



The 65th ASH Annual Meeting Abstracts

POSTER ABSTRACTS

114. SICKLE CELL DISEASE, SICKLE CELL TRAIT AND OTHER HEMOGLOBINOPATHIES, EXCLUDING THALASSEMIAS: CLINICAL AND EPIDEMIOLOGICAL**Addressing Reproductive Education Among Young Adults with Sickle Cell Disease (SCD): Sickle Cell Reproductive Outreach and Education (ROE) Project**Bria Carrithers, MD¹, Rachel Klein, MD², Julie Kanter, MD³¹Department of Internal Medicine, University of Alabama at Birmingham, Birmingham, AL²Division of Academic General Pediatrics, Division of Hematology and Oncology, University of Alabama at Birmingham, Birmingham, AL³Division of Hematology and Oncology, University of Alabama At Birmingham, Birmingham, AL

Background:

As children with sickle cell disease (SCD) survive into adulthood, it is important to address emerging reproductive health concerns. This population faces unique fertility challenges, including balancing the desire for biological parenthood, risk of pregnancy-associated complications, unintended pregnancy, and fertility concerns with the use of SCD modifying therapies (DMTs) (Smith-Whitley, Blood, 2014, Pecker, Br J Haematol, 2021). Recent research identified knowledge gaps that impact reproductive care for adults with SCD (Carrithers, Frontiers, 2023). To overcome these gaps, we need to evaluate the baseline knowledge of young adults with SCD regarding reproduction to understand the complex implications of reproductive decision-making. This study was done to gauge young adults' knowledge of reproduction, understanding of fertility, and current reproductive behaviors in order to develop educational material to support young adults' with SCD reproductive decisions.

Methods:

This IRB-approved, cross-sectional study included young adults living with SCD (ages 18-35) from University of Alabama-Birmingham's Lifespan Comprehensive SCD Center. Patients were recruited during routine clinic visits to complete an electronic 33-question survey to evaluate reproductive health topics adapted from the Sisters Informing Sisters About AIDS (SISTA) questionnaire (CDC, 2008), including demographics (age separated into younger age (18-25) and older age (26-35)), sexual health behaviors (contraception, sexually transmitted infection (STI) prevention), family planning, patient advocacy, and attitudes towards reproductive education. Responses were recorded as "Yes, No, Don't Know", unless questions specifically asked for participants to choose an option. Attitudes toward reproductive education were graded on 5-point Likert scale (1=strongly disagree to 5=strongly agree). Data analysis includes averages to evaluate subgroup comparisons and independent student's t-test to compare subgroups with statistical significance set at $p < 0.05$.

Results:

We enrolled 47 participants (55% women and 51% were of older age). In this cohort, 87% completed high school and 60% were sexually active. Among those who were sexually active, 86% had previously undergone STI testing and 36% had prior history of STI (22% men vs. 77% women, 22% younger age vs. 77% older age, $p < 0.05$). Thirty-eight percent identified personal or partner contraceptive use. Regarding children, 19% had birthed/fathered a child(ren) (55% men vs. 45% women, 22% younger age vs. 77% older age, $p > 0.005$) among whom 11% knew their child had SCD, 55% knew their child had sickle cell trait (SCT), and 33% did not know if their child had SCD/SCT. Only 26% were aware of contraceptive options for people with SCD (17% men vs. 83% women, $p < 0.05$). Importantly, 89% recognized high risk sexual activity as a risk factor for STIs but no one in the cohort recognized the risk of infertility due to STIs. When asking about their partners, 32% knew if their partner had SCD/SCT (20% men vs. 80% women, $p < 0.05$). Notably, 79% desired biologic children. Among those who desired children, 41% felt that their SCD changed their decision to have children and 26% were previously told they could not have children due to SCD (12% men vs. 88% women, 25% younger age vs. 75% older age, $p < 0.05$). Notably, 57% were interested in conceiving if pregnancy was planned (41% men vs. 59% women, 37% younger age vs. 63% older age, $p < 0.05$). When asked if patients wanted to discuss their reproductive health, 87% wanted to discuss this with their hematologist but only 51% would discuss this with PCPs.

Conclusion:

In this study, we identified evaluated 4 tenets of reproductive health knowledge: contraceptive use, STI prevention, family planning, and patient advocacy. We identified gaps in knowledge in these areas that can be addressed to improve reproductive education in young adults with SCD. Young adults with SCD in our cohort have low contraceptive use and were often not aware of contraceptive options for people with SCD or their partner's SCD/SCT status. Our cohort also reported a significant history of STI but was unaware of the associated increasing risk for infertility. Importantly, young adults are especially interested in discussing reproductive health with their hematologists, which provides an opportunity to improve reproductive education within this unique population.

Disclosures Kanter: *Watkins, Lourie, Roll&Chance:* Consultancy; *Chiesi:* Honoraria, Membership on an entity's Board of Directors or advisory committees; *Beam:* Consultancy, Honoraria; *Fulcrum:* Consultancy; *Guidepoint Global:* Consultancy; *Bausch:* Honoraria; *ECOR1:* Consultancy; *Austin Therapeutics:* Honoraria, Membership on an entity's Board of Directors or advisory committees; *Bluebird Bio:* Consultancy; *Novartis:* Consultancy, Honoraria, Membership on an entity's Board of Directors or advisory committees; *Vertex:* Consultancy, Honoraria.

