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Perception of Young Adults with Sickle Cell Disease or Sickle Cell Trait about Participation in the CHOICES Randomized Controlled Trial

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Abstract

Aims—To gain an in-depth understanding of the perceptions of young adults with sickle cell disease and sickle cell trait about parenthood and participating in the CHOICES randomized controlled trial that used computer-based, educational programs.

Background—In the United States, there is insufficient education to assure that all young adults with sickle cell disease or sickle cell trait understand genetic inheritance risks and reproductive options to make informed reproductive decisions. To address this educational need, we developed a computer-based, multimedia program (CHOICES) and reformatted usual care into a computer-based (e-Book) program. We then conducted a two-year randomized controlled trial that included a qualitative component that would deepen understanding of young adults' perceptions of parenthood and use of computer-based, educational programs.

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1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;

2) drafting the article or revising it critically for important intellectual content.

* http://www.icmje.org/recommendations/

Conflict of Interest

No conflict of interest has been declared by the authors.

Design—A qualitative descriptive approach completed after a randomized controlled trial.

Methods—Sixty-eight men and women of childbearing age participated in semi-structured interviews at the completion of the randomized controlled trial from 2012 to 2013. Thematic content analysis guided the qualitative description.

Results/Findings—Three main themes were identified: (1) Increasing Knowledge and New Ways of Thinking and Behaving; (2) Rethinking Parenting Plans; and (3) Appraising the Program Design and Delivery. Most participants reported increased knowledge and rethinking of their parenting plans and were supportive of computer-based learning. Some participants expressed difficulty in determining individual transmission risks.

Conclusion—Participants perceived the computer programs as beneficial to their learning. Future development of an Internet-based educational programs is warranted, with emphasis on providing tailored education or memory boosters about individual transmission risks.

Keywords

computerized intervention; genetic education; Internet research; patient education; qualitative research; randomized control trial respondents; reproductive knowledge; sickle cell disease

INTRODUCTION

Sickle cell disease (SCD) is one of the most prevalent, severe single-gene disorders (Rees *et al.* 2010), with estimates of more than 276,000 affected infants born globally each year (Modell & Darlison 2008). High frequency of SCD is historically linked to areas where falciparum malaria has been widespread; individuals with sickle cell trait (SCT) have protection against the morbidity and mortality associated with malaria (Bunn 2013). However, largely due to global population movements, countries such as those in Northern and Western Europe have experienced increased incidence of SCD, particularly in the past 50 years (Modell *et al.* 2007). Education about genetic inheritance and reproductive options for those affected and at risk for transmitting SCD is of growing global concern (Roberts & de Montalembert 2007, Modell & Darlison 2008, Jastaniah 2011, Yusuf *et al.* 2011). Background

In the United States, 1 in 500 African American births has SCD and 1 in 12 African Americans has SCT (National Heart, Lung and Blood Institute 2012). Reportedly 50-80% of parents in the USA lacked sufficient knowledge of their genetic inheritance of SCD or SCT and were surprised when their first child was born with SCD (Acharya *et al.* 2009, Gallo *et al.* 2009). In the United Kingdom, young adults with SCT may not be aware of their risks of having a child with SCD (Asgharian *et al.* 2003).

SCD is an autosomal recessive blood disorder of hemoglobin that damages and deforms red blood cells (Creary *et al.* 2007). The most common manifestations are multisystem and related either to anemia (e.g., fatigue, jaundice and shortness of breath) or to obstruction of blood flow by sickle-shaped red blood cells (e.g., pain and ischemic organ damage; Creary *et al.* 2007, Rees *et al.* 2010).

There are several common types of SCD. Individuals with SCD who have the most severe and frequent manifestations inherit two mutated copies (i.e., homozygotes) of the hemoglobin beta-globin (HBB) gene ('S'; Creary *et al.* 2007, Centers for Disease Control and Prevention 2014). Individuals that inherit one mutated copy of the HBB gene ('S') along with either one mutated gene for another abnormal type of hemoglobin ('C') or a beta-thalassemia gene ('beta') also have SCD, although the clinical manifestations are generally less severe. Individuals who inherit the HBB gene mutation from one parent but whose other copy of the gene is normal (i.e., heterozygotes) are typically healthy carriers (Creary *et al.* 2007) and are referred to as having SCT.

