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POSTER ABSTRACTS

114.SICKLE CELL DISEASE, SICKLE CELL TRAIT AND OTHER HEMOGLOBINOPATHIES, EXCLUDING THALASSEMIAS: CLINICAL AND EPIDEMIOLOGICAL

Menopause in Sickle Cell Disease: Unchartered Territory

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Menopause is a natural part of every women's life, but it may also be a time of change leading to biopsychosocial complications. Perimenopause is the time during which the body transitions to menopause, marking the end of the reproductive years. The Society for Women's Health Research Menopause Working Group cites that signs of progression toward menopause such as menstrual irregularity may be noted in the 40s, but some women may notice changes as early as their mid-30s. Perimenopause can last several years. Perimenopausal care plays an important role in the promotion of healthy aging and quality of life. For some, symptoms of menopause can have a detrimental impact on quality of life and pose serious risks to bone, cardiovascular and genitourinary health. There is a paucity of literature in menopause and sickle cell disease (SCD). A longitudinal study in Brazil of 15 women with SCD and a multi-center study of hydroxycarbamide exposure and ovarian reserve by Pecker et al have both indicated that women with SCD may have early menopause. Our exploratory study sought to determine menopause health-literacy and describe bothersome menopausal symptoms in women with SCD.

A multi-faceted approach (one-on-one semi-structured interview, focus group, and registry analysis) was used for this single-institution exploratory study. Individuals were recruited during their routine clinic visit. Inclusion criteria included age >30 and ongoing menstruation OR prior menstruation. Exclusion criteria included pregnancy, breast-feeding, and history of stem-cell transplant. First, a mixed-methods survey was utilized. Next, a focus group was conducted to further elicit the views of patients about menopause and the role of healthcare providers in management of menopause for individuals with SCD. The focus group discussion was transcribed and then examined for recurring themes. The individual surveys and focus groups indicated a perceived exacerbation of SCD symptoms and complications as individuals became perimenopausal. To further assess this, data from the Sickle Cell Disease Implementation Consortium (SCDIC) registry from our site was analyzed to compare healthcare utilization between age-matched males and females.

A total of 17 individuals were interviewed individually with a semi-structured questionnaire during their routine clinic visit. Individuals with HbSS on hydroxyurea underwent menopause at a median age of 50 years while those on no disease modifying treatment underwent menopause at a median age of 39 years. Many patients felt uninformed about menopause. Those who felt knowledgeable about the topic received their information from their own career in healthcare, friends, family, and the internet (Table 1).

The focus group consisted of 5 female participants (3 perimenopausal and 2 post-menopausal) to elicit each individual's experiences around menopause and menopause specific care. Participants indicated worsening of SCD, hot flashes, and genitourinary complaints as their most bothersome issues with menopause. Participants reported having more frequent crises as they went through the menopause transition. Overall participants indicated that, after menopause, pain crises and hot flashes improved but genitourinary symptoms persisted. In addition, participants cited frustration over inability to address menopause related symptoms with their healthcare providers and even mentioned that providers were dismissive of their symptoms or attributed them to SCD without considering menopause transition.

Further information was gathered and analyzed from the SCDIC registry; results showed that non-pregnant women have increased numbers of admissions as they enter age group of 30-40 years (Poisson regression $e\beta$ [95% CI]: 1.4 [1.3-1.7], P <0.001), while admissions for men decrease as they enter age group of 30-40 years (Poisson regression $e\beta$ [95% CI]: 0.49

[0.36-0.68], P <0.001). For the 30-40 age group, women are more likely to have admissions compared to men (Table 2). This finding could potentially be related to premature menopause contributing to increased admissions.
While this study is limited due to the small size and exploratory nature, our preliminary work indicates that menopause is unchartered territory, and that many gaps exist in menopause health literacy and menopause related care delivery for women with SCD. Our findings highlight the need for further research on menopause in SCD.

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Table 1. Results from individual survey (age of menarche, age of menopause if applicable based on HU use, baseline knowledge of menopause, how do patients gain knowledge of menopause, bothersome symptoms)

	Age (Years, median)	Age of Menarche (Years, median)	Age of Menopause with HU use (Years, median)[b]	Age of Menopause without HU use (Years, median)	Baseline Knowledge of Menopause	From Where Patients Gain Knowledge of Menopause	Reported Bothersome Symptoms
Total Number of Patients (n=17)	44	13 (n=17)	50 (n=3)	39 (n=6)	None = 3/17 Little = 8/17 Moderate = 3/17 High = 3/17	Physician = 1/17 Friends/Family /Internet/Career = 9/17 None = 7/17	Worsening SCD = 52.9% Hot Flashes = 70.5% Night Sweats = 58.8% Genitourinary = 17.6% Mood Changes = 58.8%

[a] Median calculated by basic statistics
[b] One patient who had a history of HU use was excluded from the analysis of age of menopause because she underwent endometrial ablation which contributed to her lack of menarche. Out of the 17 total patients, 9 underwent menopause and 8 reported not having underwent menopause.

Table 2. Fischer's exact test: females are more likely to have admission(s) for 30-40 yr old group.

age group	Male (n=92)		Female (n=143)		OR_{female} (95% CI)	P-value
	#admission=0 (%)	#admission>= 1 (%)	#admission= 0 (%)	#admission>=1 (%)		
<30	32 (52.5)	29 (47.5)	35 (49.3)	36 (50.7)	1.1 (0.54-2.4)	0.73
30-40	22 (66.7)	11 (33.3)	25 (40.3)	37 (59.7)	**2.9 (1.1-8.0)**	**0.018**

Figure 1

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