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Reproductive Health CHOICES for Young Adults with Sickle Cell Disease or Trait: Randomized Controlled Trial Immediate Posttest Effects

Diana J Wilkie, PhD, RN, FAAN[1] **[Professor, Harriett H. Werley Endowed Chair for Nursing Research, and Director of the Center of Excellence for End-of-Life Transition Research]**, **Agatha M. Gallo, PhD, RN, FAAN**[1] **[Professor Emerita]**, **Yingwei Yao, PhD**[1] **[Research Associate Professor]**, **Robert E. Molokie, MD**[1,2] **[Assistant Professor]**, **Christine Stahl, MD**[1] **[Assistant Professor]**, **Patricia E. Hershberger, PhD, RN**[1] **[Assistant Professor]**, **Zhongsheng Zhao, PhD**[1] **[Research Assistant Professor]**, **Marie L. Suarez, PhD**[1] **[Senior Research Specialist]**, **Robert J. Labotka, MD**[1] **[Professor Emeritus]**, **Bonnye Johnson, MS, RN**[1] **[Community Coordinator]**, **Rigo Angulo, BS**[1] **[Research Specialist]**, **Veronica Angulo, BS**[1] **[Research Specialist]**, **Jesus Carrasco, BS**[1] **[Research Specialist]**, **David Shuey, BA**[1] **[Research Specialist]**, **Stephanie Pelligra**[3] **[Sickle Cell Program Coordinator]**, **Edward Wang, PhD**[1] **[Research Assistant Professor]**, **Dennie T. Rogers, MD**[4] **[Assistant Professor]**, and **Alexis A. Thompson, MD**[3,5] **[Professor]**

[1]University of Illinois at Chicago, Chicago, IL

[2] Jesse Brown Veterans Administration Medical Center, Chicago, IL

[3]Ann and Robert H. Lurie Children's Hospital of Chicago, Division of Hematology/Oncology/Stem Cell Transplantation, Chicago, IL

[4] Rockford Health System, Rockford, IL

[5] Northwestern University-Feinberg School of Medicine, Chicago, IL

Abstract

Background—People with sickle cell disease (SCD) or sickle cell trait (SCT) may not have information about genetic inheritance needed for making informed reproductive health decisions. CHOICES is a web-based, multimedia educational intervention that provides information about reproductive options and consequences to help those with SCD or SCT identify and implement an informed parenting plan. Efficacy of CHOICES compared with usual care must be evaluated.

Objective—The purpose was to compare immediate posttest effects of CHOICES versus an attention control usual care intervention (e-Book) on SCD/SCT-related reproductive health knowledge, intention, and behavior.

Methods—In a randomized controlled study, we recruited subjects with SCD/SCT from clinics, community settings, and online networks with data collected at sites convenient to the 234 subjects with SCD (n = 136) or SCT (n = 98) (age ranged from18-35 years, 65% were female, and

Correspondence concerning this article should be addressed to Diana J. Wilkie, PhD, RN, FAAN, 845 S. Damen Avenue, Room 660 (MC 802), University of Illinois at Chicago, Chicago, IL 60612-7352. diwilkie@uic.edu.

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94% were African American). Subjects completed a measure of sickle cell reproductive knowledge, intention, and behavior before and immediately after the intervention.

Results—Compared to the e-Book group, the CHOICES group had significantly higher average knowledge scores and probability of reporting a parenting plan to avoid SCD or SCD and SCT when pretest scores were controlled. Effects on intention and planned behavior were not significant. The CHOICES group showed significant change in their intention and planned behavior; the e-Book group did not show significant change in their intention, but their planned behavior differed significantly.

Discussion—Initial efficacy findings are encouraging but warrant planned booster sessions and outcome follow-ups to determine sustained intervention efficacy on reproductive health knowledge, intention, and actual behavior of persons with SCD/SCT.

Keywords

sickle cell disease; sickle cell trait; reproductive behavior; young adult; randomized controlled trial

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Despite longstanding scientific knowledge about genetic inheritance of sickle cell disease (SCD) or sickle cell trait (SCT), translation of that knowledge to the affected community has been insufficient. Pregnancies in the at-risk population may occur with little forethought or opportunity for well-informed reproductive health decisions and may be based on insufficient or erroneous knowledge about genetic inheritance (Gallo, Knafl, & Angst, 2009; Long, Thomas, Grubs, Gettig, & Krishnamurti, 2011). To address this problem, we demonstrated feasibility of a web-based, multimedia, targeted, and interactive intervention (CHOICES) to foster informed reproductive health decisions by people with SCD or SCT (Gallo et al., 2010; Gallo et al., in press). We now report pretest and immediate posttest findings from a randomized controlled trial of the CHOICES intervention for young adults with SCD or SCT.

