

Provider Views on Sexual and Reproductive Health for Adolescent and Young Adult Women with Sick Cell Disease

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Abstract

Background/Objectives With dramatic improvements in life expectancy, adolescents and young adults (AYA) with sickle cell disease (SCD) increasingly face sexual and reproductive health (SRH) concerns. Despite the high risk of maternal-fetal morbidity and mortality, over half of women with SCD experience pregnancy by age 21, indicating a gap in SRH care. This study examined SCD providers' practices and attitudes related to SRH, particularly with regards to contraception. **Design/Methods** We distributed an adapted web-based survey to a national sample of SCD providers to identify their attitudes and practices in addressing SRH with their female patients. We analyzed results using descriptive statistics, independent sample t-tests, Chi-squared and Fishers exact tests. **Results** Ninety-two SCD providers completed the survey (84% pediatric and 13% adult providers). All respondents rated SRH discussions as moderately important or higher, with the majority (85%) agreeing this care should be standardized. Most respondents (76%) reported discussion of SRH, such as menses, pregnancy, and contraception, with their female patients with SCD at least annually. Although most providers refer SCD patients for birth control (87%), 37% favored the use of hormonal intrauterine devices in this population and 37% the use of injectable contraception among respondents who endorsed a preferred method. Approximately half of respondents (52%) felt the use of combined hormonal contraceptives (CHC) was unacceptable. **Conclusion** SCD providers consider SRH important for their female patients and largely believe these conversations should be standardized in their clinics. However, the range of conversations and contraceptive recommendations from SCD providers is broad, suggesting that this care can be improved.

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Abbreviations Key:

ASPHO	American Society of Pediatric Hematology/Oncology
AYA	Adolescents and Young Adults
CDC	Centers for Disease Control and Prevention
CHC	Combined Hormonal Contraception
DMPA	Depo-medroxyprogesterone acetate
Heme/onc	Hematology/Oncology
IUD	Intrauterine device
MEC	Medical Eligibility Criteria
OCP	Oral Contraceptive Pill
REDCap	Research Electronic Data Capture
SCD	Sickle Cell Disease
SRH	Sexual and Reproductive Health
WHO	World Health Organization

ABSTRACT

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With dramatic improvements in life expectancy, adolescents and young adults (AYA) with sickle cell disease (SCD) increasingly face sexual and reproductive health (SRH) concerns. Despite the high risk of maternal-fetal morbidity and mortality, over half of women with SCD experience pregnancy by age 21, indicating a gap in SRH care. This study examined SCD providers' practices and attitudes related to SRH, particularly with regards to contraception.

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Conclusion

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INTRODUCTION
Adolescent and young adults (AYA) with sickle cell disease (SCD) have shown an increase in average life expectancy with continued advancements in therapy and management.¹ A vast majority of patients with SCD live to adulthood, and many AYA with SCD have expectations for their sexual and reproductive health (SRH) that are similar to their healthy peers.^{2,3} Unfortunately, AYA women in the United States ages 15-24 years of age experience the highest rates of sexually transmitted infections and unintended pregnancy.⁴⁻⁷ Unintended pregnancy rates are particularly high in AYA with SCD, with up to 56% of women with SCD having at least one pregnancy by age 21.⁸⁻¹⁰ Pregnancy in SCD, whether planned or unplanned, bears a high risk of maternal and fetal morbidity and mortality.¹¹ Thrombogenicity during pregnancy and iatrogenic pregnancy complications from medications prescribed for SCD are an additional unique concern for AYA women with SCD that require well-timed and managed pregnancies, including the use of contraception pre- and post-pregnancy.¹²

Providers of SCD often face challenges in advising patients about many aspects of SRH and family planning, but in particular about contraception. Hematologists must weigh the risk of unintended pregnancy with the risks of contraception. Oral contraceptive pills (OCPs) are the most commonly used hormonal method in sexually-active AYA in the US.¹³ Guidance for estrogen-containing combined hormonal contraceptives (CHC) use in SCD by the Centers for Disease Control and Prevention (CDC) and the World Health Organization (WHO) in the medical eligibility criteria (MEC) for contraceptive use indicates “advantages generally outweigh theoretical or proven risks,” and many women with SCD report prior use of CHC.^{11,14} However, theoretical risk may lead providers to advise *against* CHC use because of the increased separate risk of thrombotic events both in SCD and from estrogen.^{9,15,16} There is some data that depo-medroxyprogesterone acetate (DMPA, injectable contraception) has potential benefits for women with SCD, including reduced sickling and pain crises.¹⁷ However, loss of bone density with prolonged use is a concern for a population who may already be a risk for osteopenia.¹⁸ These examples demonstrate the complexity of prescribing contraception within this chronic disease population.