Understanding the SCD transmission risk to future children is critical for young adults with SCD or SCT in making informed reproductive decisions. For example, a young couple who both have SCT have a 25% (1 in 4) chance of transmitting SCD to each of their children (see Gallo *et al.* 2013). There is a need to educate these young adults about their reproductive decisions (Smith & Aguirre 2012). To facilitate educational efforts, we developed a computer-based, educational program (CHOICES) to help young adults with SCD or SCT make informed reproductive decisions. We also reformatted usual care education into a computer-based program (e-Book).

The CHOICES program was developed with considerable input from the affected communities, using focus groups (Gallo *et al.* 2010) and cognitive interviews (Gallo *et al.* 2013), input from an advisory board of young adults with SCD or SCT and professional review for accuracy. Details about the educational programs are presented in Table 1. We then conducted a two-year randomized controlled trial (RCT) where the immediate posttest effects of the CHOICES program demonstrated increased reproductive health knowledge and intentions to implement a parenting plan prior to pregnancy compared with the e-Book or usual care program (Wilkie *et al.* 2013). Although these findings were encouraging, insights about the participants' views regarding parenthood and study participation would strengthen educational efforts and guide development of a national representative intervention study. With this goal in mind, our purpose in designing a qualitative component in the RCT was to gain in-depth understanding about participants' perceptions of parenthood and study participation. The qualitative findings were intended to supplement the final quantitative results (Gallo *et al.* In review).

THE STUDY

Aims

Our aim for the qualitative component at the completion of the RCT was to obtain participants' perceptions about parenthood and participating in the study.

Design

A descriptive approach (Sandelowski 2000, 2010) guided the qualitative component. Consistent with this approach, tenets of content analysis (Graneheim & Lundman 2004, Elo & Kyngäs 2008) and data matrices (Miles & Huberman 1994) were integrated into the analysis.

Sample/Participants

For the purposeful, qualitative sample reported here, sample selection was guided by criterion sampling (Patton 2002a) that included participants' sickle cell status (SCD or SCT), RCT group (CHOICES or e-Book), immediate posttest knowledge scores and willingness to participate in the qualitative interview component of the study. The criteria for selection of the participants for the RCT are reported elsewhere (Wilkie *et al.* 2013).

Data Collection

Semi-structured, digitally recorded, face-to-face interviews were conducted by two male research specialists after completion of the last data collection session (at 24 months). The research specialists were trained by an expert in qualitative methods (author AMG) and were selected as interviewers because they had established a relationship with the participants during the quantitative data collection sessions for the RCT and were familiar with research. The interview guide, developed by the investigators, consisted of a series of open-ended questions and probes (Table 2) to elicit participant responses. Interviews occurred at sites convenient for participants, such as their homes, a quiet clinic room, or a community location (e.g., public library, coffee shop). Interview data were collected over nine months from July 2012 to April 2013. The length of the interviews varied from a mean of 11.49 minutes (range 5.49 minutes to 47.44 minutes) per participant.

Ethical Considerations

The Institutional Review Board at the principal investigators' institution approved the study and its procedures. All participants gave both verbal and written informed consent prior to the onset of the study.

Data Analysis

The interviews were transcribed verbatim and checked for accuracy. Initial coding and analysis of the 68 interviews began with an iterative process by authors AMG and PEH. First, AMG read and reviewed all participant interviews to ensure immersion in the data. AMG then identified each participant's responses to the interview questions and placed these responses into computer-generated data matrices for each participant, which was consistent with our data management and analysis approach (Miles & Huberman 1994). AMG and PEH then initiated coding and condensing of each of the meaning units or incidents as described by Graneheim and Lundman (2004) and Elo and Kyngäs (2008).