Few research findings are available about reproductive health knowledge and decisions of the 100,000 Americans with SCD or the more than 3 million Americans of African descent with SCT (Modell & Darlison, 2008; Yusuf et al., 2011). Annually in the United States (US), about 2,000 infants are born with SCD (Modell & Darlison, 2008), and one of 12 African American children is born with SCT. With improved detection, treatment, and preventative care measures, children with SCD now live longer (Powars, Chan, Hiti, Ramicone, & Johnson, 2005) and grow into adulthood, where they, and people with SCT, face serious decisions about childbearing. Yet, we found only three descriptive studies addressing reproductive knowledge of individuals with SCD or SCT (Acharya, Lang, & Ross, 2009; Hill, 1994) or their intention and behavior related to becoming a parent (Asgharian, Anie, & Berger, 2003).

For people with SCD/SCT, reproductive decision-making includes consideration of the responsibilities of parenthood associated with the serious stress and profound disruption that may occur if they have a child with SCD (Casey & Brown, 2003; Lemaneck, Buckloh, Woods, & Butler, 1995; Logan, Radcliffe, & Smith-Whitley, 2002; Moskowitz et al., 2007; Panepinto & Bonner, 2012). Parents provide daily care to the child with SCD and are involved with preventative care measures, vigilant observation for symptoms, and decision-making if symptoms worsen (Beyer & Simmons, 2004). Parents and health care providers must also work to help the children be ready to take on their own self-management as they age (Oliver-Carpenter, Barach, Crosby, Valenzuela, & Mitchell, 2011; Yoon & Godwin, 2007). Children must cope with fatigue and pain that may result in multiple hospitalizations, daily medications, life-threatening infections, disabilities such as stroke or avascular

necrosis, and possible blood transfusions to prevent complications including stroke. The child with SCD may suffer the emotional pain of stigma and feeling different from friends, missing school for illness events, avoiding some physical activities, and wondering why they suffer from the condition (While & Muller, 2004). Despite significant impact of the disease on individuals and families, and $2.4 billion annual cost to the US health care system (Lanzkron, Carroll, & Haywood, 2010), no one has calculated the non-medical disease burden for SCD in the US.

The impact of SCD manifestations and consequences play a critical role in the health of adults living with SCD. Adults with SCD have a shortened life expectancy, primarily related to chronic lung disease and pulmonary hypertension or renal or other organ failure (Darbari et al., 2006). Pregnant women with SCD are at risk for pregnancy-related complications such as bleeding, infection, hypertension/preeclampsia, and preterm labor, and more sickle cell manifestations during pregnancy, such as worsening anemia and more frequent pain episodes (Rogers & Molokie, 2010). Mothers may deliver premature or small-for-gestational-age neonates or the pregnancy can end in an early spontaneous loss, an intrauterine fetal demise, or maternal mortality (Howard & Oteng-Ntim, 2012).

Adult men and women with SCD or SCT are confronted with the challenge of communicating their status to partner(s) and deciding with their partners what their plans will be in advance of pregnancy (parenting plan). The timing of this communication is important; it sometimes presents an awkward situation depending on the stage of the relationship (Asgharian et al., 2003). Women and perhaps men, too, do not want to have the conversation too late for the sake of openness in the relationship or too early to avoid presumption of a long-term commitment early in the relationship (Asgharian et al., 2003). They need to repeat this type of communication as partners change throughout the childbearing years.

Once partners have communicated about their SCD or SCT status, the first decision may be whether to have a baby, a decision that may be influenced by the social network (Asgharian et al., 2003). If a man or woman with SCD decides to have a baby and wants to be certain that the baby does not have SCD, a partner must have neither SCD nor SCT, or be aware of the advances in assisted reproductive technology and prenatal testing that are available to support this decision. The woman also needs to be fully aware of the potential physical consequences to herself during a pregnancy (Rogers & Molokie, 2010). If both partners have SCT or one has SCD (and the other SCT), they need to decide whether to utilize in vitro fertilization with preimplantation genetics or fetal prenatal testing for SCD. If sexually active people with SCD decide to avoid conception, they need to know about the available options for contraception. Finally, people with SCD or SCT who decide to forgo the options for biological children but want to be parents can consider non-childbearing parenting options such as adoption or foster-parenting.

For individuals at high risk of their children inheriting a serious genetic condition such as SCD, the reproductive health decisions and behaviors relate to disease burden, the right to decide for themselves, and the right to make informed decisions. However, acting on these rights requires reproductive health knowledge specific to SCD and SCT. Although extensive research is available about sex education in general, little research is available about reproductive health knowledge and decisions of adults with SCD or SCT (Acharya et al., 2009; Hill, 1994). In a sample of young adults with SCD or SCT randomized to CHOICES or the usual care e-Book control intervention, our specific aim was to compare immediate posttest effects on reproductive health knowledge, intention, and planned behavior change. We hypothesized that compared to the usual care group, the CHOICES group would report

increased reproductive health knowledge, intention, and planned behavior changes consistent with their parenting plan, when pretest scores were controlled.

