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POSTER ABSTRACTS

904.OUTCOMES RESEARCH-NON-MALIGNANT CONDITIONS

Association of Health-Related Quality of Life and Work Productivity with Clinical Characteristics in Adults with Sickle Cell Disease

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Introduction: Adults with sickle cell disease (SCD) suffer from periodic episodes of severe acute pain, chronic pain, fatigue, acute complications, end-organ damage and early mortality. We explored clinical characteristics associated with health-related quality of life (HRQoL) and work productivity and activity impairment (WPAI) in adults with SCD.
Methods: Between January 2022 and June 2023, we recruited 87 adults aged ≥18 years with a diagnosis of SCD from four U.S. NASCC recognized SCD centers participating in the Globin Research Network for Data and Discovery (**GRNDaD)** registry. We collected data on patient socio-demographics, fatigue, chronic pain, WPAI, and HRQoL measured by EQ-5D-5L and ASCQ-Me via patient survey. Medical history checklist (MHC) score sums 9 SCD complications and treatment history. Clinical charateristis on SCD subtype and baseline hemoglobin were obtained from the medical record. Clinical characteristics and self-reported MHC, chronic pain associated with HRQoL, and WPAI scores were assessed by Student T-tests or Pearson correlation.
Results: Mean age was 38.0±13.4 (standard deviation) years, 58.6% of the sample was female, 64.3% had hemoglobin (Hb) SS disease, 73.6% reported chronic pain (experiencing pain on ≥3 days per week in the past 6 months). Mean EQ visual analogue scale (VAS) was 71.3 (lower than the U.S. 35-44 age mean of 81.8). Mean EQ index score was 0.73 (lower than the U.S. 35-44 age group population norm 0.85). Mean fatigue score was 52.1 (range 33.7-75.8) and was negatively correlated with HRQoL scores, indicating higher fatigue correlated with lower patient's self-rated health, including the EQ VAS (correlation coefficient r=-0.49, p<0.0001), EQ index score (r=-0.53, p<0.0001), and all domain of ASCQ-Me scores including pain (r=-0.52, p<0.0001), stiffness (r=-0.55, p<0.0001), sleep (r=-0.43, p<0.0001), emotion (r=-0.65, p<0.0001), and social functioning score (r=-0.64, p<0.0001). Fatigue score was correlated with pain episode frequency (r=0.29, p=<0.001, indicated more frequent pain episodes correlated with higher fatigue), and pain episode severity score (r=0.34, p=0.002). Fatigue score also correlated with overall activity impairment due to SCD (r=0.47, p<0.0001). MHC score was negatively correlated with EQ VAS (r=-0.32, p=0.003), EQ index score (r=-0.35, p=0.001), ASCQ-Me pain (r=-0.25, p=0.02), stiffness (r=-0.28, p=0.009), emotion (-0.23, p=0.03), social (r=-0.28, p=0.01), pain episode severity score (r=0.26, p=0.02) and fatigue score (r=0.35, p=0.0009). Hemoglobin was not correlated with HRQoL or fatigue scores. MHC score significantly correlated with overall activity impairment (r=0.22, p=0.04). As compared to patients who had MHC≤2, those with score>2 had significantly lower mean EQ-VAS, EQ index score, ASCQ-Me domain impacts in pain, stiffness, sleep, emotion, social funtioning, and pain episode severity, but higher fatigue score and greater absenteeism. Patients who reported chronic pain had significantly lower mean EQ VAS, EQ index score, ASCQ-Me domain impacts in pain, stiffness, sleep, emotion, social functioning, higher pain episode frequency, pain episode severity, and fatigue score, greater presenteeism score (impairment while working), overall

work productivity loss and overall activity impairment than those without chronic pain. SCD subtype was not associated with HRQoL and fatigue scores.

Conclusions: Hemoglobin and SCD subtype were not significantly associated with HRQoL and fatigue in this sample (possibly due to selection bias, where higher functioning patients were more likely to be selected for study participation). Fatigue in adults with SCD is moderately correlated with EQ-5D-5L scores, ASCQ-Me domains on pain, stiffness, sleep, emotion, and social functioning, as well as overall activity impairment, but weakly correlated with pain episode frequency and severity. MHC had weak correlation with EQ-5D-5L scores, ASCQ-Me domains on pain, stiffness, emotion, and social, and activity impairment. Individuals who had higher fatigue score, MHC score≥2, and reported chronic pain showed lower HRQoL and higher impairment of work productivity and activity. Future analyses will explore how multiplicity problems that SCD patients suffer impact HRQoL and work productivity and activity impairment in longitudinal data, which will identify the opportunity on intervention to improve patient care.