During the coding process, AMG and PEH began to identify patterns in the data that led to emerging sub-categories, categories and themes. Additional data matrices and summaries were generated for each of the emergent sub-categories and categories, for which we recorded and counted the number. Use of numeric frequency counts in lieu of verbal counts (e.g., 'few,' 'some,' 'many') is appropriate for descriptive (i.e., minimally interpretive) qualitative studies (Chang *et al.* 2009).

AMG and PEH met weekly or biweekly during data analysis for peer debriefing and to compare and evaluate analytic processes including inter-rater coding, emerging categories and saturation and development of the descriptive themes. All coding differences were

discussed and changed through consensus. As the analysis progressed, all co-authors provided additional analytic insight.

Rigor

To ensure and enhance trustworthiness (Lincoln & Guba 1985, Graneheim & Lundman 2004, Elo & Kyngäs 2008), we carefully conducted the qualitative descriptive approach to achieve the study aim (credibility); used prolonged engagement with the participants over the 24-month study (credibility); enhanced participant variability through establishing criteria for participant selection by sickle cell status and study group (credibility); incorporated analytic meetings and peer debriefings (credibility); engaged multiple investigators to establish investigator-triangulation (credibility) and used inter-rater coding agreement in the analytic process (dependability); delineated the analytic process to allow for replication of analytic steps by other investigators (dependability); provided rich descriptions with detailed quotes or 'voices' of the participants (credibility and neutrality) along with contextual and nuanced findings (neutrality) in the Findings section; and identified other areas in the Discussion section where the findings can be applied (transferability).

The interview guide was developed by the multiple PIs on the team (AMG and DJW). One PI (AMG) is a highly experienced qualitative researcher with a history of performing multiple qualitative sickle cell and genetic families research. The other PI (DJW) is a highly experienced quantitative researcher with extensive expertise in RCT studies. Additional guidance was obtained from an expert in performing qualitative interviews on sensitive reproductive topics (PEH), our interdisciplinary team members and our prior qualitative work with the sickle cell population (Gallo *et al.* 2010).

Our efforts to enhance rigor included addressing reflexivity (Rolfe 2006, Jootun *et al.* 2009), where we acknowledged our values that reproductive choices are a personal decision best made by an informed individual. We also incorporated audience review, a form of triangulation described by Patton (2002b) whereby we presented preliminary findings at the 2014 Midwest Nursing Research Conference in St. Louis, Missouri, USA to Health of Diverse Populations session attendees. Feedback obtained from the audience, composed of practicing nurses and other nurse scientists in the field, was supportive of the findings and supported our preliminary analysis.

FINDINGS

Participants

The interview sample consisted of 68 young adults (mean age = 25.0 years, SD 4.8) with SCD (n = 39; 62% female) or SCT (n = 29; 86% female). Most participants (n = 54; 79%) completed the CHOICES intervention. Mean income was US$22,500 (SD = $24,000; median = $15,000), but one participant's income level was not reported. Most participants were Black or African American (91%), four were Hispanic or Latino and the remaining identified as 'multi-racial' or 'other'; none were White. Most participants were never married (88%), with about 7% married and 4% separated or divorced. All participants had

completed high school, with 48% completing some college or obtaining an undergraduate (16%) or graduate (4%) degree.

Descriptive Themes

We identified three main themes that cut across the educational programs: (1) Increasing Knowledge and New Ways of Thinking and Behaving; (2) Rethinking Parenting Plans; and (3) Appraising the Program Design and Delivery. To aid in illustrating each theme, we provide substantive quotes from the participants and, when appropriate, reference the participant's educational program, gender, sickle cell status (i.e., SCD or SCT), or participant's de-identified study ID number, to enhance understanding and portray nuances.