Methods

Design

The study was a randomized clinical trial with pretest and multiple posttest measurements; the first posttest results are reported here. Stratified by SCD or SCT condition, we randomly assigned subjects in permuted blocks (Matts & Lachin, 1988) to e-Book (attention control usual care) or CHOICES treatment groups using the random digit-based *RandomAssignment* software program (Pain & Symptom Management Research Group, Chicago, IL). Group assignments resided in a hidden folder on a secure database server to which none of the investigators or study staff had access, except for the study programmer, until after data were collected. The Institutional Review Boards at the University of Illinois at Chicago and the Ann and Robert H. Lurie Children's Hospital of Chicago approved the protocol.

Setting

We used a variety of settings for subject identification, including the sickle cell clinics at the two health care institutions, community organizations, public settings (such as university student centers or grocery and drug stores), and online networks (e.g., facebook.com, Craigslist.org). We collected data at sites convenient to subjects, including clinical settings, subject homes, or other community settings such as coffee shops.

Sample

Included were 18- to 35-year-old adults reporting SCD or SCT, who were able to understand spoken English and read English, and who had the ability and desire to have children in the future. Individuals who were legally blind, physically unable to have children or unable to complete the study were excluded. Also excluded were individuals who reported knowing or being a friend or relative of a subject already enrolled in the study (to reduce potential for contamination).

We recruited and obtained consent from 242 eligible subjects, and 234 subjects completed the immediate posttest measures (see Consort Figure 1). The 234 subjects had either SCD (n = 136) or SCT (n = 98), 65% were female and 94% were African American. The mean age for the CHOICES group was 25.3 years (SD = 4.9) and for the e-Book group was 26.4 years (SD = 4.9); the difference was not statistically significant (p = .09). Other sample demographic characteristics appear in Table 1. Comparisons of sample demographic characteristics showed no significant difference between the CHOICES and e-Book groups (Table 1).

Procedures

Clinicians referred patients with SCD or parents of children with SCD to well-trained research specialists (RS). We also sought self-referral of people with SCD or SCT through recruitment activities online and in community settings, such as posting flyers and displaying an exhibit poster at public events. All RSs were experienced and highly competent to work with subjects from diverse racial, ethnic, and cultural groups. RSs validated eligibility of referred people, including coordinating the necessary laboratory screening to verify reported SCD or SCT status, if other evidence of previous hemoglobin fractionation was not available. RSs obtained signed informed consents and obtained pretest measures using a pentablet computer. After the pretest measures, the subject received the

assigned intervention via the pentablet computer and afterward completed the posttest. The RSs gave the subject $25 in cash for their time and travel expenses.

Intervention

CHOICES—In a prior study, cognitive interview methods validated the cultural appropriateness and literacy level of CHOICES for the target audience (Gallo et al., 2010; Gallo et al., in press). The CHOICES intervention includes information targeted to the subject's gender and sickle cell status. Kolb's experiential learning theory (ELT) (Kolb, Boyatzis, & Mainemelis, 2000) guided the content delivery, and the theory of reasoned action (TRA) (Ajzen & Fishbein, 1980) guided the content.

Following ELT, CHOICES begins with a video (*concrete experience)* of two young men discussing the birth of one man's daughter, who has SCD, and the issue of the mother and father not knowing that they both had SCT. In the *reflective observation* section, the computer asks the study subjects to type responses to questions about the video. The *abstract conceptualization* section then provides detailed reproductive information for people with SCD or SCT. This content includes genetics-related and TRA-related information about the full range of options, from having a child with SCD to having a child without SCD or SCT. For example, some options include testing to know SC status, disclosing SC status and talking with a partner about plans to be a parent, taking the chance, avoiding pregnancy, adopting a child, testing the fetus, achieving pregnancy with donated ova or sperm, and knowing the risks of pregnancy in the woman with SCD. Information about the risk of genetic inheritance of SCD and SCT and the potential complications of SCD and SCT is also included. Then in the *active experimentation* section, a variety of scenarios present couples discussing their SCD or SCT status, the reproductive decisions they made, and what life is like for them given their decisions. After viewing the scenarios, subjects select the one that best represents their personal situation and decision. After completing the study posttest measure, the computer presents a parenting plan that summarizes their decisions. Subjects indicate if the parenting plan is accurate or what is inaccurate; then the subject receives a copy of the parenting plan by e-mail.

CHOICES includes 57 web pages with text and graphic content narrated by both a female and a male voice; subjects have the option to select either the male or the female narration or to engage the content without narration. CHOICES also includes 14 video clips of couples discussing issues related to reproductive options, and 17 graphical animations that demonstrate issues such as the mechanism of genetic inheritance, risks of a child inheriting SCD or SCT, and how advanced reproductive technologies work. All the educational materials are at an 8th grade reading level. Subjects completed CHOICES in an average of 76.8 minutes (*SD* = 32.5; *Mdn* = 71.6).

Attention control usual care—Cognitive interview methods validated the attention control usual care e-Book intervention for cultural appropriateness and literacy level for the target audience (Gallo et al., 2010; Gallo et al., in press). The e-Book is a 9-page web-based educational program that includes sickle cell content that staff members from Chicago-area sickle cell programs usually share with parents, patients, and the community. It includes graphics and photographs and is visually engaging. As in the CHOICES content, the same male and female voices narrate the e-Book content. All the educational materials are at an 8th grade reading level. Subjects completed the e-Book in an average of 9.9 minutes (*SD* = 6.2; *Mdn* = 8.6).