Table 1. Demographic characteristics of survey participants stratified by sex and age. Survey response rate was 100%.

	All N = 47	Men N = 21	Women N = 26	Younger age N= 23	Older age N=24
Demographic characteristics, n (%)					
Completed high school	41 (87)	17 (41)	24 (59)	21 (51)	20 (49)
Sexual history characteristics, n (%)					
Sexually active	28 (60)	14 (50)	14 (50)	10 (36)	18 (64)
Prior STI testing among sexually active	24 (86)	8 (33)	16 (67)	8 (33)	16 (67)
Prior history of STI among sexually active	9 (36)	2 (22)	7 (78)	2 (22)	7 (77)
Personal/partner contraceptive use	18 (38)	7 (39)	11 (61)	7 (39)	11 (61)
Withdrawal	2 (11)	0 (0)	2 (100)	0	2 (100)
Condoms	11 (61)	10 (91)	1 (9)	6 (55)	5 (45)
Oral contraceptive pills	3 (16)	0 (0)	3 (100)	2 (67)	1 (33)
Depo-provera	6 (33)	2 (33)	4 (67)	3 (50)	3 (50)
Intrauterine device (IUD)*	1 (5)	0 (0)	1 (100)	0 (0)	1 (100)
Not using contraception	21 (51)	9 (43)	12 (57)	9 (43)	12 (57)
Fertility-related characteristics					
Given birth/fathered a child(ren)	9 (19)	5 (55)	4 (45)	2 (22)	7 (77)
Knew child(ren)'s SCD status	1 (11)	0 (0)	1 (100)	0 (0)	1 (100)
Knew child(ren)'s SCT status	5 (55)	2 (40)	3 (60)	0 (0)	5 (100)
Trying to conceive	3 (6)	1 (33)	2 (67)	1 (33)	2 (67)
Discussed family planning with PCP	23 (49)	9 (39)	14 (61)	9 (39)	14 (61)
Discussed family planning with hematologist	15 (32)	5 (33)	10 (67)	5 (33)	10 (67)

*Indicates one participant used two forms of contraception

Table 2. Survey questionnaire responses among reproductive health topics stratified by sex, age, and sexual activity subgroupings. Survey response rate was 100%.

Survey Topic	All N = 47	Men N = 21	Women N = 26	Younger age N= 23	Older age N=24	Sexually Active N=28	Non- Sexually Active N=19
Contraceptive use, n (%)							
Knew a safe contraceptive option for people with SCD	12 (26)	2 (17)	10 (83)	4 (25)	8 (75)	6 (50)	6 (50)
Discuss contraceptive use with partner	39 (83)	18 (46)	21 (54)	16 (41)	23 (59)	27 (69)	12 (39)
Discuss contraceptive options with PCP	35 (75)	14 (40)	21 (60)	16 (46)	19 (54)	25 (71)	10 (29)
Discuss contraceptive options with hematologist	34 (72)	14 (41)	20 (58)	18 (53)	16 (47)	24 (71)	10 (29)
STI Prevention, n (%)							
Recognizes high-risk sexual activity is a risk factor for STIs	42 (89)	19 (45)	23 (55)	20 (48)	22 (52)	28 (67)	14 (33)
Recognizes individuals with prior STIs may be infertile	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Knew safest option to prevent STIs	43 (92)	19 (44)	24 (56)	17 (40)	26 (60)	26 (60)	17 (40)
Recognizes need for STI testing if exposed via sexual activity	43 (92)	19 (44)	24 (56)	21 (49)	22 (51)	26 (60)	17 (40)
Family Planning, n (%)							
Knew if partner had SCD/SCT	15 (32)	3 (20)	12 (80)	8 (53)	7 (46)	8 (53)	7 (46)
Desired child(ren)	37 (79)	17 (46)	20 (54)	16 (43)	57 (21)	23 (62)	14 (38)
SCD diagnosis changed decision about having child(ren)	22 (47)	12 (55)	10 (45)	10 (45)	12 (55)	13 (59)	9 (41)
Told no child(ren) due to SCD diagnosis	12 (26)	2 (12)	10 (12)	3 (25)	9 (75)	6 (50)	6 (50)
Interested in planned pregnancies	27 (57)	11 (41)	16 (27)	10 (37)	17 (63)	19 (70)	8 (30)
Patient Advocacy, n (%)							
Discuss reproductive health with hematologist	41 (87)	17 (41)	24 (59)	20 (49)	21 (51)	25 (61)	16 (41)
PCP referral if identified reproductive health concern (i.e. painful menses, priapism)	26 (55)	7 (27)	19 (73)	14 (54)	12 (46)	15 (58)	11 (42)
Discuss reproductive health plan with PCP during routine visits	24 (51)	5 (21)	19 (79)	12 (50)	12 (50)	13 (54)	11 (46)

Figure 1

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