Therefore, education on family planning and SRH becomes an essential part of healthcare delivery for patients with SCD.^{3,12,19} Frequent clinic visits with SCD providers often lead to AYA with SCD to identify their subspecialist as their “main physician”.^{20,21} In this scenario, SRH counseling may occur due to SCD providers’ experience and training, the frequency of clinic visits, and potential lack of primary care providers (PCPs) within the population.²¹ SRH concerns such as menstruation, planning for pregnancy, contraceptive choice, and teratogenic medication use may require specific knowledge from the SCD provider. However, SCD providers’ views, attitudes, practices and consensus around SRH have not been well-studied.

This study evaluates SCD providers’ attitudes, preferences and practices regarding SRH for AYA women with SCD. We hypothesized that they recognize the importance of SRH discussions, but report infrequently discussing SRH. We also hypothesized that providers feel uncomfortable with prescription of CHC in SCD, but accept CHCs if alternative options are not available or preferred. Understanding barriers and preferences of providers of SCD can help inform future studies and interventions for education and healthcare provision to improve this aspect of care for AYA women with SCD.

METHODS

We distributed a survey to SCD providers, including physicians (MDs, DOs) and advanced practice providers, investigating their attitudes and practices regarding SRH in SCD. The survey was adapted from a study for providers of women with cystic fibrosis and piloted among hematologist colleagues.²² The survey included

three sections: importance and priority of SRH topics for this population, practices around SRH discussions, attitudes toward SRH care provision, attitudes towards menstrual suppression and contraceptive use, barriers and facilitators to SRH care in the population, and demographic information, including Likert-style and multiple-choice questions (Appendix 1).

We distributed the survey via electronic mail to the 231 members of the hemoglobinopathy special interest group listserv of the American Society of Pediatric Hematology and Oncology (ASPHO) in May of 2019. An additional distribution was sent via electronic mail to 121 program directors of adult hematology and oncology fellowship programs with the request to pass to colleagues in February and April of 2020. This study was approved by Indiana University School of Medicine's institutional review board #1906487088.

Research Electronic Data Capture (REDCap) tools hosted at the Indiana Clinical and Translational Sciences Institute were used to collect and manage study data.²³ REDCap is a secure, web-based application designed to support data capture for research studies, providing 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources.

For this paper we focused specifically on providers' attitudes and practices about SRH topics. Descriptive statistics were used to measure respondent demographics, characteristics, attitudes, and practices towards SRH in AYA with SCD. Responses for recommended contraception, acceptability of CHC as well as other methods, were compared in adult versus pediatric providers using Chi-squared, Fisher exact tests and independent sample t-tests. For this analysis, retired and combined program directors (n=2) were not included. Likert-scale ratings were measured from 1 (not at all important) to 5 (very important). Mann-Whitney tests were used to compare ordinal data between groups of pediatricians and adult providers. Missing data was excluded from analysis and ranged from 0 to 3 for various survey items. All analyses were conducted using IBM SPSS version 26.

RESULTS

Demographics

A total of 92 providers completed the survey. The response rate for ASPHO members was estimated at 33% (77/231) based on currently available membership numbers. The majority of participants were pediatric providers (84%); 13% were adult providers and 1 participant was combined medicine-pediatrics provider (Table 1). Over 4% (n=4) reported they were adult SCD program directors, 19% (n=18) reported they were pediatric SCD program directors, 1.1% (n=1) reported being a combined pediatric and adult SCD program director and 2 did not respond.

Attitudes toward SRH discussions with female patients with SCD

Over 84% of respondents (n=78) reported that SRH should be standardized for SCD patients in U.S. care centers; there was no significant difference between pediatric and adult providers. No respondents rated the importance of SRH discussions as unimportant, 4.3% (n=4) rated them as neutral, and 96% (n=88) of respondents rated the importance of SRH discussions as somewhat or very important for AYA women with SCD. Nearly half of respondents (46%, n=41) believe the SCD care provider/team should have the primary role in discussing SRH with AYA with SCD; 24% (n=21) responded that the primary care provider had this responsibility, 17% (n=15) responded adolescent medicine, 12% (n=11) responded obstetrician/gynecologist, 1.1% (n=1) reported "it depends." There was no significant difference between pediatricians and adult providers in those that thought the SCD team had primary responsibility versus other providers.

Regarding the ideal age to discuss SRH topics with women with SCD, 1 respondent reported that SRH topics should not be discussed, 34% (n=33) reported under age 13 years, 52% (n=48) between age 14 and 16 years, and 5.4% (n=5) between age 16 and 18 years. No respondents reported discussions should occur after age 18 years.