Instrument

Development of the SCKnowIQ instrument was guided by the TRA. Items were selected or modified from other existing tools (Kaslow et al., 2000; Koontz, Short, Kalinyak, & Noll, 2004; Rosengard, Phipps, Adler, & Ellis, 2004, 2005) or created to measure the four study outcomes below and demographic characteristics. Validity and reliability of the SCKnowIQ scales have been published or are in press (Gallo et al., 2010; Gallo et al., in press). Table 2 includes the reliabilities for the SCKnowIQ scales in this study sample.

Outcomes

Parenting plan—This outcome is a measure derived from two items focused on the importance to the respondent of having a child without SCD or SCT. Responses options are 0 (*not at all important*), 1 (*not very important*), 2 (*somewhat important*), 3 (*very important*), and 4 (*extremely important*). We classified importance responses 2, 3 and 4 as indicating a preference for avoidance of having children with SCD/SCT and responses 0 and 1 as indicated a preference for not wanting to avoid having children with SCD/SCT. Based on the pattern of responses to the two items, we generated a single ordinal outcome with three levels of increasing avoidance: 0 (*no avoidance of having child with SCD or SCT*), 1 (*avoid having child with SCD but not SCT*), and 2 (*avoid having child with SCD or SCT*).

Knowledge—There are 18 knowledge outcome items focused on genetic transmission of SCD and SCT (4 hypothetical items, 3 participant-specific items), SCD etiology and risks, and parenting options for people with SCD or SCT. Response options are multiple choice with one correct answer scored as 0 (*not correct*) or 1 (*correct*). Scored item responses were summed to create a total knowledge score that could range from 0 to 18. The Cronbach's alpha in this sample was .66 to .74 (Table 2). Test-retest reliability in the e-Book group was . 70.

Reproductive health intention—This outcome is a measure with eight items. Items focus on intention to avoid having children to prevent them having SCD or SCT, to bear a child who is unaffected (without SCD) or affected by SCD, to abort a pregnancy due to health concern or to prevent SCD or SCT, to use a variety of advanced reproductive technologies, and to seek other non-childbearing options (i.e., foster, adopt). The five response options ranged from 0 (*not at all likely*) to 4 (*extremely likely*). The range of possible scores for the reproductive intention scale is 0 to 32. The Cronbach's alphas in this sample ranged from .55 to .70, and the test-retest reliability in the e-Book group was .75 (Table 2).

Reproductive health behavior—This outcome includes ten items focused on behaviors to implement the parenting plan engaged in *ever or during the past* 6 months (pretest) or *planned in the next 6 months* (posttest). The behaviors include frequency of using birth control, talking with partner, prenatal testing, adopting or fostering a child, seeking other parenting options such as advanced reproductive technologies, and agreeing that all things that I am doing help me to avoid having a child with SCD or SCT. Response options were descriptive for each item, but we coded responses based on consistency with the parenting plan. Codes for the nine items were 0 (*inconsistent with parenting plan)* or 1 (*consistent with parenting plan*); the remaining item was scored as 0 (*inconsistent*), .5 (*somewhat consistent*), or 1 (*consistent with the parenting plan*). The range of possible total behavior outcome scores was 0 to 10. The Cronbach's alphas in this sample ranged from .63 to .74 (Table 2). Test-retest reliability was not estimated in this study because the item language differed from pretest to posttest.

Demographics—Items focused on age, gender, marital status, education, income, ethnicity, race, and genetic status of the subject and partner. An item also focused on experience with a family member with SCD.

Time to complete—The average subject required 35 minutes to complete the SCKnowIQ at pretest and 25 minutes at posttest. After the immediate posttest, the computer prompted subjects to indicate what it was like to participate in the study and what they thought about the educational programs.

Analysis

We compared demographic characteristics of the two groups using Student's t- test for continuous variables and chi-square or Fisher's exact test for categorical variables. There was a small amount of missing data (less than 1%). Multiple imputation was used to impute the missing entries. We did not include block in the analysis because all the subjects were recruited within 10 months and the intrablock correlations for the knowledge, intention, and behavior outcomes were below .03, indicating there would be little to gain from using a blocked analysis. Controlling for pretest values and sickle cell status (randomization stratification), we used a cumulative logit link model for the 3-level ordinal parenting plan outcome and linear regression analysis for the other outcomes (knowledge, intention, behavior) to examine the intervention effects on values at posttest. For the ordinal regression, the proportional odds assumption held for group effect and sickle cell status effect, but not for the baseline parenting plan. We therefore used a partial proportional odds model allowing the coefficient for baseline to change with the level. There were no significant interactions between predictors. Statistical significance was set at a two-sided alpha level of .05. We performed all statistical analyses using the statistical software package R (R Development Core Team, 2011).