Theme 1: Increasing Knowledge and New Ways of Thinking and Behaving—

Participants reported that the educational information contained in the computer programs increased their knowledge about SCD and SCT and its inheritance. Among the e-Book participants, 64% ($n = 9$) used the term 'learned a lot.' CHOICES participants also 'learned a lot' (31%, $n = 17$); however, an additional 46% ($n = 25$) indicated a fuller educational experience by using terms such as: 'loved' the CHOICES intervention or found it 'fun,' 'cool,' 'enlightening,' 'really good,' 'eye opening,' 'great experience,' and 'wow!'

Some participants expressed that the study information enhanced their personal learning or helped them consider shifting their attitudes and behaviors about having a child with SCD. Thirty-four percent ($n = 23$) of participants reported that the educational information moved them to think and feel differently or expand their thinking (i.e., they noticed improvement in themselves) about their knowledge and thoughts regarding reproduction or SCD. For example, a woman with SCD (Study ID Number #267) in the CHOICES group who already had two children but wanted another indicated, 'It actually makes me think…it opened my eyes…to think a little harder and make a better plan about having kids instead of just having kids.' A male participant with SCD (#367) said the CHOICES program 'had me think about things that I never thought about as far as talking with [the] doctor or having the eggs fertilized….' A female e-Book participant with SCT (#428) indicated that although she did not have a current partner:

> [M]y sickle cell trait had always been in the back of my mind, but this study has just made me a little more conscious of talking to partners before I get serious with them just to kind of figure out, 'Do you have sickle cell trait or disease?' [and] 'What options would you consider if we were to have children?'

Many participants ($n = 47$) indicated that they searched other information sources to increase their knowledge about SCD and SCT during the study period. Sixteen of these noted that they either searched for information in the past or wanted to learn more about SCD and available treatments. When probed to identify the sources of information, participants mentioned one or more sources. The Internet was the main source ($n = 25$), followed by information obtained from family members and friends ($n = 14$), pamphlets, articles, group sessions attended at the Sickle Cell Disease Association of Illinois ($n = 11$) and health care professionals ($n = 7$). Several individuals recalled accessing other information sources but were unable to recall the source or did not give source-specific information during the

interview (n = 2). Regarding whether these other information sources helped participants to answer the study questions (i.e., increase their knowledge about SCD or SCT), participants were split, with 47% (n = 22) responding 'yes' and 51% (n = 24) responding 'no.' Fifteen of the participants who responded yes (n = 9 CHOICES; n = 6 e-Book) noted that they either looked up information on inheritance or wanted to check their answers on the post-test questionnaire.

The remaining participants (n = 21) reported that the information contained in the study was their exclusive source of sickle cell information during the study period, with almost equal reporting by CHOICES (n = 16; 30%) and e-Book (n = 5; 36%) participants in the study. Only one woman with SCT (#342) in the e-Book group offered insight into the difficulties of using and accessing other information sources, 'but with the books and stuff I can't read that well [and] I don't have Internet.'

Most participants accurately responded to questions about the transmission of SCD (n = 64) or SCT (n = 56) to their children. Most participants grasped key ideas about their own individual genetic risk affecting transmission (e.g., having SCD or SCT) and were able to associate this information to their current or future partner's sickle cell status. As one woman with SCD (#299) in CHOICES said:

> Yeah, I think I do have a chance [to have a child with SCD] because I have sickle cell disease. I don't have a mate at the moment, but if the father didn't have the trait or disease then my baby wouldn't have the disease… my baby would just have a chance at having the trait.

Some participants were also aware of other factors that could influence genetic risk, such as their ability to use donor eggs or adopt children.

Among the participants that responded inaccurately, only four (6%) responded inaccurately as to whether they could transmit SCD. However, ten (15%) participants responded inaccurately about the transmission of SCT and two (3%) did not respond to the question. Most often, individuals responding inaccurately to questions about transmission of SCT had SCD and would underestimate the risk of transmitting SCT to their children. As one woman with SCD (#299) in CHOICES who minimized her chances of having a child with SCT (100% actual chance) said:

> I have the full blown disease and my partner probably nine times out of ten will not have the disease or trait, that will give it [a future child] about twenty-five percent chance of maybe having the trait when the child is born.