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Table 1, HRQoL, Fatigue, and WPAI Stratified by ASCQ-Me Medical History Check List Score and Chronic Pain

Variable	Total (N=87, 100%)	ASCQ-Me MHC Score		P Value[a]	Chronic Pain		P Value[a]
		Low/medium (≤2) (N=48, 55.2%)	High (>2) (N=39, 44.8%)		No (N=23, 26.4%)	Yes (N=64, 73.6%)	
EQ-5D-5L[b]							
EQ VAS	71.0 (20.4)	75.7 (17.8)	65.2 (22.1)	0.02	86.4 (12.8)	65.5 (19.8)	<0.0001
EQ index score	0.73 (0.24)	0.79 (0.21)	0.65 (0.26)	0.01	0.87 (0.18)	0.68 (0.25)	0.001
ASCQ-Me[c]							
Emotion impact	51.7 (9.5)	54.1 (8.2)	48.8 (10.2)	0.01	58.4 (8.6)	49.4 (8.7)	<0.0001
Social functioning impact	52.4 (9.3)	55.1 (9.1)	49.1 (8.5)	0.002	60.6 (8.0)	49.4 (7.8)	<0.0001
Stiffness impact	51.5 (8.1)	53.4 (7.9)	49.3 (7.7)	0.02	58.0 (6.4)	49.2 (7.3)	<0.0001
Sleep impact	50.8 (8.7)	52.8 (6.8)	48.4 (10.2)	0.02	56.5 (6.2)	48.8 (8.6)	0.0002
Pain impact	50.9 (9.2)	53.2 (8.4)	48.2 (9.4)	0.01	58.5 (6.9)	48.2 (8.3)	<0.0001
Pain episode frequency[d]	46.7 (11.1)	46.0 (10.9)	47.7 (11.5)	0.49	40.7 (11.4)	49.0 (10.3)	0.002
Pain episode severity[d]	51.0 (9.7)	49.0 (10.7)	53.4 (7.8)	0.04	45.5 (11.7)	53.1 (8.1)	<0.01
Fatigue[d]	51.9 (10.9)	48.2 (9.9)	56.5 (10.5)	0.0003	44.7 (10.3)	54.6 (10.0)	0.0001
WPAI: SHP domain[e]							
Absenteeism	15.7 (26.8)	6.2 (12.3)	27.3 (34.8)	0.047	6.2 (11.6)	21.8 (31.9)	0.06
Presenteeism (impairment while working)	33.4 (28.4)	30.0 (25.5)	38.3 (32.7)	0.45	19.1 (21.2)	42.2 (29.2)	0.03
Overall work productivity loss	38.9 (31.3)	33.8 (27.4)	46.0 (36.2)	0.31	24.0 (24.4)	47.9 (32.2)	0.04
Overall activity impairment	43.0 (29.5)	38.3 (29.9)	48.7 (28.3)	0.10	18.7 (24.0)	51.7 (26.3)	<0.0001

Abreviations: HRQoL, health-related quality of life; ASCQ-Me, Adult Sickle Cell Quality of Life Measurement Information System; MHC, Medical history checklist; EQ-5D-5L, EuroQol 5-level EQ-5D; EQ VAS, EuroQoL Visual Analogue Scale; WPAI:SHP, Work Productivity and Activity Impairment: Specific Health Problem.

[a]P values were calculated from Student T-tests. [b]Higher scores indicated better health. [c]Higher ASCQ-Me domain scores indicate better functioning. [d]Higher scores indicate wrose health. [e]Higher WPAI:SHP scores indicate greater impairment. Absenteeism scores were calculated for patients who were employed at the time of the survey (N = 31). Presenteeism and overall work productivity scores were calculated for patients who were both employed and reported working in the past 7 (N = 29). Overall activity impairment scores calculated for all patients (N = 87).

Figure 1

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