Results

Descriptive findings for the parenting plan appear in Table 3. Most participants expressed a preference for avoiding having a child with SCD or SCT. Table 4 shows descriptive data for the knowledge, intention, and behavior outcomes at pretest and posttest by e-Book and CHOICES groups. Average pretest scores were similar in the two groups. Knowledge scores were low in both groups (on average, about 50% of the 18 items were answered correctly). Inferential analyses appear in the following sections.

Parenting Plan Outcome

Table 5 presents the coefficient estimates for effects of intervention group and sickle cell status on the parenting plan outcome. Subjects in the CHOICES group had significantly higher odds of adopting a more proactive parenting plan to avoid having a child with SCD or SCT ($OR = 2.3$, $p = .04$) at posttest than the e-Book group when controlling for the pretest parenting plan. Although statistically not significant ($p = .1$), an interesting trend was that subjects with SCD had a lower odds of adopting a more proactive plan than subjects with SCT ($OR = .5$). The estimated thresholds for crossing from level 0 to level 1 and from level 1 to level 2 were −0.46 and 0.07, respectively.

Knowledge

The coefficient estimates for effects of intervention group and sickle cell status on the knowledge scores appear in Table 5. Controlling for pretest values, subjects receiving the CHOICES intervention had significantly higher knowledge scores at posttest than the e-Book group ($p < .001$). Subjects with SCD had lower posttest scores than those with SCT ($p < .001$). Both groups improved from pretest to posttest, as indicated by the 95% confidence

intervals for mean test score changes: [0.57, 1.41] for the e-Book group and [2.26, 3.30] for the CHOICES group. (These confidence intervals can be computed from the means and *SD*s presented in Table 4.)

Reproductive Health Intention

As shown in Table 5, we did not find that the effects of either intervention group or sickle cell status on the posttest intention scores were significant. The CHOICES group, however, did show a trend for a higher score than the e-Book group ($p = .10$). Confidence intervals for mean pretest to posttest score changes indicated statistically significant change for the CHOICES group [0.43, 1.67], but nonsignificant change for the e-Book group [−0.30, 0.88].

Reproductive Health Behavior

The effects of both intervention group and sickle cell status on the consistency of reproductive behaviors with personal parenting plan were statistically insignificant (Table 5). Confidence intervals obtained from statistics presented in Table 4 indicated that both groups had statistically significant increase in scores from pretest to posttest: [0.24, 1.10] for the e-Book group and [0.57, 1.45] for the CHOICES group. Although not significant, the mean scores in Table 4 show the change in scores was in the hypothesized direction (i.e., that the subjects in the CHOICES group would have more behaviors consistent with their parenting plan than the subjects in the e-Book group).

Qualitative Findings

Overall, subjects gave positive responses about the interventions, including “great learning experience,” “great program,” “interesting,” “helpful,” and “informative.” Although a few subjects in the e-Book group saw the content as a “refresher,” most other subjects in both groups found the content new and beneficial to their learning. Some subjects noted that the information would help stimulate awareness about SCD and SCT in individuals and communities. More of the CHOICES group than the e-Book group “enjoyed” the program and liked the various ways the program delivered the information, including the videos. Some subjects clearly indicated that the computer was an easy, convenient, and “wonderful” way to convey this information; one subject said, “It beats classroom learning!” Interestingly, subjects in the e-Book group often commented that they were glad they had been assigned to the experimental group, which means that they were not aware the e-Book was the attention control condition despite its length being shorter than the CHOICES.

Discussion

This study is the first to test an intervention designed to improve knowledge, intention, and behavior related to reproductive health in young adults with SCD or SCT who specified their parenting plan in advance of pregnancy. This intervention has potential to serve as primary prevention for SCD and offers education in a multimedia, web-based format that is highly reproducible and relevant for young adults. We showed that the odds of a CHOICES group subject endorsing a parenting plan to avoid having a child with SCD or a child with either SCD or SCT are 2.3 times those of an e-Book group subject. We also showed that compared to the e-Book group, the CHOICES group had a statistically significant improvement in knowledge immediately after a one-hour web-based, multimedia educational program. Intervention group differences in intention and behavior outcomes were not statistically significant, but trends were in the hypothesized direction. To optimize the reproductive behavior change, these immediate posttest findings support our plan to deliver intervention boosters and to conduct repeated posttests over 2-years.

CHOICES provides young adults with SCD and SCT the opportunity to consider their reproductive options, to talk with their partners about their sickle cell status, and to plan for future pregnancies. There is a heightened need to help young adults with SCD or SCT understand their reproductive risks for having an affected child, the genetic inheritance of SCD, other hemoglobinopathies, and SCT, reproductive options, and risks and benefits of pregnancy for women with SCD. Young adults with SCT may or may not know their SCT status (despite the now-universal practice of newborn screening for hemoglobinopathies in the US), and they may not understand the mechanisms of genetic inheritance of the disease. Nor do many young adults with SCD or SCT understand all of their reproductive options, such as advanced reproductive technologies using sperm or eggs from persons with normal hemoglobin (Kuliev, Pakhalchuk, Verlinsky, & Rechitsky, 2011) to control genetic inheritance.

