. Older participants (18+) reported better perceptions of understanding of SCD (10 vs 8, p = 0.02) but worse emotional response to SCD (6 vs 3, p =0.03) compared to younger participants (10-17 years). Patients with higher self-reported medication adherence using ARMS-7, perceived less SCD-related consequences (4 vs 0, p=0.03) and symptoms (4 vs 2, p=0.01), and had better treatment control (10 vs 8, p=0.03). In Table 1, patients with less perceived personal control of SCD and more emotional response to SCD reported worse social isolation (r_s= -0.29, p=0.03; r_s=0.33, p<0.01), mobility ($r_{s=}$0.34, p<0.01; r_s= -0.26, p=0.04), anxiety (r_s= -0.26, p=0.04; r_s=0.41, p<0.01), depression (r_s= -0.27, p=0.03l; r_s=0.48, p<0.001), and fatigue (r_s= -0.39, p<0.01; r_s=0.32, p=0.01), respectively. Further, more perceived personal control was associated with less physical stress (r_s= -0.50, p<0.001), pain (r_s= -0.30, p=0.02), and greater mobility (r_s=0.34, p <0.01). Participants with more negative perceptions of SCD-consequences and concerns reported more physical stress (r_s=0.30, p=0.02; r_s=0.26, p=0.04), depression (r_s=0.40, p<0.01; r_s=0.52, p<0.001), and fatigue (r_s=0.32, p=0.01; r_s=0.41, p<0.01) (Table 1). Most patients (80%) endorsed ≥1 statement related to stigma and those who reported greater stigma had more perceived SCD-related consequences (p=0.03), concerns (p=0.02) and emotional response (p=0.04).

Summary/Conclusion:

The multifaceted relationship between medication adherence, illness perception and stigma related to HRQOL in adolescents and young adults relies upon patients' perceived control over their illness. Future evaluation of influential factors involving patients' perceived control are needed to improve SCD-clinical outcomes.

Table 1: Patients' perceptions of SCD and medication in relation to their HRQOL using PROMIS®



	Self Efficacy Manage Medications	Self Efficacy Manage Symptoms	Physical Stress	Psychological Stress	Social Isolation	Mobility	Anxiety	Depression	Fatigue	Peer Relationships	Pain
B-IPQ Domains											
Consequences	-0.01 (0.91)	-0.11 (0.40)	0.30 **(0.02)**	0.23 (0.09)	0.17 (0.19)	-0.19 (0.15)	0.15 (0.24)	0.40 **(<0.01)**	0.32 **(0.01)**	-0.13 (0.34)	0.26 **(0.05)**
Personal Control	0.17 (0.19)	0.15 (0.26)	-0.50 **(<0.001)**	-0.23 (0.08)	-0.29 **(0.03)**	0.34 **(<0.01)**	-0.26 **(0.04)**	-0.27 **(0.03)**	-0.39 **(<0.01)**	0.18 (0.17)	-0.30 **(0.02)**
Treatment Control	0.13 (0.31)	0.21 (0.11)	-0.10 (0.45)	-0.01 (0.95)	-0.06 (0.66)	0.16 (0.23)	0.06 (0.68)	-0.02 (0.86)	0.06 (0.64)	0.46 **(<0.001)**	-0.13 (0.33)
Identity	-0.07 (0.61)	-0.17 (0.19)	0.24 (0.07)	0.16 (0.23)	0.002 (0.99)	-0.12 (0.36)	0.23 (0.09)	0.37 **(<0.01)**	0.31 **(0.02)**	-0.10 (0.50)	0.25 (0.06)
Concerns	0.08 (0.53)	-0.01 (0.93)	0.26 **(0.04)**	0.45 **(<0.001)**	0.22 (0.10)	-0.20 (0.12)	0.34 **(<0.01)**	0.52 **(<0.001)**	0.41 **(<0.01)**	-0.03 (0.82)	0.04 (0.78)
Understanding	0.31 **(0.02)**	0.32 **(0.01)**	-0.6 (0.67)	-0.67 (0.61)	-0.15 (0.27)	0.15 (0.27)	-0.01 (0.92)	-0.32 **(0.01)**	-0.05 (0.70)	0.10 (0.42)	-0.10 (0.43)
Emotional Response	-0.0003 (0.99)	-0.16 (0.23)	0.21 (0.12)	0.57 **(<0.001)**	0.33 **(<0.01)**	-0.26 **(0.04)**	0.41 **(<0.01)**	0.48 **(<0.001)**	0.32 **(0.01)**	-0.06 (0.67)	0.14 (0.29)

B-IPQ = Brief illness perception questionnaire; PROMIS® Patient Reported Outcomes Information System
P-value ≤0.05 was statistically significant (highlighted in bold)
Higher PROMIS® domain scores indicated worse severity for depression, anxiety, fatigue, and physical stress, but better mobility, self-efficacy, and peer relationships
Higher B-IPQ scores indicated worse perceptions of SCD-related consequences, concerns, and emotional response, but better perceptions of understand of SCD and personal control

Keywords: Quality of life, Patient reported outcomes, Sickle cell disease