Nearly two-thirds of respondents (61%, n=56) believed parents or guardians should be present during discussions about menses. Approximately one-third believed they should be present during discussions around teratogenic medication use and future pregnancy (38%, n=35 and 32%, n=29, respectively). One of five respondents (21%, n=19) believed parents or guardians should be present during contraceptive discussions. Only 1 respondent believed parental presence was advised during discussions around sexual activity.

SRH care discussions in the SCD care setting

More than three-fourths of respondents (76%, n=68) answered that they discuss menses with AYA female patients, with pediatric providers more likely to discuss than adult providers (81% vs. 50%, $p = .03$). When asked about frequency of discussions about menstruation, 24% (n=22) reported never or rarely, 17% (n=16) reported annually, 59% (n=54) reported multiple times per year or every visit.

Over 80% of respondents (n=72) reported discussing pregnancy with their AYA female patients with no significant difference between pediatric and adult providers. When asked about frequency of discussions about planning for pregnancy in the setting of SCD, 45% (n=41) reported never or rarely, 38% (n=35) reported annually, 14% (n=13) reported multiple times per year or every visit. All adult providers reported that they discuss teratogenic medications with their patients, and 70% (n=54) of pediatric providers reported these discussions ($p = .03$). When asked about frequency of discussions about teratogenic medications, 22% (n=21) reported rarely discussing teratogenic medications, 30% (n=28) reported annual discussions, and 34% (n=31) reported multiple times per year or every visit.

All adult providers and most pediatric providers (93.3% overall) reported discussing contraception with their patients. When asked about frequency of discussions about contraception, 8.7% (n=8) reported never or rarely, 39% (n=36) reported annually, 51% (n=47) reported multiple times per year or every visit.

Contraceptive and pregnancy attitudes and practices

Eighty-seven percent (n=78) of respondents reported they refer patients to other providers for counseling and management of contraception, 11% (n=10) reported they recommend birth control to selected patients and prescribe it themselves, and 2 participants reported they recommend birth control to no one.

Over a third (38%, n=35) respondents reported a preferred method of contraception for AYA female patients with SCD. Of this subset, 37% (n=13) preferred the hormonal IUD, 37% (n=13) preferred contraceptive injection, 11% (n=4) preferred progestin-only pills, 5% (n=2) preferred the copper IUD, 5% (n=2) preferred Nexplanon, and 1 chose the combined OCP. Half of respondents did not deem CHC acceptable for birth control in this population (52%, n=48). There were no statistical differences between pediatric and adult providers.

Regarding attitudes around CHC and pregnancy in SCD, 36% agree or strongly agree that CHC should never be used in AYA with SCD (Table 2). Almost half agree that CHC can be used if no other risk factors are present. About a quarter agree or strongly agree with the CDC recommendation that CHC is unacceptable in women with SCD. The majority (89%) believe that pregnancy is high risk in any woman with SCD. We found no significant differences between pediatric and adult providers related to the strict avoidance of CHC in AYA with SCD ($p = .10$), agreement with the CDC recommendation that CHC as unacceptable in women with SCD ($p = .15$), and belief that pregnancy is considered high risk in women with SCD ($p = .23$). Overall, pediatric providers were significantly more agreeable to using CHC if there were no other contraindications, with 51% (n=38) of pediatric versus 25% (n=3) of adult providers agreeing or strongly agreeing that CHC can be used if there are no other risk factors; however, 58% (n=7) of adult providers, compared to 21% (n=16) of pediatric providers, disagreed or strongly disagreed with CHC use even if no other contraindications were present ($p = .03$).

Barriers and facilitators to SRH care in SCD

When asked about what limits SRH discussions with their AYA female patients, 73% of respondents cited lack of time, 47% presence of parents in the room, 46% cited lack of SRH knowledge, 28% patient discomfort,

and 21% lack of rapport. Half of adult providers and 17% of pediatric providers reported lack of rapport limited SRH discussions ($p=.02$). No significant differences between provider types existed for other barriers.

When asked about facilitators to SRH discussions with their AYA female patients, 77% endorsed training curricula or modules, 66% endorsed guidelines from the Foundation for SCD Research (FSCDR), 39% endorsed small group discussions at the SCD Association of America (SCDAA) conference, 74% of respondents believed a standardized partnership with SRH specialists would improve this aspect of care. Related to type of educational resources, 83% preferred online resources, 77% pamphlets or books, 72% a mobile device application with information and resources, and 44% video-based educational modules.