Our study has potential for positive impact related to Healthy People 2020 goals. Our study is particularly relevant because Healthy People 2020 includes a developmental objective to increase the proportion of hemoglobinopathy carriers who know their own carrier status (healthypeople.gov/2020). Our study also includes information about the importance of being tested and talking with a partner about the partner's sickle cell status in advance of sexual activity--some of the primary prevention activities for those whose parenting plan indicates they want to avoid having a child with SCD.

Our study is the first to use the TRA to investigate reproductive health behaviors in young adults with SCD or SCT. The TRA has been used extensively in research focused on other reproductive-related health behaviors (Baker, Morrison, Carter, & Verdon, 1996; Doswell, Braxter, Cha, & Kim, 2011; Koniak-Griffin, Lesser, Uman, & Nyamathi, 2003), reproductive decision-making (Koniak-Griffin, Lesser, Nyamathi et al., 2003; Koniak-Griffin & Stein, 2006; Pivetti & Melotti, 2013; Wesley et al., 2000) among other populations, and on diabetes management (Wang, Charron-Prochownik, Sereika, Siminerio, & Kim, 2006).

When used with at risk couples who indicate that it is important to them to avoid having a child with SCD, the CHOICES intervention helps in selection of reproductive health behaviors and options that support implementation of their parenting plan. If demonstrated in a future national trial to be effective in supporting informed reproductive health behaviors in people with SCD or SCT, CHOICES could become a standard program for use in US sickle cell clinics and could be translated and adapted for use throughout the world.

Findings also support our plan to provide booster intervention sessions based on knowledge deficits at 6 and 12 months after the original intervention session. The low mean scores for knowledge indicate that subjects did not grasp the knowledge needed for informed reproductive decision making during the initial educational session. A single one-hour education session may not have been a sufficient dose for learning the complexities of the genetic inheritance knowledge. In the future, we will determine if one or two additional sessions are sufficient for subjects to retain the knowledge needed to implement behavior consistent with their parenting plans.

Our study has some limitations. The study was conducted in one geographical location in the US, and it is possible that intervention effects will vary in other locations with different cultural norms. The study included mainly individuals of African descent, although other ethnic populations can have SCD and other hemoglobinopathy traits. We did not include a measure of cognitive ability, and subjects with SCD may have had cognitive impairment from prior silent strokes or low hemoglobin, which may affect their learning. Finally, we are unable to conclude what the long-term effects of the CHOICES intervention will be until we

have completed the 12, 18, and 24 months data collection and analysis. At that time, we will have sufficient evidence to plan the next steps for this research.

Conclusion

These findings are the first to show efficacy for an intervention to help young adults with SCD or SCT to implement their personal parenting plan in an informed manner. Predominately, the subjects reported that they wanted to avoid having a child with SCD or SCT. To do so, people of African descent in the US (where 1 in 12 are carriers of SCT) need to implement reproductive behavior choices that are consistent with their parenting plans. Compared to the e-Book attention control group, our CHOICES intervention provided information about such options and did so in a manner that was not only acceptable to the subjects, but also was effective in significantly increasing their knowledge and showed trends for intention and planned behavior relevant to their parenting plan. Actual behavior change will be determined at subsequent follow-ups.