Theme 2: Rethinking Parenting Plans—Participants overwhelmingly (n = 53, 78%) indicated that participating in the study helped them to rethink or revise their individual parenting plans. Intended activities included one or more of the following: talking to their partners about their own sickle cell status or finding out about their partner's sickle cell status (n = 28), evaluating or reevaluating reproductive options such as birth control, tubal ligation, prenatal testing, or adoption and foster parenting (n = 15), taking steps to obtain additional information about reproductive options (n = 10), teaching offspring about their genetic risk and how risk is influenced by a reproductive partner's sickle cell status (n = 4)

and disclosing to others personal information about their sickle cell status and desire for future children ($n = 2$).

For participants who indicated that the information contained in the computer programs did not affect personal parenting plans ($n = 10$ in CHOICES, $n = 1$ in the e-Book group), about one-half ($n = 5$) offered a specific reason: two said they were already knowledgeable of their genetic inheritance risk, one thought she may be infertile and transmission was not a concern and two believed transmission of SCD/SCT was 'up to fate' (#241 & #411).

When asked to describe what it would be like to have a child with SCD, participants replied with a wide variety of responses about their perception of issues and challenges about living with a child that had SCD. For example, participants most frequently used terms such as: 'difficult' or 'very difficult' ($n = 22$); 'hard' or 'very hard' ($n = 14$); 'afraid,' 'very afraid,' or 'scared' ($n = 10$); 'worry' ($n = 7$); and 'challenging' ($n = 7$). Yet, some participants ($n = 7$) interjected affirmations of their ability to overcome challenges by using words such as: 'can deal with it' ($n = 5$) and 'easy' ($n = 2$).

Participants offered additional insights by expressing their underlying reasons for whether perceived challenges might influence their intended behavior about future parenting. Individuals ($n = 30$) who voiced strong agreement with preventing the birth of a child with SCD (either pre- or post-conception) stated their concerns about a future child's experiences of pain and symptoms, the necessary management of the disease related to surgeries and hospitalizations, sacrificing childhood activities and even experiencing early death. As one man with SCD (#247) in the CHOICES intervention group explained:

> You don't want to see your child in the hospital with the sickle cell suffering, in pain and just crying a lot… I don't want to see my child going through the stuff I'm going through.

Other participants ($n = 21$) went on to explain that they were in a middle ground (i.e., both agreed *and* disagreed) about whether to conceive a child with SCD. These individuals stated they wanted children regardless of the risk and two CHOICES participants noted that they were glad they were born. Although participants understood the disease symptoms and effects, they also perceived SCD as a manageable condition and said individuals can 'deal with it' and 'survive.' A couple of individuals mentioned that they should have the choice of making their own decisions about having children. A woman with SCD (#455) expressed the feeling of many in this middle-ground group when she remarked:

> I should definitely take some steps [to avoid having a child with SCD]… but does that mean I skip over the love of my life and not have a child with [him] because this kid could have sickle cell disease? I have the disease and I had a great childhood. I'm sick sometimes but it's been worth it. I see where they're coming from, but I think that it's just different when you're in those shoes.

The remaining participants ($n = 17$) disagreed with doing all you can to prevent the birth of a child with SCD. These participants often spoke about treatments that make SCD manageable and an understanding that 'life is precious' and that imperfections exist in everyone. One

women with SCT (#418) in the e-Book group explained why she disagreed with doing all you can to prevent the transmission of SCD:

> I don't agree [with doing all you can] because even though there's health issues that if you are blessed with a child and that's the child that you take care of and attend to -- that's what God intended -- them to be here. Everyone's not perfect or the same.