DISCUSSION

This survey explored the attitudes and practices of SCD providers related to SRH of their AYA female patients. The majority of respondents agreed that SRH is an important topic for discussion with AYA women with SCD, SCD provider should be the ones discussing SRH with their patients, and such discussions should be standard practice within SCD clinics. However, there were discrepancies as to the timing, content, and approach of such discussions with this population. The majority of respondents agreed that SRH discussions should happen after menarche in early adolescence\out. There was wide variation in frequency of discussion of contraception, pregnancy, and teratogenic medications, though providers largely did discuss these at least once. There was a wide variety in providers' comfort level with use of estrogen-containing CHC, with most preferring these methods and instead opting for progestin-only methods.

Patients, especially AYA, with chronic diseases including SCD, cystic fibrosis, and epilepsy have been shown to have gaps in their SRH knowledge and access.^{22,24,25} Ownership of SRH discussion is often lacking when a PCP is seen infrequently, especially if an adult subspecialist takes over a pediatric subspecialist's care of a chronic illness originating in childhood. Discussion of SRH is often complicated by multiple subspecialists. Subspecialists often discuss issues of interest or those more medically specific to the chronic illness to the parents and thus find it uncomfortable or time-consuming to have private discussions with the patients, which has been shown in studies of other providers of patients with chronic illness^{22,24,25} This may require a larger shift to incentivize or standardize time alone with the AYA to address important SRH concerns.

Our results demonstrate a wide discrepancy in SCD provider attitudes toward forms of contraception that are preferred and acceptable for use by AYA women. We found that providers we surveyed prefer DMPA over other methods, which is supported in the literature.^{11,15,17,26} There is less evidence for use of hormonal IUDs, but were equally preferred to DMPA by providers in our study, likely due to both having associated benefits of lighter menses and high efficacy.²⁷ There was a substantial proportion of respondents that preferred the copper IUD, which has the adverse effect of worsening dysmenorrhea and menorrhagia, but avoids the reported risks of estrogen.²⁸ When recommending restrictions, the CDC and WHO must balance the risk of pregnancy against the risk of CHC in SCD, where there is limited data.^{14,29} It is interesting that pediatric providers are more likely to agree with CHC prescription barring other contraindications, indicating that adult providers may assess the risk of CHC more cautiously. This may be due to the greater incidence of thrombosis in adult SCD patients and the long-term sequelae as added risk factors to their CHC use.^{30,31} Providers of pediatric patients may be more sensitive to the other risks of adolescent unplanned pregnancy.

Similar to providers, women with SCD also lack clarity in contraceptive choice. Finding reliable SRH information is a challenge for any AYA, and AYA women with SCD have particular gaps in knowledge in contraception, puberty, fertility, and pregnancy-related health outcomes.³² Standardizing or incentivizing visits alone with AYA, such as in teen or transition clinics, can help facilitate SRH discussions and, thus, improve patient knowledge.

Strengths of this study include that it is a geographically diverse sample and novel in the SCD population. Limitations include selection bias, as providers who are interested in SRH may have been more likely to complete the survey. Additionally, the survey primarily represented pediatric trained physicians, and therefore, is not representative of all providers of SCD, particularly adult SCD providers. Comparisons shine a light on potential differences across provider types, but should be interpreted cautiously due to our small sample

size of adult providers. Recruitment of adult providers as a whole was difficult due to lack of a targeted listserv. The response rate of ASPHO listserv members was limited by email recruitment, and because of the nature of the recruitment strategy, response rate of adult providers was difficult to calculate.

Providers and AYA with SCD would benefit from further evidence-based guidance regarding SRH, especially contraception. Data about contraceptive choice, especially in women with SCD, is a necessary next step to create best practices. Future research in this area could track adverse events following different contraceptive choices in this population. Understanding these choices and patient preferences is essential for providers to adequately counsel patients and give recommendations. Additional data on the use of CHC and levonorgestrel IUDs in this population is also necessary to guide decision-making and prescribing practices. Second, these findings suggest the need that providers of SCD (with others thought leaders in reproductive health) develop some type of consensus on how SRH can be addressed consistently with this population of patients. Respondents endorsed online educational modules and resources, as well as clinical partnerships with SRH providers, would improve their ability to provide SRH care for this population. Some programs have already initiated these partnerships, and this study indicates a need for improvement and standardization.³³ This study may be able to help build future programs in education and interventions to improve SRH knowledge and access for patients with SCD.

Overall, this study supports that there is no standardization, wide variety, and clear barriers to SRH discussions for patients with SCD. There is a need for ongoing studies to examine the safety of various methods and training of providers to address reproductive health. Future research related to this study may include patient perspectives on SRH, as well as dissemination of existing SRH information to improve communication and SRH outcomes.

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