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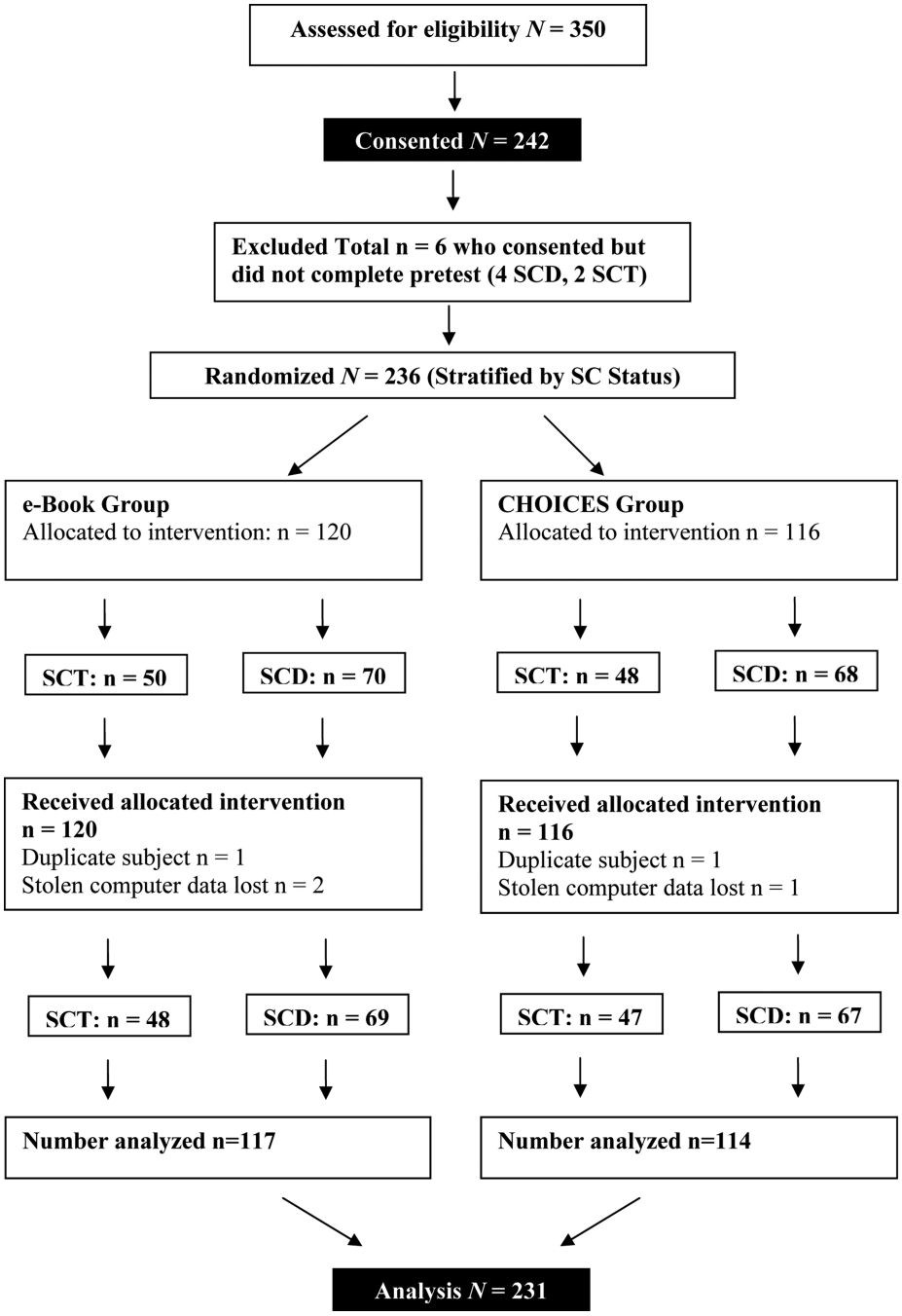

Figure 1.
CHOICES Study CONSORT flowchart. (SC = sickle cell, SCD = sickle cell disease, SCT = sickle cell trait)

Table 1

Sample Demographics

	Overall (*N* = 234)		CHOICES (*n* = 115)		e-Book (*n* = 119)		
Characteristic	***N***	**(%)**	***n***	**(%)**	***n***	**(%)**	***p*-value**
Gender							.31
Male	82	(35.0)	44	(38.3)	38	(31.9)	
Female	152	(65.0)	71	(61.7)	81	(68.1)	
Marital Status							.77
Never married	193	(82.5)	96	(83.5)	97	(81.5)	
Married	31	(13.2)	13	(11.3)	18	(15.1)	
Separated	2	(0.9)	1	(0.9)	1	(0.8)	
Divorced	8	(3.4)	5	(4.3)	3	(2.5)	
Education							.89
High school (9-12)	78	(33.3)	40	(34.8)	38	(31.9)	
Vocational school	5	(2.1)	1	(0.9)	4	(3.4)	
Some college	85	(36.3)	42	(36.5)	43	(36.1)	
2-year college degree	24	(10.3)	12	(10.4)	12	(10.1)	
4-year college degree	28	(12.0)	13	(11.3)	15	(12.6)	
Graduate degree	14	(6.0)	7	(6.1)	7	(5.9)	
Income							1.00
Less than $10,000	84	(35.9)	41	(35.7)	43	(36.1)	
$10,000 to $29,999	62	(26.5)	31	(27.0)	31	(26.1)	
$30,000 to $49,999	37	(15.8)	18	(15.7)	19	(16.0)	
$50,000 or more	36	(15.4)	18	(15.7)	18	(15.1)	
Unknown	15	(6.4)	7	(6.1)	8	(6.7)	
Ethnicity							.53
Hispanic or Latino	10	(4.3)	6	(5.2)	4	(3.4)	
Not Hispanic or Latino	224	(95.7)	109	(94.8)	115	(96.6)	
Race[a]							.60
Black	110	(47.0)	51	(44.3)	59	(49.6)	
African American	109	(46.6)	56	(48.7)	53	(44.5)	
Other	15	(6.4)	8	(7.0)	7	(5.9)	
Has sickle cell disease	136	(58.1)	68	(59.1)	68	(57.1)	.79
Has sickle cell trait	98	(41.9)	47	(40.9)	51	(42.9)	.79
Partner with sickle cell disease[b]							.93
No	145	62.8	72	(63.2)	73	(62.4)	
Yes	6	2.6	2	(1.8)	4	(3.4)	
Don't know	20	8.7	10	(8.8)	10	(8.5)	
No partner	60	26.0	30	(26.3)	30	(25.6)	
Partner with sickle cell trait[c]							.59
No	117	50.9	54	(47.4)	63	(54.3)	

	Overall (*N* = 234)		CHOICES (*n* = 115)		e-Book (*n* = 119)		
Characteristic	***N***	**(%)**	***n***	**(%)**	***n***	**(%)**	***p*-value**
Yes	23	10.0	14	(12.3)	9	(7.8)	
Don't know	30	13.0	16	(14.0)	14	(12.1)	
No partner	60	26.1	30	(26.3)	30	(25.9)	
Has relative with sickle cell disease[d]							.95
Yes	113	49.3	56	(49.6	57	(49.1)	
No	116	50.7	57	(50.4	59	(50.9)	

Note.