Theme 3: Appraising the Program Design and Delivery—Many participants in the CHOICES group (n = 38; 70%) indicated that the predominant strength of the educational program was the focus on reproductive options. A male with SCD (#451) exemplified many participants' views about the strength of the CHOICES program by remarking, 'it gave me insight to what to do or different ideas I could do as far as having a kid.' Participants mentioned other strengths: information on pregnancy (n = 4), genetic inheritance (n = 5), transmission of SCD or SCT to children (n = 13), how to care for a child with sickle cell disease (n = 1) and the ability to 'refresh' understanding of SCD (n = 6). Information presented on communication and its role with reproductive partners regarding the transmission of sickle cell was also beneficial to CHOICES participants (n = 3).

Participants also reported their views about the mechanisms used in the design and delivery of the content. For example, CHOICES participants reported more nuanced benefits, including how the use of repeat questions and videos or 'movies' enhanced educational experiences. Other design features that were found helpful among the CHOICES participants were how the program would recap information about genetic inheritance; use of reflective questions when a participant's answer was incorrect; and the use of Punnett squares, graphics and animation to explain risks and probabilities.

Participants offered suggestions particularly around the way knowledge was evaluated in the quantitative pre- and post-test questionnaires. In response to, 'How to improve the computer program?' 22 participants thought there were too many questions. Several participants offered more nuanced suggestions that were tailored to their individual preferences. A male CHOICES participant (#283) thought the intervention was too female-centered as he remarked, 'Not knowing the answers to *women* questions' (italics added for emphasis). Two participants (one CHOICES and one e-Book) found the content on abortion distasteful and one lesbian participant pointed out that most of the CHOICES reproductive content had limited applicability for same-sex couples.

About 40% (n = 27) of participants called for or encouraged the researchers to expand the intervention to help others or help the participants retain and distribute information. For example, a man with SCD (#411) in CHOICES encouraged the researchers to, 'keep fighting the sickle cell fight… and trying to prevent it.' Also in the CHOICES group, a woman with SCD (#305) suggested that the researchers, 'Just don't stop; continue the research - it is people that can be helped.' Several participants, especially those with SCT in both the CHOICES and e-Book groups, suggested that the computer programs be expanded into schools and also recommended wide distribution and advertisement of the intervention. One woman with SCT (#311) in the e-Book group said that to extend the program to other people

with SCD and SCT the researchers should, ‘Definitely try to reach out to them [by] social networking sites such as Twitter, LinkedIn, Facebook.’

DISCUSSION

Our inclusion of a qualitative component following the completion of a two-year RCT enriched our understanding about participants’ perceptions of parenting and their involvement in the study. Other investigators have called for the use of qualitative approaches in evaluating complex RCTs (Campbell *et al.* 2000) and our descriptive work enhanced our understanding about how computer-based education can foster learning and what steps to take in subsequent research to improve design (e.g., inquire about Internet use).

Most participants were able to articulate understanding about key ideas related to SCD or SCT genetic risks and inheritance by children. However, even after completing the study, some individuals had difficulty accurately applying the information to themselves when asked to determine the risk of their children inheriting SCD or SCT. This finding highlights the importance of research into understanding how best to communicate and portray health risks, an area that is only beginning to be understood (Price *et al.* 2007, Timmermans *et al.* 2008). It also highlights an area where many individuals with SCD or SCT may need more focused or tailored education to ensure correct understanding of their transmission risks. One practical solution for nurses to consider to help individuals remember is giving individuals with SCD or SCT a meaningful physical keepsake (i.e., bracelet) or an easily accessible computer keepsake (i.e., e-Photo) that lists their personalized risk with their current or future sexual partners. Building on similar experiences of nurses providing education to diabetic individuals, routine visits could include an assessment of the use and benefit of these keepsakes (Stallwood 2005).

An important finding in Theme 1 was the number of individuals who reported a self-identified shift in their knowledge and thinking that caused them to feel or think differently regarding future reproduction or SCD. Noteworthy were participants who stated that their understanding and approach to having a future child had changed. For example, participants felt more confident in talking to partners about their sickle cell status and the risk of their child inheriting SCD or SCT.

Little is known about the beliefs and values of individuals with SCD or SCT about having children who are at risk for SCD or SCT (Long *et al.* 2011, Smith & Aguirre 2012). Although we found that some participants agreed or disagreed with the notion of ‘do all you can to avoid having a child with SCD or SCT,’ we also identified participants who reported a ‘middle-ground’ (i.e., both agreed and disagreed) regarding doing all you can to avoid your child inheriting SCD or SCT. Similar middle-ground findings among other at-risk genetic individuals has been noted (Hershberger *et al.* 2012). Taken together, these findings provide evidence that young adults often construct alternative and broader ways of approaching reproductive decisions than typical dichotomous options of agreeing or disagreeing. In the future, nurses that develop educational programs for individuals with SCD or SCT should consider these middle-ground deciders when crafting language about reproductive options.

We were surprised to learn about the high number of participants that used the Internet to obtain additional health information about SCD or SCT ($n = 25$) compared with the few that sought information from health care professionals ($n = 7$) among the 47 participants who reported seeking outside sources of information in Theme 1. Based on their responses, some participants may have searched the Internet because they were excited about participating in the study and wanted to learn more, or in a few cases, to correctly answer the RCT post-test questions. Nevertheless, this finding adds to a growing body of literature that points to young adults' increasing use of technologies like the Internet to either seek or add to their learning about health issues (Rutten *et al.* 2005). In future studies of the CHOICES intervention, it will be important to ask about use of the Internet and other sources to obtain information about the study topic. Responses could be used to examine the effect of information-seeking on study outcomes, especially knowledge-related outcomes measured longitudinally. Participants in Theme 3 also encouraged investigators to continue the research and seek additional computer-based strategies for possibly mainstreaming the education. Public health leaders and those in clinical practice may want to consider joint opportunities for advancing health education for individuals with SCD or SCT through innovative technological methods based on these findings.

Participants were supportive of computer technologies to enhance learning; however, they provided insight about how the study could be improved. Almost one-third of participants reported that the number of questions in the pre- and post-test questionnaire was too high, despite our using the smallest number of questions advisable for adequate representation of the theoretical constructs under study in the RCT. Participants also interpreted the intervention content within their individual experiences with SCD or SCT and their values and beliefs surrounding reproductive options. Only a few participants suggested the content on abortion was distasteful or recommended that additional information be included for same-sex couples. Developers of computer-based or other educational technologies may need to consider these findings as science and technology move toward providing more targeted and tailored interventions.

Limitations

There are several limitations of the study. Foremost, our sample was predominately composed of individuals that completed the CHOICES intervention ($n = 54$, 79%) and our understanding of individuals that completed usual care education (e-Book) is limited, but intentional, because we sought primarily to understand the experiences of the CHOICES group and secondarily the e-Book group. We found that the themes cut across participant responses in both groups. Because our sample was collected from a largely urban population willing to use a computer for data collection, our findings may be limited. Future research is warranted among people with SCD or SCT who may not have access to a computer, are health literacy-challenged, or are from other geographical areas (e.g., rural areas, other countries) where cultural and societal norms may be different. However, our findings may be helpful to nurses and other professionals as a guide for developing educational materials for individuals with SCD or SCT or other genetic disorders, especially when targeting reproductive options or parenting plans.

CONCLUSION

Young adults of childbearing age in this study were genuinely interested in learning about SCD and SCT and their reproductive options. Participants perceived the CHOICES and e-Book information as helpful to their learning; yet when asked, participants struggled with determining their individual transmission risks to children. Developers of educational programs should consider adding tailored education and memory boosters such as a physical or electronic keepsake. A large proportion of the young adult participants indicated they used the Internet as opposed to health care professionals to supplement or confirm the information discussed in the computer program. Because all participants were amenable to using computers, studies that address individuals who are computer or health literacy challenged are important foci for future research. Findings also highlight the need for research that examines how nurses and other clinicians can better communicate transmission risks and integrate computer-based education about reproductive options into routine healthcare to benefit individuals with SCD or SCT.