[a] Participants identified themselves as either Black or African American.

[b] *n* = 231

[c] *n* = 230

[d] *n* = 229 due to missing data.

Table 2

Reliabilities for the SCKnowIQ Scales

	Cronbach's alpha				Test-Retest Reliability
	CHOICES		e-Book		e-Book only
Scale	Pre	Post	Pre	Post	ICC
Knowledge (18 items)	.67	.73	.66	.74	.70
Intention (8 items)	.70	.70	.55	.68	.75
Behavior (10 items)	.67	.74	.63	.68	NA[a]

Note. N = 231. Pre = pretest; Post = posttest; ICC = intraclass correlation; NA = not available.

[a]Behavior items were not exactly the same; pretest items focused on behaviors in the previous 6 months, and posttest items focused on planned behaviors in the next six months. Test-retest reliability for the behavior scale will be assessed in a future report when the items will be exactly the same.

Table 3

Parenting Plan Frequencies by Intervention Group at Pretest and Posttest

	Pretest				Posttest			
	e-Book		CHOICES		e-Book		CHOICES	
Parenting Plan	***n***	**(%)**	***n***	**(%)**	***n***	**(%)**	***n***	**(%)**
Avoid having child with SCD or SCT	93	(79.5)	89	(78.1)	91	(77.8)	98	(86.0)
Avoid having child with SCD but not SCT	16	(13.7)	17	(14.9)	17	(14.5)	12	(10.5)
No avoidance of having child with SCD or SCT	8	(6.8)	8	(7.0)	9	(7.7)	4	(3.5)

Note. $N = 231$. SCD = sickle cell disease; SCT = sickle cell trait.

Table 4

Knowledge, Intention, and Behavior by Intervention Group at Pretest and Posttest

		Knowledge		Intention		Behavior	
Group	**Occasion**	***M***	***(SD)***	***M***	***(SD)***	***M***	***(SD)***
e-Book	Pretest	9.78	(3.06)	5.94	(4.29)	5.16	(1.99)
	Posttest	10.77	(3.30)	6.23	(4.79)	5.83	(2.13)
	Post - Pre[a]	0.99	(2.32)	0.29	(3.23)	0.67	(2.35)
CHOICES	Pretest	9.38	(3.06)	5.58	(4.64)	4.76	(1.93)
	Posttest	12.16	(3.18)	6.63	(4.88)	5.77	(2.30)
	Post - Pre[a]	2.78	(2.81)	1.05	(3.39)	1.01	(2.40)

Note. $N = 231$.

[a]Post - Pre = average difference between posttest and pretest scores within groups.

Table 5

Regression Effects of Pretest, Intervention Group, and Sickle Cell Status on Outcome Variables

Outcome	Predictor	Estimate	(*SE*)	*z*	*p*
Parenting Plan[a]	Pretest 1: Cut-off = 0/1	−2.31	(0.91)	−2.53	.01
	1: Cut-off = 1/2	0.23	(0.64)	0.35	.72
	2: Cut-off = 0/1	−3.23	(0.72)	−4.51	< .001
	2: Cut-off = 1/2	−2.61	(0.61)	−4.29	< .001
	Intervention[b]	0.85	(0.41)	2.09	.04
	Sickle Cell Status[c]	−0.68	(0.42)	−1.62	.11
Knowledge	Pretest	0.71	(0.05)	13.96	< .001
	Intervention[b]	1.67	(0.31)	5.36	< .001
	Sickle Cell Status[c]	−1.09	(0.32)	−3.45	< .001
Intention	Pretest	0.82	(0.05)	17.06	< .001
	Intervention[b]	0.69	(0.42)	1.64	.10
	Sickle Cell Status[c]	−0.27	(0.43)	−0.61	.54
Behavior[d]	Pretest[e]	0.40	(0.07)	5.77	< .001
	Intervention[b]	0.10	(0.27)	0.36	.72
	Sickle Cell Status[c]	0.23	(0.28)	0.82	.41

Note. $N = 231$.

[a] Parenting Plan values are 0 = *preference for no avoidance of child with SCD or SCT*; 1 = *preference for avoiding SCD but not SCT*; 2 = *preference for avoiding both SCT and SCD.*

[b] Reference group is the e-book attention control.

[c] Reference group is sickle cell trait.

[d] Behavior is reproductive behavior consistent with implementation of personal parenting plan.

[e] Behavior pretest scores are self reports of behaviors over the past six months; posttest scores are planned behaviors over the next six months.