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SUMMARY STATEMENT

- Why is this research needed?
  - Sickle cell disease is a major public health concern in many countries.
  - There is growing concern about the insufficient education for young adults with sickle cell disease or sickle cell trait on their genetic inheritance risks and reproductive options.
  - Quantitative findings about the intervention efficacy are essential; qualitative interviews regarding participants' perceptions of study procedures can provide key insights to plan future studies or implement the intervention in practice.
- What are the key findings?
  - Young adults are eager for education that will increase their knowledge about inheritance of sickle cell disease and sickle cell trait and about reproductive options.
  - Some participants expressed difficulty in determining individual risk for transmitting sickle cell disease or sickle cell trait based on real or hypothetical partner's sickle cell status.
  - When participants sought additional information about sickle cell disease or sickle cell trait, most used the Internet versus obtaining information from health care professionals.
- How should the findings be used to influence policy/practice/research/education?
  - Nurses and other professionals can use the findings to guide development of educational programs for individuals with sickle cell disease or sickle cell trait.
  - Participants encouraged researchers to seek additional computer-based strategies for mainstreaming the educational programs, such as Twitter, LinkedIn and Facebook.
  - Future research examining how computer-based education can spark communication between health care professionals and individuals with sickle cell disease or sickle cell trait would be beneficial.

Table 1

Overview of the CHOICES and e-Book computer programs

	CHOICES Intervention	**e-Book Intervention**
Design	Computer-based. Tailored, multimedia educational program about SCD, reproductive options and consequences. Designed to help young men and women with SCD or SCT implement their preferred parenting plans.	Computer-based. Educational program designed using the content shared by the Chicago area sickle cell clinic programs with individuals and their families affected by SCD or SCT.
Sound	Narrated by either a female or a male voice. Participants select the voice or engage the material without narration.	Narrated by either a female or a male voice. Participants select the voice or engage the material without narration.
Length	57 web pages	9 web pages
Graphics and Content	14 video clips and 17 graphical animations. Clips included couples discussing issues related to reproductive options and animations that demonstrate: • Genetic inheritance of SCD. • Risks of a child inheriting SCD or SCT if the parents have SCD, SCT, or normal hemoglobin. • How advanced reproductive technologies work. • All available parenting choices (e.g., take the chance of SCD or SCT inheritance, prenatal testing, abortion, advanced reproductive technologies, adopt, or foster children). • Reproductive behaviors needed to achieve the parenting choice.	No video clips. Some illustration and animation enhanced content that included information on: • Incidence and inheritance of SCD and SCT. • Management of SCD. • Health problems associated with SCD and SCT. • Effects of SCD on pregnancy.
Questionnaires (Number of Items)	Pre-Test = 85 items. Post-Test (completed immediately) = 66 items. Post-Test (completed at 24 months) = 78 items.	Pre-Test = 85 items. Post-Test (completed immediately) = 66 items. Post-Test (completed at 24 months) = 78 items.

Table 2

Interview guide example questions

1	What was it like for you to participate in this study?
2	Please tell me about your plans to become a parent now. What will you do differently about having children because you participated in this study? Why? What will you keep the same? Why?
3	Do you think that you have a chance to have a child with sickle cell disease? Why or why not?
4	Do you think that you have a chance to have a child with sickle cell trait? Why or why not?
5	What would it be like to have a child with sickle cell disease?
6	Some individuals or groups think you should do all you can do to not have a child with sickle cell disease. Do you agree with them? Why or why not?
7	What information have you searched out from other sources while you participated in the study (Internet, hard copy books, pamphlets, health professionals, friends, family)? Did the information that you received from these sources help you to answer the questions in the program? If so, how?
8	What do you feel were the strengths of the computer program? What are the things you really like about the program?
9	What do you feel were the weaknesses of the computer program? What are the things you did not like about it?
10	How can we improve this computer program? What do you recommend?
11	Your comments about the computer program are particularly helpful. These are the types of information that we were trying to get at. Is there anything else you want to add?